

The Institute for Clinical Social Work

The Experiences of Parents Who Unknowingly Adopt a Child with FASD

A Dissertation Submitted to the Faculty of the
Institute for Clinical Social Work in Partial Fulfillment
for the Degree of Doctor of Philosophy

By

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Abstract

This qualitative study explored the lived experiences of parents who unknowingly adopted a child with Fetal Alcohol Spectrum Disorder (FASD). Six adoptive parents were each interviewed two times and in-person, following the methodological frame of Interpretative Phenomenological Analysis. The epistemological interchange between the participants' lived experiences and analysis of the data allowed for an exploration that was flexible and in detail. The data revealed a comprehensive understanding of the personal, familial, and therapeutic experiences of these parents. Five super-ordinate themes emerged from the data including:

- The Process of Adoption: Fantasies vs. Realities
- Something is Off
- Trauma and Isolation
- Systems: The Good, The Bad, and The Ugly
- Seismic Shifts

Attachment, neuropsychological, and psychodynamic theories were used to interpret the findings. This study highlights the need for clinicians and professionals working in adoption-related fields to develop a better understanding of how Fetal Alcohol Spectrum Disorders may impact a child and their family. The results also identified areas for future research to better understand the phenomenon.

For my mother, Patricia—my first and most influential role model,
and for Dirk—my beloved husband

You are a mystery
to me, yet so familiar.
Like a song I've never
heard before, and a
tune I've known
my entire life.

~Pavana □□□

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Chapter I

Introduction

General Statement of Purpose

The purpose of this qualitative study was to explore and discover the lived experiences of parents who unknowingly adopted a child with Fetal Alcohol Spectrum Disorders (FASD). For this research study, Fetal Alcohol Spectrum Disorders is used to describe the overarching diagnostic terminology for children who are exposed to alcohol in utero. FASD is known to cause adverse effects comprised of a continuum of disabilities. Interpretative phenomenological analysis is the qualitative methodology used to explore the nuances of the everyday experiences of these parents, ultimately showing a more complete picture of their life world in raising these children.

Significance for Clinical Social Work

Many clinical social workers, including those who work specifically in the field of adoption, do not have an in-depth understanding of how Fetal Alcohol Spectrum Disorders may impact a child and their family. Unfortunately, there is also limited awareness and understanding of prenatal substances of abuse as a whole among professionals who work in adoption and related fields (Wedding, Kohout, Mengel, Ohlemiller, Ulione, Cook, Rudeen & Braddock, 2007; Caley, Syms, Robinson, Henry, & Shipkey, 2008). Research indicates that FASD can profoundly impact a child throughout their lifetime and the

effects on the child's family can be devastating (Riley & McGee, 2005; Mattson, Crocker & Nguyen, 2011). In this study, the analysis of the data is compiled from parents who unknowingly adopted a child with FASD. The data reveals an in-depth understanding of the multifaceted personal, familial, and therapeutic experiences of these parents.

Formulation of the Problem

The reason one chooses to adopt a child varies extensively among individuals and couples. Many adopt not knowing what disabilities or challenges their child may face, while others intentionally choose to adopt a child with developmental challenges or special needs. This study focused on the former in respect to Fetal Alcohol Spectrum Disorders (FASD), a neurocognitive deficit that often results in long-term challenges for the child and their family. For the purposes of this study it is important to note that FASD is not a diagnostic term, rather, an umbrella term used to describe a broad range of effects associated with alcohol use during pregnancy. Children born with an FASD may exhibit a range of deficits, from mild behavioral difficulties to severe life-long social, emotional, and cognitive dysfunctions (Streissguth, Sampson, Carmichael, Olson, Bookstein, Barr, Scott, Feldman & Mirsky, 1994).

Most children who have an FASD do not have the distinct facial features of children who have Fetal Alcohol Syndrome (FAS), the most severe of the diagnoses under the FASD umbrella. As of 2017, the criterion for FAS diagnosis requires the presence of specific facial disfiguration including short palpebral fissures (opening between eye lids), a thin upper lip, a smooth and elongated philtrum (the groove above and in the center of the upper lip), as well as a history of growth retardation (Streissguth et al., 1994). For

children who meet the criterion for FAS, there must also be evidence of Central Nervous System (CNS) impairment. CNS impairment often includes a small head circumference (microcephaly), structural brain changes that can be seen in imaging studies: agenesis of the corpus callosum (complete or partial absence of the midline structure of the brain which connects the two hemispheres), damage to the basal ganglia, or reduced size of the cerebellum.

CNS impairment is also identified through psychological testing, revealing deficits in emotional, behavioral, and cognitive functions (Goh et al., 2016). Unfortunately, many children with an FASD are often misdiagnosed and misunderstood, which increases the likelihood of problems at home, in their school, and within their communities (Chasnoff, Wells, & King, 2015). This is especially true for many of these children who do not have the physical characteristics often associated with FAS. Yet, despite the absence of FAS physical abnormalities (dysmorphology), many struggle with significant deficits in executive functioning, which includes a dearth in cause-and-effect thinking, poor judgment, impulsivity, and emotional lability (Chasnoff et al., 2015; Streissguth & Kanter, 1997). Executive function can also be described as “the ability to maintain an appropriate problem-solving set for attainment of a future goal” (Welsh & Pennington, 1988). For all of these aforementioned reasons, FASD is often referred to as an *invisible disability*.

Current research indicates that parenting a child with an invisible disability like FASD can often be exhausting and highly stressful (Brown, Mather & Giles, 2014). These parents frequently feel overwhelmed and isolated, not knowing where to turn or how to best help their child. Many parents raising a child with FASD will need the assistance or support of community resources, often including the services of mental

health practitioners, pediatricians, clinical social workers, and other supports. Another significant variable to consider is the way in which parents may respond to their child, especially when negative or difficult behaviors arise. Parents' own attachment history and style, in addition to their adopted child's attachment patterns, may also interfere with the development of secure and healthy bonds within the family (O'Connor, Sigman & Kasari, 1992; O'Connor, Kogan & Findlay, 2002). The literature review delves into these specific variables, in addition to other studies that have focused on this topic.

Study Objectives

This study focused on the subjective and lived experiences of parents who unknowingly adopt a child with Fetal Alcohol Spectrum Disorders. Study objectives included:

1. Learning about parents' lived experiences of adopting and raising an adopted child and the point at which concerns arose around their child's overall development.
2. Exploring the complexities of FASD and how adopting a child with FASD impacts individual and familial dynamics.
3. Providing valuable insights about working with families who are raising a child with FASD for the clinical, child welfare, and adoption communities.

Theoretical and Conceptual Framework

The rationale for using Interpretative Phenomenological Analysis (IPA) for this study was to fully explore the lived experiences of parents who unknowingly adopted a

child with Fetal Alcohol Spectrum Disorders. From the hermeneutical frame of IPA, this study's intent was to "make sense of the participant who is trying to make sense of what is happening to them" (Smith, Flowers, & Larkin, 2009, p. 3). The epistemological interchange between the participants' lived experiences and analysis of the data allowed for an in-depth exploration that was flexible and in detail. During the interview process, reflective journaling and regular consultations with an advisor were utilized so that my interpretation of the data was a part of the dynamic and constant process. This practice is commonly utilized in IPA. Further, this methodology also allows for in-depth exploration of even the smallest unit of meaning within the wider context of each interview as themes emerge (Smith et al., 2009). Because FASD is not often recognized or diagnosed in the general population, or even in many clinical settings (Chasnoff et al., 2015), it is a phenomenon that is highly relevant in relation to adoption, parenting, child development, family systems, and relationships.

Research Question

This qualitative study was designed to address the following research question, "What is the lived experiences of parents who unknowingly adopt a child with Fetal Alcohol Spectrum Disorders (FASD)?" This study provides an exploration of the lived experience of parents whose child was later diagnosed with Fetal Alcohol Spectrum Disorders. Interpretative Phenomenological Analysis (IPA) is the methodology that was used to explore the true essence of parents' subjective experiences.

Statement of Assumptions

In IPA, a critical part of the research process is creating a statement of assumptions, also referred to as bracketing or Epoche. This process sets aside personal biases, experiences, biases, and preconceived notions about the research topic and subsequent findings (Smith et al., 2009). For Moustakas (1994), bracketing is simply the setting aside of personal prejudices. Gadamer (1997) proposes the aim of bracketing in the research process is to make intelligible all subjectivity and that “what is” may emerge and show itself.

The following list of assumptions is drawn from the researcher’s clinical experiences in addition to academic and theoretical research:

1. An FASD is often an invisible disability.
2. Children with an FASD have executive functioning deficits.
3. An FASD is a life-long disability and there is no cure.
4. Parents’ initial thoughts about adoption often do not match the reality of raising an adopted child with an FASD.
5. Parenting a child with an FASD is often challenging and isolating.

Chapter II

Literature Review

Introduction

This section looks at the history of adoption, the reasons individuals choose to adopt, the psychodynamic literature on adoption, and adopting a child with special needs. I have also explored literature related to challenges families face when adopting a child, including some policy issues, and parenting an adopted child with special needs. Next are reviews of relevant literature on Fetal Alcohol Spectrum Disorders (FASD), including the experiences of parenting an adopted child with FASD. Finally, I present an overview of the literature on attachment theory, including its foundational rooting in psychoanalysis, followed by contemporary thought on attachment theory and literature on neurobiology. In all, this literature supports the value of the study at hand, which is to explore and understand what it is like to parent a child who is diagnosed with Fetal Alcohol Spectrum Disorders.

Historical Overview of Adoption

Adoption: to take by choice into a relationship; especially, to take voluntarily, a child of other parents, as one's own child (Miriam-Webster, 2014). Myths dating back to 2800 B.C. have referred to adoption as “nurturing a child, not of one’s own,” defining this

as “the taking into one’s family a child, not of one’s own blood” (Clothier, 1939). Legally speaking, adoption is “the act of one who takes another's child into his own family, treating him as his own, and giving him all the rights and duties of his own child” (The Law Dictionary, 2017). The formal practice of adoption in the United States was formed in the 1800s, not only to care for the expanding number of homeless children, but also to ensure legal inheritances that were otherwise restricted to birth relatives (Zamostny, O'Brien, Baden, & Wiley, 2003).

From all sources, both international and domestic, there are about 135,000 children adopted in the United States each year (Selman, 2009; Jones, 2009). It is estimated that about 59% are from the foster care system, 26% are from other countries, and 15% are voluntarily relinquished newborn babies from within the United States (Moriguchi, 2012). The 2010 U.S. Census reports that the number of adopted children who are younger than 18 years old is about 1.5 million. Other reports indicate there are currently five to six million adopted individuals in the United States alone (Kreider & Lofquist, 2010). In all, adoption is very common and, according to a Benchmark Adoption Survey by the Evan B. Donaldson Adoption Institute (1997), “six in 10 Americans have had personal experience with adoption... and a third of those have considered adopting a child at least somewhat seriously.”

Reasons Individuals Choose to Adopt

The literature suggests that there are a variety of reasons why individuals and/or couples choose to adopt a child, with the most common reason being infertility (Blum, 1983; Kraft et al., 1980; Daniluk et al., 2003; Fisher, 2003). The Child Welfare

Information Gateway (2016) compiled a comprehensive document that explored the reasons one may choose to adopt, including infertility and other possible reasons. In cases of infertility, there may be significant grief and loss issues for the adoptive parent(s), even long after the adoption of their child (Burns, 1990). Some experts suggest that when parents who have experienced infertility come to the point of adopting a child, they “need to reach beyond the sadness to the idea of parenting a different child than the one they could not have” (Nickman, 2004). For many people, this may be a complex process.

Adoptive parent, Janine de Payer (2013, p.), poignantly writes:

As an adoptive parent, I am reminded how important it is to attempt to resolve my own issues around my son’s adoption and birth origins so that he can emotionally trust that I can welcome and handle his questions. Easier said than done. One doesn’t necessarily finish one’s grieving before the baby arrives, and different aspects of grief present themselves with different degrees of severity as life events, such as births, personal accomplishments, and parental deaths occur. Recognition of one’s ultimate parental powerlessness is hard for any parent to face but is compounded with particular force by the “baggage” of adoption.

Blum (1983) posits that adoptive parents’ emotional state at the time of adoption may have a profound effect on how they respond to their adopted child. If one becomes a parent through adoption, there may be a kind of deprivation that one wouldn’t feel if they were to prepare for parenthood through their own pregnancy. If there was infertility prior to the decision to adopt, there may be a “need to resolve the loss of fertility and to develop the parental attitudes necessary to form a firm, nurturing attachment” (p. 76) to the

adopted child (Kraft, Palombo, Mitchell, Woods, & Schmidt, 1985). Of course, these experiences undoubtedly vary as much as adoptive families vary.

In our modern society, adopting a child has become more common. In addition to young, married couples, there has been a steady increase of others who pursue adopting a child including, single parents (Haugaard, Palmer & Wojslawowicz, 1999; Shireman & Johnson, 1985; Dougherty, 1978), gay and lesbian couples (Gates, Badgett, Macomber, & Chambers, 2007), and older parents (Jones, 2008; Dougherty, 1978). Yet, even though adopting a child has become more common for more people, there are now fewer healthy infants available for adoption than ever before. One reason is due to legalized birth control and abortion (Bitler & Zavodny, 2002; Westoff, 1988). Another is less societal stigma involved in having a baby out of wedlock (Bock, 2000; Bumpass & McLanahan, 1989). Consequently, those who have desire to adopt a child may find themselves looking beyond what was once considered a traditional adoption (Wade, 2010) including international adoption, open adoption, and private adoption (Mason & Narad, 2005; Brooks, Allen & Barth, 2002; Siegel, 1993; Demick & Warner, 1988).

Adopting a child may bring up a host of complex matters, including transracial issues, disabilities, and grief and loss (Frank & Bernstein, 2013; Lee, 2003). For instance, the literature on adoption reveals that most adoptive parents believe they are receiving sound information from their respective adoption agency before the adoption is finalized (Rycus, Freundlich, Hughes, Keefer, & Oakes, 2006). Unfortunately, this is often not the case. D'Amato (2008), writes that there are often sparse details about the adopted child when adopting internationally. Furthermore, there are many agencies, domestic and international, that may knowingly or unknowingly exclude important information about

the child, including important prenatal information such as exposure to a substance of abuse in utero (Blair & Brower, 1991). There is also a financial element for prospective adoptive parents to consider and this can vary greatly. D'Amato's (2010) study on international adoption estimates the cost to be over \$20,000 per adoption, whereas other studies have illustrated the cost of adoption can range from about \$4,000 to upwards of \$50,000 (Goodwin, 2006); the later often tied to black-market adoptions (Posner, 1987). Some or all of these above-mentioned issues can impact the adoptive parents long before the adoption is finalized.

Psychodynamic Literature on Adoption

With respect to psychodynamic literature, very little focuses specifically on adoptive parents and their experiences. Most of the psychodynamic literature on adoption concentrates heavily on the loss that the adopted child endures due to separation from the birth mother. Bonovitz (2004) supports these findings, suggesting "much of the psychoanalytic literature on adoption focuses almost exclusively on the emotional world and fantasy life of the adoptee, often disregarding the adoptive parents' unconscious fantasies concerning adoption" (p. 1).

Brinich (1980) is one who focused on the adoptive parent, writing about self and object representations associated with adoption. He proposes, "the adoption of a child is, in human terms, always a painful and potentially traumatic event" (p. 107). Blum (1983) also explored psychoanalytic contributions of the adoptive parent by addressing the generalities and problems that adoptive parents often encounter, including the "gratifying, defensive, and developmental implications for the adoptive family" (p. 142). Blum also

addresses intergenerational conflicts, specifically how they may positively or negatively impact “the adoptive parents’ attainment of parental identity, attachment, and confidence in their rearing of the child” (p. 161).

For most adoptive parents, there are fantasies of the adoption and of their adopted child. Freedgood (2013), who is also an adoptive mother, wrote, “Adopting parents are caught in the illusion that their love will heal all” (p. 28). She further suggests that there are layers upon layers of dynamics that may become barriers to a successful adoption, including positive and negative influences from the child’s biological and environmental history. Wade (2010) refers to adoption as a “developmental milestone” and questions why clinicians and researchers have not fully explored adoptive parents’ pre-adoptive experiences. She states, “these are intense emotional dramas, not infrequently involving false starts, plans that change, and adoptions disrupted before or after adoption ... infertility is rarely an easy route to parenthood” (p. 26). All of the aforementioned issues are relevant to this study, which will partially use a psychodynamic lens in analyzing the lived experiences of parents raising a child with an FASD.

Adopting a Child with Special Needs

Since the Adoption Assistance and Child Welfare Act of 1980, there has been more focus on encouraging individuals to adopt children with *special needs* or under complex circumstances. This includes a wide range of populations of children, not only those who have emotional, intellectual, or physical disabilities but also includes older children, minority children, and children with multiple siblings (Stolley, 1993). The literature is saturated with studies and articles on adopted children who have special needs

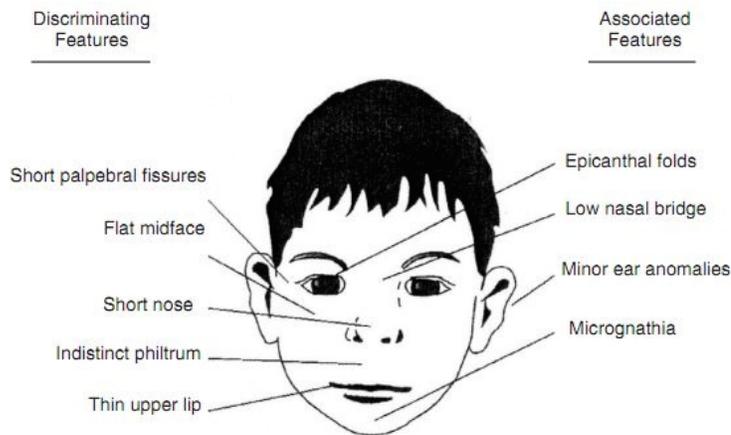
(Leung & Erich, 2002; Hughes, 1999; Johnson, 1997; Rosenthal, 1993; and Macaskill, 1991). Yet, most focus on children with physical disabilities or developmental disabilities such as cerebral palsy, Down syndrome, or autism. As a whole, there is limited literature on the experiences of adopting and raising a child with Fetal Alcohol Spectrum Disorders.

Fetal Alcohol Spectrum Disorders

Fetal Alcohol Spectrum Disorders is an umbrella term for birth defects that develop due to alcohol exposure in utero (Mela, 2006). Under the umbrella of FASD, there are several diagnostic terms that fall within the spectrum. Experts on prenatal substances of abuse maintain that prenatal alcohol exposure (PAE) is one of the most common preventable causes of intellectual and developmental disabilities (Chasnoff, Wells, Telford, Schmidt, & Messer, 2010; Mattson, Schoenfeld, & Riley, 2001). Because alcohol is a teratogen (an agent that can cause a birth defect), brain development of a fetus may be significantly altered if exposed to alcohol in utero (Senturias & Asamoah, 2014; Welch-Carre, 2005). The greatest impact of PAE on brain development may occur via numerous pathways at all stages of fetal development (Riley, Infante, & Warren, 2011), resulting in damaged or altered developmental trajectories. Individuals who have experienced substantial PAE in utero are more likely to have reduced brain plasticity, lower IQ, and more severe facial abnormalities or disfiguration (Lebel, Mattson, Riley, Jones, Adnams, May, Bookheimer, O'Connor, Narr, Kan, Abaryan & Sowell, 2012).

The diagnosis considered the most severe in the FASD spectrum is Fetal Alcohol Syndrome (FAS), which includes face and brain abnormalities, growth impairment, and central nervous system (CNS) dysfunction (Chasnoff et al., 2010). Currently, the criterion

for FAS requires a presence of facial disfiguration or abnormalities (dysmorphology) including short palpebral fissures, a thin upper lip, and a smooth, flat philtrum, as well as a history of growth retardation (see figure below – Streissguth, et al., 1994).



For children who meet criterion for FAS, there must also be evidence of Central Nervous System (CNS) impairment, which likely includes a small head circumference (microcephaly), structural brain changes noted in imaging studies, or emotional, behavioral, and cognitive deficits that are identified through neuropsychological testing.

Fetal Alcohol Syndrome was first defined in the United States in a 1973 peer-reviewed article, which was written by researchers at the University of Washington (Jones, Smith, Ulleland, & Streissguth, 1973). Since then, research has established that many individuals who are prenatally exposed to alcohol likely have significant structural and functional changes within the brain, even though there is an absence of overt physical dysmorphology (Mattson et al., 2001). Individuals with minimal to moderate facial abnormalities or even those with no abnormalities but who have intellectual, behavioral,

emotional deficits (with known PAE in utero) were once diagnosed with having fetal alcohol effects (FAE).

Within the past several years, the National Task Force on Fetal Alcohol Syndrome and Fetal Alcohol Effect, the Centers for Disease Control and Prevention, and the National Center on Birth Defects and Developmental Disabilities (NCBDD) have come together to ascertain a diagnostic criterion that can be applied to children, adolescents, and adults who were prenatally exposed to alcohol (May, Baete, Russo, Elliott, Blankenship, Kalberg, & Hoyme, 2014). Before the latest version of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5), which was released at the American Psychiatric Association's Annual Meeting in May 2013, there was a wide range of terminology used including: partial FAS (pFAS), alcohol related neurodevelopmental disorder (ARND), and alcohol related birth defects (ARBD). Currently, the DSM-5 has developed the term neurodevelopmental disorder with prenatal alcohol exposure (ND-PAE), which is in the DSM-5 as a "Condition for Further Study" and is intended to replace the term Alcohol Related Neurodevelopmental Disorder (ARND), also formerly known as Fetal Alcohol Effects. For this study, I refer to the umbrella term, FASD, and am not specific with any of the aforementioned differential diagnoses.

Parenting a Child with an FASD

As referred to in a previous section, the literature on parenting a child with special needs more frequently focuses on children who have disabilities such as autism (Pottie, Cohen & Ingram, 2009; Davis & Carter, 2008; Dumas, Wolf, Fisman & Culligan, 1991), Down syndrome (Hodapp, Ricci, Ly & Fidler, 2003; Van Riper, Ryff & Pridham, 1992;

Dumas, et al., 1991), and cerebral palsy (Glenn, Cunningham, Poole, Reeves & Weindling, 2009; Brehaut, Kohen, Raina, Walter, Russell, Swinton & Rosenbaum, 2004).

In the qualitative research literature, there is minimal research on the phenomenology or lived experience of an adoptive parent, as most studies focus specifically on the child or on the parent-child relationship (Kraft, et al. 1985). There are very few studies that have focused on parenting a child with FASD, and only a handful of those are done so with qualitative methodology. One in particular is Morrissette's (2001) qualitative study of parents who are raising a child diagnosed with Fetal Alcohol Syndrome. The primary focus looks at the instrumental role of a family counselor and the impact on the family of a child with FAS. Through analysis, seven predominant themes emerged, all of which supported the critical role of connection to a family counselor who has expertise in FAS.

In another study, the authors conducted a qualitative exploration of the experiences of five parents raising a child with FASD, specifically using hermeneutic phenomenology methodology (Phung, Wallace, Alexander & Phung, 2011). Three main themes emerged from this study including quality of life for parents and the child, school issues, and the need for supportive services. Sanders & Buck (2010) also used hermeneutic phenomenology methodology to explore biological and non-biological parents' experiences raising children with FASD. In their study, a total of 11 parents were interviewed and nine main themes emerged:

1. Something's not right;
2. Receiving a diagnosis;
3. Attitudes toward birth parents;

4. Living in a war zone;
5. Understanding my child;
6. Getting support;
7. Re-defining success;
8. Lifelong parenting; and
9. My child's gifts.

A more recent qualitative study was found that focused on the in-depth exploration of critical costs and life experiences for foster/adoptive families who are raising a child with FASD (Nelson & Friesz, 2015). Eight themes emerged from the findings, including:

1. Implications of FASD for the children who experience this condition;
2. The critical costs of raising children with FASD;
3. Life awareness;
4. Financial accommodations;
5. Lack of services;
6. Education;
7. Coping mechanisms; and
8. Benefits.

Many of the qualitative and mixed-methods studies around parenting a child with FASD have utilized standardized measures, some of which measure the stress levels of parents raising these children. For example, one study (Paley, O'Connor, Frankel & Marquardt, 2006) examined various child characteristics and family factors such as predictors of stress in parents of children with FASD, as measured by the Parenting Stress Index (Abidin, 1995). Another study conducted a mixed-methods study on the impact of

raising a child with FASD and found that most of the parents in their study experience high levels of stress and often feel unsupported and blamed (Mukherjee, Wray, Commers, Hollins & Curfs, 2013). In all, the research that concentrates on parenting a child with FASD appears to be increasing, yet, there has yet to be a qualitative study that analyzes the data using attachment theory, neurobiological, and psychodynamic perspectives.

Theoretical and Conceptual Frameworks of Study

Attachment theory overview.

When we explore the various facets adoption, attachment theory can provide foundational understanding of the adoption triad, which includes the birth parent(s), the adoptive parent(s), and the adoptee. Attachment theory not only helps us to understand a key aspect of psychological functioning, but it also illustrates biologically based roles in human development. As Donald Winnicott eloquently stated, “a baby is a baby only in the context of another” (Galatzer-Levy & Cohler, 1993, p. 36). In other words, the quality of a relationship that a child has with primary caretakers influences their development in various ways, in childhood and throughout their lifetime (Cozolino, 2002). Thus attachment is a foundational concept that is relevant in understanding some of the complex issues explored in this study.

It is important to examine foundational ideas derived from earlier psychoanalytic and attachment theories, in particular, three important early first contributors. First, Sigmund Freud’s exploration of development, psychological structure, and libidinal investment in others provides an important foundation for contemporary theory. Freud’s early theory of melancholia has contributed greatly to our current understanding of

libidinal investment in others and how it is foundational in all relationships, including a parents experience with their child.

Another early contributor is Rene Spitz, whose work in the 1930s and 1940s drew from scientific fields relevant to both psychoanalytic and attachment theories. Spitz's critical studies observing and comparing the experiences of infants in two orphanages helped provide us with an understanding of the "primary importance to the role of the mother and the mother-infant relationship interaction in a theory of developmental stages" (Fonagy, 2001, p. 55). This was a different approach than most developmental analysts, as he "empirically investigated infants instead of inferring their development from the analysis of adults" (Palombo, Bendicson & Koch, 2009, p. 82). In one of his most famous studies (1945), Spitz gathered his data from two orphanages, one in Argentina and one in Mexico. Infants in both orphanages had their basic needs met; they were fed, changed, and sheltered. However, the infants in the Argentinian orphanage were those of incarcerated women and they had no contact with their mothers; they were bottle-fed and they were rarely handled or received any interpersonal interactions besides feeding and changing. This group of infants suffered from what Spitz eventually referred to as *hospitalism*, which is similar to what we now refer to as *failure to thrive*. A startling percentage of the babies in Argentina eventually died.

In contrast, the infants at the Mexican orphanage had regular contact with their mothers and were breastfed. These infants were on track developmentally and were overall healthy. Spitz found confirmation in his research that was in line with Freud's psychoanalytic concepts related to early development; in particular, that depression and lack of human connection can lead to fatality (Tyson & Tyson, 1993). Spitz also proposed

that basic communication is present in infancy, an idea which is foundational in the work of many developmental and attachment theorists (Palombo et al, 2009). Additionally, Spitz's work observing infants was eventually outlined in his alternative developmental model, where he proposed the new emergence of mental organization in infants (Fitzgerald & Barton, 2000). This work eventually led to future research in the interpersonal interactions of infants (Fonagy, 2001).

A third important precursor in the development of contemporary attachment theory is the work of Anna Freud. She, along with Dorothy Burlingham, were charged with overseeing three nurseries during World War II, described in the literature as the *Hampstead War Nurseries* (Hellman, 1983). During this time, both women kept detailed notes on the psychological impact of the children who were separated from their parents because of the war. Their published works, including *Infants without families* (Burlingham & Freud, 1944) and *Reports on the Hampstead Nurseries* (Freud & Burlingham, 1973), describe what infants need for normal development during their first year of life, including connections to their mother. The reports determined there are three major developmental needs of infants for normal and healthy development: a) intimate interactions with a primary caregiver; b) consistent stimulation of innate potentiality; and c) unbroken continuity of care (Palombo, 2009, p. 65).

Today it is known that these are all critical elements that contribute to healthy relationships and development. Further, all are foundational in both traditional and contemporary attachment theories and in child development. These foundational elements are important when exploring the dynamics and the experiences parenting a child with

FASD, since the attachment style of both may be essential in overcoming the risk factors associated with FASD.

Traditional theories of attachment.

The origin of attachment theory, which differed from drive theory, began with John Bowlby, a physician and psychoanalyst from Great Britain. Bowlby developed his theory of attachment after many years of observing the impact that loss and separation had on infants, children, and adults (Bowlby, 1958). Although Bowlby began his training under Melanie Klein, he eventually abandoned her belief that attachment is only based on internal motivation. Through his work at the Tavistock Clinic, Bowlby strongly believed that development of an attachment is based predominantly on the child-primary caretaker relationship. Bowlby's views were further strengthened from watching the poignant films of Rene Spitz, which displayed the devastating effects of a child's separation from their caregiver.

Although it is known today that Bowlby's theories are the foundation of attachment theory, his stance resulted in being shunned for many years by most of the psychoanalytic community (Palombo, Bendicksen, & Koch, 2009, p. 288). For instance, Bowlby's emphasized that the quality of an attachment between the child and their primary caregiver was critical to future psychopathological and healthy development. This was not a mainstream psychoanalytic idea at the time. Moreover, his alignment with animal behaviorists, such as Konrad Lorenz's geese imprintation theory and Harry Harlow's rhesus monkey experiments, set him further apart from psychoanalytic circles. However, his stance on attachment theory was further strengthened (Goldberg, 2014).

Through his work, Bowlby argued, “many forms of psychoneurosis and character disorders were attributable either to deprivation of maternal care or to discontinuities in the children’s relationship with their mother figure” (Palombo, et al, 2009, p. 287). He coined important concepts such as *proximity seeking*, *attachment figure*, *secure base*, and *models*, all of which are accepted as foundational ideas today. From his work and observations, he formulated his theory on the following ethological and evolutionary principles that were based on three phases of separation:

1. Protest – the infant exhibits severe emotional distress;
2. Despair – what occurs if the mother shows no response to the infant’s distress; and
3. Detachment – when there is no reunion with the mother. This is the infant’s defense against painful feelings.

In the psychoanalytic community, Bowlby was highly criticized for his publications, yet he continued his work (Goldberg, 2014). One very important aspect of his work was the concept of *internal working models (IWMs)*, which was developed to stress how positive interactions between a child and their caregiver develops healthy ways of understanding and experiencing the relationship (Pietromonaco & Barrett, 2000). For adoptive parents who are raising a child with FASD, the internal working models may be disrupted due to the complex neurodevelopmental challenges of the prenatally exposed child.

The subsequent work of Mary Ainsworth and Mary Main tested Bowlby’s theories, leading to the development of assessment tools that measured the social connectedness of the child-caregiver dyad. Out of these studies, Mary Ainsworth created an attachment category system that became more reliable over time. These various

attachment patterns, or schemas, are formed from a child's summation of early experiences with the primary caregiver. In addition, an "infant's strategies for negotiating comforting contact with caregivers are constructed in a series of mutually regulated negotiations" (Lyons-Ruth, Bruschiweiler-Stern, Harrison, Morgan, Nahum, Sander, Stern & Tronick, 1998).

Mary Ainsworth's *strange situation* in-home study was a method developed to distinguish the various attachment styles of children with their caregivers. The four categories—secure, avoidant, anxious-ambivalent, and disorganized—were developed from Bowlby's theory that *being left alone evokes stress* (Powell, Cooper, Hoffman & Marvin, 2009). In addition to child attachment classifications, Main developed what is known as a "second revolution in attachment studies" (Karen, 1994, p. 216). While examining videos of families, Main built upon Bowlby's internal working models of attachment and developed the *Adult Attachment Interview* (Main, George & Kaplan, 1985). In the research, Main eventually noticed the emergence of four patterns, which correlated with the aforementioned infant attachment patterns.

Attachment theory helps us better understand how growing up with an attuned caregiver can provide a better chance of those individuals having healthy attachments with their own children. On the other hand, individuals who grew up with parents who were abusive, chaotic, or unpredictable may develop some form of psychopathology if another attuned adult (or other protective factors) were not present during their childhood (Fonagy, 2001). Despite these theories, a child who has FASD may not be capable of securely attaching to their adoptive parent due to the child's neurocognitive deficits, even if their adoptive parent provides adequate attunement, nurture, and love. Thus, it's important for

us to look further into neurodevelopmental attachment theories to better understand this phenomenon.

Neurodevelopmental theories of attachment.

From a neurobiological and physiological perspective, a secure attachment enhances mechanisms in the brain and central nervous system that promote growth, regulation, and optimal immunological functioning. Insecure and disorganized attachment patterns are correlated with a greater likelihood of emotional, psychological, and physical illness (Cozolino, 2002). This is an important step toward a new paradigm on which Allan Schore and Peter Fonagy have focused their work (Schore, 2001; Fonagy, 2001).

Allan Schore has made great contributions to this emerging field. He posits that both neural health and a secure attachment are dependent on an intersubjective, attuned relationship between a caregiver and their child. Moreover, his interest in recreating Freud's Project has also led him to explore how a mother's right orbital frontal region can help process regulatory functions in the infant (Schore, 1997). So, if the mother is attuned to their infant, the infant's brain is *nourished*, thus increasing the infant's capability to modulate stress. Schore posits that the development of this part of the brain also helps the child tolerate increased levels of emotion while maintaining self-regulation and keeping levels of stress hormones at optimal levels (1997). This stresses the importance of an individual's ability to form attachments so that they may not only succeed in the social world, but also increase their ability to regulate impulses and emotions.

Fonagy also has made significant contributions in this area. In his work, he illustrates several concepts that were derived from traditional attachment theorists. Earlier

in his career, Fonagy received training by Mary Main to administer the Adult Attachment Interview in his work. This experience eventually led him to build on the concept of mentalization, which is defined as “the capacity to be specifically aware of mental status as such and to use this awareness in regulating affect and negotiating interpersonal relationships” (Allen & Fonagy, 2006). Fonagy asserts that infants need to be both physically protected by caregivers as well as develop a secure connection and the attachment to ensure emotional survival. Consequently, this “shift between attachment theory’s concept of internal working models and psychoanalytic theory’s mental representation had to include a shift from a behavioral perspective to an understanding of the role that internal representations play in social relatedness” (Palombo, et al, 2009, p. 338). In other words, a primary caregiver must have an adequate level of sensitivity toward their infant for the development of a secure attachment.

Fonagy also developed the concept of Interpersonal Interpretive Mechanism (IIM) to expand his views on development of the self (Fonagy & Target, 2002). This neurobiological mechanism allows children to interpret various situations to which they are exposed. In doing so, the neural process will activate the capacity for self-regulation. If this process fails, the child is likely to have an insecure attachment (Palombo et al, 2009; Fonagy, 2001). Traumatic stress is an example of an event that can interrupt the attachment process, especially if this occurs very early on. Bringing attachment and neurobiological mechanisms together is more much more complex than traditional attachment theories. Here, the dynamics of the regulatory systems are also crucial in the child’s development. For a child with FASD, the attachment processes can be disrupted in

the same way as if they were to experience traumatic stress. Thus, disrupting a parent's ability to adequately attune and co-regulate their child.

Summary

Adopting a child is commonplace in the world today, especially in the United States. Yet, there can be many complex and adverse unknowns regarding the child's history. A child may have been exposed to a great many environmental challenges in utero including toxic substances, excessive fluctuations in stress hormone levels, and/or lack of or insufficient prenatal care. After birth, the child may experience neglect during early months of life, stress from inconsistent caregiving, and/or being placed for adoption. Any of these risk factors may impact neurocognitive development in addition to influencing the development of a secure attuned attachment.

Attachment, which is a biologically based bond between a caregiver and their child, is rooted in ensuring the child's safety, security, and survival. When a child is adopted and has special needs, many of these factors may be compromised, hindering a child's ability to be physically and psychologically close to their primary caregiver (Fonagy, 2001). This can also negatively impact a parent's experience of parenting their child, hindering patterns of arousal and regulation, which are needed to handle stressful situations. Because a major function of attachment is an ability to control stress and self-regulate, early relational attachments are critical and impact future health (Applegate & Shapiro, 2005). When considering the adoption of a child, and all the potential corollaries, attachment theory has gained considerable status in the field of social sciences and social work (Haight, Kagle, & Black, 2003; Arredondo, 2000).

From a research perspective, a multitude of studies have been carried out in the attempt to understand the psychological and emotional impact of adoption. However, very few have focused on the lived experience of the adopting parent, especially those who unknowingly adopt a child with Fetal Alcohol Spectrum Disorders. This qualitative study explores the lived experiences of such parents and the data will be analyzed through Interpretative Phenomenological Analysis, using attachment theory, neuropsychological, and psychodynamic perspectives.

Theoretical & Operational Definitions of Major Concepts

For the purposes of this study, terms will be defined as follows:

Adoption: To take by choice into a relationship; especially, to take voluntarily, a child of other parents, as one's own child (Merriam-Webster, 2014). Also, replacement of abandoned, relinquished, or orphaned children within an adoptive family (Juffer & van Ijzendoorn, 2007).

Attachment: A biologically based bond between a child and their caregiver, which is rooted in ensuring the child's safety, security, and survival (Cassidy, Jones, & Shaver, 2013).

Attachment Theory: A theory that (a) suggests an evolutionary advantage, especially in primates, for the forming of close emotional bonds with significant others, and (b) characterizes four different types of relationships between human infants and caregivers. The patterns of attachment established in infancy have been shown to affect the individual's later emotional development, relationships, and emotional stability (Schore & Schore, 2008).

Fetal Alcohol Spectrum Disorders (FASD): An umbrella term for birth defects that develop from alcohol exposure in utero (Mela, 2006).

Fetal Alcohol Syndrome (FAS): The most severe condition associated with extreme maternal alcohol intake during pregnancy. It shows a low birth weight and retarded growth, craniofacial anomalies, and neurobehavioral problems (May, Keaster, Bozeman, Goodover, Blankenship, Kalberg, & Robinson, 2015).

Hermeneutics: From the Greek word *to interpret* or *to make clear*; the theory of interpretation (Smith et al., 2009).

Internal Working Models (IWMs): Bonds that facilitate the development and maintenance of mental representation of self and others. A psychological sense of felt security and, as a mediator of attachment-related experience, it is the cornerstone of attachment theory (Pietromonaco & Barrett, 2000).

Chapter III

Methodology

Type of Study and Design

The qualitative phenomenological methodology used in this study is Interpretive Phenomenological Analysis (IPA), developed by Smith, Flowers, & Larkin (2009). The foundations of IPA include “the fundamental principles of phenomenology, hermeneutics, and idiography” (Pietkiewicz & Smith, 2014). The phenomenological facet of IPA has underpinnings tied to Husserl, who is considered the founder of phenomenology (Smith & Larkin, 2008). Husserl proposed the *method* of phenomenology would enable “basic concepts to be framed in a rigorous way,” which is “concerned with the primary reality, the thing itself as it appeared: that is, the ‘phenomena’” (Smith & Larkin, 2008, p. 11). The experience is subjective and was accessed through interpretation by the researcher (Spinelli, 2005). IPA also emphasizes that the research exercise is a dynamic process with an active role for the researcher in that process.

The second foundational principal of IPA is hermeneutics, the theory of interpretation. Hermeneutics, from the Greek word *to interpret* or *to make clear*, offers a critical part of the theoretical insights for IPA; therefore, it is important to recognize the work of Heidegger. In this methodology the researcher’s *dual role* was to make the interpretation process dynamic and constant. Heidegger suggests that, because appearance

has a double quality, we must be cognizant of that which “may be latent or disguised as it emerges into the light” (Smith et al., 2009, p. 24). Further, Heidegger’s perspective focuses on “*person-in-context*, and the phenomenological concept of intersubjectivity” (Smith et al., 2009, p. 17). Thus, the dynamic process between the researcher and the participant allowed for “the shared, overlapping, and relational nature of our engagement in the world” (p. 17). When conducting IPA and understanding its theoretical insights, Heidegger’s attribution of phenomenology as a hermeneutic initiative is noteworthy.

The third foundational principle of IPA that was used in this study is idiography, which focuses on the details of individual people. Smith et al., 2009, describes idiography as “an argument for a focus on the particular... [leading] to a re-evaluation of the importance of the single case study” (p. 32). In other words, this study was an in-depth analysis of individuals, focusing on their distinctive circumstances around adopting and raising a child with an FASD. This component of IPA allowed me to analyze the in-depth experience of each of the participants, followed by generating important themes to compare and contrast.

The overall intent for using IPA for my study was to comprehensively explore what it is like to be a parent who unknowingly adopted a child with an FASD. From a hermeneutical frame of IPA, this study attempted “to make sense of the participant who is trying to make sense of what is happening to them” (Smith, Flowers, & Larkin, 2009, p. 3). The subjective experiences of each individual were fully explored and the analysis of the data allowed for an in-depth exploration that was flexible and in detail. Moreover, my interpretation of the data was part the dynamic and constant process, as IPA methodology

includes a repetitive dialogue between the smallest unit of meaning and the wider context of each interview as meanings emerge (Smith et al., 2009).

Population and Sampling

Purposive sampling was used to recruit adoptive parents for this study. This method of sampling involved selecting participants according to the needs of the study (Moustakas, 1994), which involves examining a unique phenomenon—parenting children who have been diagnosed with FASD. More specifically, each of the participants have adopted a child who was later diagnosed with Fetal Alcohol Spectrum Disorders and, at the time of adoption, these parents were unaware of their child’s history of prenatal alcohol exposure. To ensure for a more in-depth exploration of their experiences following their child’s diagnosis, the first interview took place at least one year from the time that their child was diagnosed with FASD. The sample size is six individual adult participants. In IPA, a range of three to eight participants allows for sufficient in-depth engagement with each case and further facilitating a “detailed examination of similarity and difference, convergence, and divergence” (Smith et al., 2008). The study allowed for couples to participate; however each person was interviewed and analyzed as individual participants. Three participants live in the greater Chicagoland area and three participants are from rural Indiana.

Data Collection Methods and Materials

The following steps were taken to conduct the research:

1. Distribution of study flyers, which include the name and address of the principal investigator and research facility; purpose of the research; a summary of criteria used to determine eligibility for the study; the time or other commitment required of the subjects; and the location of the research and the person to contact for further information (please refer to Appendix A—Study Flyer).
2. Study flyers and a recruitment letter (please refer to Appendix B—Recruitment Letter) were distributed in person, via mail, and email to individuals who specialize in evaluating and treating children who have been prenatally exposed to substances of abuse. Flyers were also distributed to greater Chicagoland area FASD parent support groups as well as agencies connected with NOFAS Illinois, the state affiliate of the National Organization on Fetal Alcohol Syndrome.
3. When potential participants contacted the principal investigator expressing interest in the study, the following phone interview script (please refer to Appendix C—Phone Interview Script) and questions were used as a foundation to determine their eligibility for the study:

Hello, my name is Amy Groessl - I am a PhD candidate at the Institute for Clinical Social Work in Chicago. I am conducting a research study about the experiences of adoptive parents who unknowingly adopt a child with Fetal Alcohol Spectrum Disorders. I have a brief survey that will take about 5

minutes of your time to complete; your participation is entirely voluntary, you may skip any of the questions that you don't want to answer, and I am not collecting any identifying information. Because I am looking for specific aspects to study, the following questions will see if you are a good match to participate.

- a. Have you adopted a child? (If yes, go on to b.)
- b. Has your child been diagnosed with an FASD? (If yes, go on to c.)
- c. Was your child diagnosed following the finalized adoption? (If yes, go on to d.)
- d. Would you be willing to participate in two interviews (in-person) and a follow-up phone interview? (If yes, ask for more contact information so that a PDF packet of information can be emailed).

The packet included a letter detailing the study - including risks, benefits, confidentiality, and the consent process. The consent was signed in-person before the initial interview began.

4. Each parent participated in two in-person interviews. Each interview lasted between 60 and 90 minutes and all were conducted in private locations. At the beginning of the first in-person interviews, the following script was followed as a frame to introduce the study and the process:

Hello, it's nice to meet you in person. As we discussed on the phone, I am conducting a research study about the lived experiences of parents who adopt a child who has been diagnosed with Fetal Alcohol Spectrum Disorders. During our time together, I will ask you specific questions about your

experiences, thoughts, and feelings about your child, which will include any challenges, triumphs, worries, and hopes. Your participation is entirely voluntary and you may skip any questions that you do not want to answer. No personal identifying information is being collected and you can choose a false name that will be used during the write up. Any personal identifiable information collected during the survey will be kept strictly confidential. The audio recordings and transcriptions of those recordings will be destroyed when the final paper is complete. If there is any point in time that you are feeling distress and wish to stop the interview, just let me know and we will stop until you are ready to resume. Do you have any questions about the research study? Are you ready to begin? (Please refer to Formal Consent Document—Appendix D).

The second interviews took place a day to several weeks following the first interviews, depending on the participants' schedules and availability. In addition to the above protocol, participants had an opportunity to read through their interview transcripts and provide feedback. This form of member checking was conducted with a phone interview for five of the participants and another in-person meeting with one of the participants who asked to do so. The member-checking process was conducted to increase the validity of the data, and all feedback was incorporated into the findings.

Interpretative Phenomenological Analysis (IPA) was the methodology used to obtain qualitative data utilizing semi-structured interview. The goal of this process was to uncover the struggles, resiliencies, hopes, and realities of the participants.

Questions/prompts for the interview for this study are detailed in the data collection section.

5. Throughout the interviews, I conducted my own reflective journaling, which is a form of independent audit. Immediately following each interview, I audiotaped reflections in addition to later writing thoughts in a logbook. I also conducted some reflective journaling throughout the data analysis process and shared this information with my advisors along the way. For IPA, reflective journaling is a critical contribution to the quality and validity of the process, as it is an established method of “interpretation and bracketing as a reflective mechanism” (Vicary, Young, & Hicks, 2016).
6. *Transcription of data* was conducted following each interview to best capture the details and individual distinctions of each interview. As instructed for IPA, the transcriptions were typed out verbatim, including “notable non-verbal utterances (such as laughter), significant pauses, and hesitations” (Smith et al., p. 74).
7. *Consultation with advisor* took place after the first several interviews, so that my own reflections could be brought into the process of analysis.

Analysis derived from the qualitative data of IPA process allowed for an in-depth answer to this study’s question, “What is the lived experiences of parents who unknowingly adopts a child with Fetal Alcohol Spectrum Disorders?” The aim was to elicit detailed, in-depth, rich, and first-person accounts of the participants’ phenomena and experiences. Semi-structured interviews allowed for a flexible dialogue in real time. The following are sample interview questions and prompts used as a frame during each of the interviews (please also refer to Sample Interview Script—Appendix E):

- Please tell me about yourself
 - *Where do you live?*
 - *Where do you work?*
 - *What is your day-to-day life like?*
 - *What are your hobbies?*
- Can you tell me about your family of origin?
 - *What happened?*
 - *What was it like?*
 - *How did that make you feel?*
- What were things like for you when you were a child?
 - *How did that feel?*
 - *What did you do?*
- Can you describe your relationship with your parent(s)?
 - *As a child?*
 - *As an adult?*
- Please tell me about your current family.
 - *Are you single, married, or in a partnership?*
 - *How many children do you have?*
 - *How many are biological? Adopted?*
 - *Other, like step-children or foster-children?*
- Please describe what first motivated you to adopt?
 - *When did you first begin to consider adoption?*
 - *What was that like? What concerned you the most?*
 - *How did your partner/spouse feel (if applicable)?*
- Explain more about how you came to the decision to adopt your child?
- Describe your fantasies/expectations of adopting a child?
 - *Is it how you envisioned it to be?*
 - *Is anything different than you expected?*
- What was your experience with the adoption agency or adoption workers?
 - *What was positive?*
 - *What kind of challenges did you have?*
- What did you notice about [your adopted child] that prompted you to get testing?
 - *How old was he/she?*
 - *What kinds of things were happening that were of concern?*
 - *At home? At school? In community settings?*
- Describe your experience of first learning about your child's diagnosis with FASD?
 - *Who told you?*
 - *What did you remember feeling or saying when you learned about the diagnosis?*
Discuss how your life has changed since learning about the diagnosis?
 - *Is anything worse? Is anything better?*
 - *What do you imagine the future to be like?*
- How have you coped since the diagnosis?
 - *Personal care?*
 - *Professional?*

- *Community/support groups?*
- What, if any, has impacted others in your family?
 - *Your spouse/partner?*
 - *Other children?*
- Who has been available for you in a supportive role?
 - *Personal?*
 - *Professional?*
 - *Community?*
- How has the FASD diagnosis impacted your relationships with others?
 - *Both positive and negative...with your child?*
 - *Other children?*
 - *Spouse/partner?*
 - *Extended family?*
 - *Your child's school teachers/administrators/support staff?*
- Is there anything else you'd like to share?

Procedures for Data Analysis

A phenomenological data analysis of my study followed the guidelines of Interpretative Phenomenological Analysis. The analysis was “an iterative process of fluid description and engagement with the transcript” (Smith et al., 2009, p. 81). The following steps were taken during the data analysis:

1. *Transcription:* During the transcription process, significant statements, sentences, and quotes were highlighted and reflected upon. This process, called horizontalization, helped to provide a more in-depth understanding of how the participants experienced the phenomena of adopting and raising a child with FASD (Creswell, 2007).
2. *Listening, reading, and re-reading:* Repeated listening and reading of the transcripts allowed for the discovery of embedded accounts of their lived experiences in addition to binding certain sections of the interview together (Smith et al., 2009, p. 82). Each re-listening and re-reading helped me immerse myself in the data, providing new insights each time.

3. *Initial Noting*: This was the most time-consuming process of the data analysis. Smith et al., (2009) explains, “The aim here is to produce a comprehensive and detailed set of notes and comments on the data” (p. 83). As I would read the transcriptions, I would highlight, underline, and take notes to begin the process of identifying emergent themes that reflected the source material.
4. *Developing emergent themes*: During this process, the main task was to turn my previous notes into emergent themes that not only reflect the participants’ original words, but also my own reflections and interpretations. The themes that emerged brought together a range of understandings relating to both.
5. *Searching for connections across emergent themes*: Smith et al., (2009) assert, “This level of analysis is not prescriptive and the analyst is encouraged to explore and innovate in terms of organizing the analysis” (p. 96). Following the authors’ suggestions, the following methods were used during the analytic process:
 - a. Abstraction: A basic form of identifying patterns between emergent themes and developing a sense of super-ordinate themes, which emerge at a higher level as a result of putting themes together.
 - b. Subsumption: Similar to abstraction but operates as bringing together a series of related themes.
 - c. Polarization: Examining transcripts for the oppositional relationships between emergent themes by focusing on differences instead of similarity.
 - d. Contextualization: Looking at the contextual or narrative elements within the emergent themes.
 - e. Numeration: Taking account the frequency with which a theme is supported.

- f. Function: Examining themes for their specific function within the transcript.
 - g. Bringing it together: Utilizing the aforementioned strategies as they fit to my transcripts.
6. In the final step, a composite description—based on the experiences of all the participants—was written in the *Results* chapter, presenting the essence of the phenomenon of adopting and raising a child with an FASD.

Statement on Protecting the Rights of Human Subjects

The risks to individuals participating in this study included some strong affect and heightened emotions due to the emotional intensity of the content, which included issues related to loss and personal familial events. Additionally, some participants' experiences of answering certain questions about their child may have altered their thoughts or feelings about their child. To reduce the adverse impact of these situations, the researcher took all necessary steps to minimize these risks, including stopping the interview when needed and the provision of referrals to appropriate resources. This included providing contact information for clinical therapists for two of the participants.

Precautions made to minimize risk also included maintaining confidentiality throughout the entire project. To ensure confidentiality, no identifying information was placed on any study materials and participants were all able to choose their own false name. A list tying the false participant names with their true identification information was kept in the researcher's office under lock and key, and this list will be destroyed at the conclusion of the written study. As data was collected, a password-protected computer database was utilized for data input, and only the researcher had access to the data and

databases. Furthermore, the informed consent forms included a section that describes how participants would be asked about their family experiences. Participants were all told that they did not have to answer any questions that they found upsetting or did not want to answer. At times when participants experienced any distress, the researcher ceased asking questions until the participant agreed to continue with the interview process

Chapter IV

Results

Introduction to Results

The participants for this study consisted of six (n=6) parents who have adopted a child who was diagnosed with an FASD after the adoption was finalized. Participants' children were all minors at the time of receiving an FASD diagnosis. Participants were not excluded from the study based on their age, gender, race, ethnicity, or religious affiliation. All were fluent in English and were able to meet in-person twice and at a private location of their choosing. The adoptive parents who participated in this study currently live in suburban Chicago, Illinois (n=3) or rural Indiana (n=3). The data collected were from a purposive sample of adoptive parents, all of whom are raising a child with an FASD. Four of the six participants are within a married couple that participated, but all participants were interviewed as individuals.

Name	Elle	Greg - Male	Victoria	Deborah	Rob	Nicole
Age	60	61	46	41	56	55
Gender	Female	Male	Female	Female	Male	Female
Marital Status	Married (to Greg)	Married (to Elle)	Married	Married	Married (to Nicole)	Married (to Rob)
Race	Caucasian	Caucasian	Caucasian	Caucasian	Caucasian	Caucasian
Work	Psychotherapist	Executive	Stay at home Mom	Part-time Para-professional	Retired Special Ed. Teacher	Admin. Assistant at University
Adopted Child	Daughter, E, age 19, adopted from Russia at age 10 months	Daughter, E, age 19, adopted from Russia at age 10 months	Daughter, A, age 9, adopted from Poland at age four	Daughter, G, age 10, adopted from Russia at age 18 months	Son, M, age 15, adopted from US at age 10	Son, M, age 15, adopted from US at age 10
Residence	Suburban Chicago, IL	Suburban Chicago, IL	Suburban Chicago, IL	Rural Indiana	Rural Indiana	Rural Indiana

Before presenting the data on each of the super-ordinate themes and component themes, the following introductory section is intended to provide basic demographics and descriptions of each participant, including their initial thoughts of adoption.

The Participants: Family Background and Initial Fantasies of Adoption

Elle.

Elle is a 60-year-old Caucasian female who is married and lives in suburban Chicago, Illinois. She and her husband have two children, a biological son and an adopted daughter. The interviews were conducted at Elle's suburban Chicago office, where she has a part-time psychotherapy practice. Elle shared some thoughts about her childhood and family of origin:

I am the oldest of three kids; I have two younger brothers. I was always a stellar student—valedictorian of high school—academics came pretty easy for me. I grew up in a southern Illinois town with a Germanic background—it was rigid and

patriarchal. My parents were very religious [but] on the liberal end. They were very socially active but also steeped in like a split: good/bad and right/wrong – and I always had to be on the right side. I did back flips for a long time trying to be on the right side.

Elle further described how there was a lot of chaos within her family of origin. She elaborated on how it was her job to keep her mother in balance and also that her father was never a compassionate man. For Elle, the years of growing up in a chaotic home lead to depression, an eating disorder, and low self-esteem. It was because of these issues above that led Elle to have doubts about becoming a parent:

I know that they loved me. I don't have any questions about that; they loved all three of us—and they still do. But, I went off to school [college] and everyone else was missing their families, and I was like, “Oh my gosh this is the best thing I've ever experienced!” But, with all that traumatic [childhood] stuff and the [eating disorder], I didn't think I could tolerate carrying a baby and watching my body change like that. And also there was a part of me that didn't want children. I didn't think I could manage having a child.

Elle met her husband, Greg, in college and they dated for several years before discussing marriage and children. She recalled their discussion of children and told him she didn't know if she wanted to have any. Elle explained, “He brought up adoption as an option and that felt okay to me. We got married right after college.” They both decided to steer away from having a family after marrying to pursue higher education. Elle has a master's degree in divinity and a doctorate in psychology.

After years of school and establishing a career, they decided to try to have a child. Elle recounted what that was like:

I got pregnant right away and we had our son—and I fell in love. It was a hard pregnancy—I had to be on bed rest for two months but, once he was born, everything was great. I will tell you, it’s the best thing I’ve ever done. It was great for me. I just wanted to hold him and that was the first time in my life. I had never experienced anything like that. I have a memory of being with him, and he’d love to fall asleep on my chest. One day I realized, oh my gosh, our breaths are completely in sync! It was the best sense of unity; this is what’s supposed to happen...this is where you get the original oneness. It was very powerful. I feel like having a child was helping to heal me—in some really deep kind of way.

Because of the positive experience of parenting and wanting to give their son a sibling, Elle and Greg tried to have another child. She shared: “I went through two miscarriages, had an ectopic pregnancy—it was horrible. I couldn’t do [it] anymore.” Elle recalls that after those experiences of difficulty and heartbreak, they decided to adopt: “If we want another child, let’s adopt. So, we started the process.”

Greg.

Greg is a 61-year-old Caucasian male who is married and lives in suburban Chicago, Illinois. He and his wife have two children; a biological son and an adopted daughter. The interviews were conducted at his office. Greg was born in Chicago, but spent the majority of his childhood in the Chicago suburbs. He described how his parents

decided to move there so that he and his siblings would have better opportunities. Here he describes his family of origin in more detail:

There were actually two [of my siblings] who were stillborn—the oldest and the youngest. My brother is now the oldest, I'm the second oldest, and I have two younger sisters. [My parents] emphasized education, so they made sure that as we were growing up, we were responsible with regard to school. As I got older, I didn't take it as seriously, so I think that was a disappointment to them.

Greg met his wife, Elle, in college and they married before they both attended graduate school. He recalls having a discussion with Elle about children, and at that point, learned that Elle may not want to become a mother, at least at that juncture in her life. He recalls being okay with that initially, but over time grew to wanting to have children. He shared that adoption was something they discussed that could be an option:

For me it was, in many ways, an outgrowth of my own experience in my [childhood] family, meaning that my parents moved to the suburbs to give their children the best opportunity for a life that they wouldn't have had if we had lived in the city—certainly a life that was different from their own. I think in some ways I imagined something like that—where, by adopting, we'd give someone an opportunity to grow and to have a life that they wouldn't have had otherwise. We had made a decision for a while that we were going to be intentionally childless—we were going to focus on our careers and our work and our relationship... so we did that. And then I remember at one point... the future for me—being a parent—was important and if [Elle] couldn't make that kind of decision—I could understand but I wasn't sure what our future would be like. We talked through

that and I think that it was a matter of timing. So, we waited a little while but then began to try to have a child.

Greg's early fantasies of adopting a child were partially altruistic, stemming from his own experience of his parents' sacrifices so that he and his siblings have more opportunities by moving to the suburbs. Greg talked about his experience of becoming a father. It was at that point that he began to reflect on his own father, whom he described as a "gentle soul." As he described becoming a father with his biological son, K, Greg's emotions became visible: "Oh, I loved it (choking up). Really special. But I had more of the kind of relationship with [K] that I wished my dad had with me." He further described wanting to have another child, but Elle had several miscarriages and it was "too painful" to go through it again: "We started talking about adoption again and I thought maybe we could be more help going to someplace where most people aren't going [to adopt children], so we happened to land on Russia."

Victoria>

Victoria is a 46-year-old Caucasian woman who was born and raised in Poland. She is married and she and her husband have three children ages 12, 9, and 8; the youngest two are adopted. They live in suburban Chicago and Victoria is a stay-at-home mother. One interview was conducted at a private office of a downtown Chicago children's agency and the second interview was at Victoria's home. During our first interview, Victoria described her experiences of being raised in Poland with her two brothers: "Poland was still a communist country, so it was a little different than what people have here." She

lived in a small home with her brothers, parents, and maternal grandparents. She shared how her childhood was a struggle in some ways:

It was kind of like two families in one. [Because of that] I never wanted to live with my parents when I had my own family—it was always tight and we were all so squeezed [together]. As a child, my emotional needs were not met, but I think it's kind of difficult for communistic countries—people don't show emotions—they don't [say]—"I love you—you're so precious to me." That wasn't easy for me, but we always felt safe and there were many good things, too. So after college, I came to the United States and saw it as an opportunity for new life experiences. I've been living here for almost 20 years.

Victoria recounted when she and her husband began to discuss children and adoption came up as a possibility if they were not able to have their own children. "We were both like—we would adopt—no question." After they had their biological son, Victoria described how adoption was still on her mind. She recounted that the decision to adopt was a very personal experience that was driven by faith:

I felt it in a very personal way, to be called to adopt. And it was pretty amazing because the first time—when I was thinking seriously about adoption—I was praying, "God, if you want us to adopt, please show me, what should I do?" After that, I read the gospel of Matthew—when Jesus takes this little child and says, "Whoever accepts a child in the name of God accepts me; whoever accepts me accepts my father who sent me." So I'm like, this is adoption; I was like, yes, we have to do it.

Deborah>

Deborah is a 41-year-old Caucasian woman who lives in rural Indiana. She has been married to her husband since 1998, and their adopted daughter is 10. Deborah has one younger brother, her parents divorcing when they were very young:

We moved around quite a bit because my father was in the military, but they divorced when I was 5. After the divorce, we moved in with my grandmother until my mother could get on her feet—which never really happened.

Deborah shared that her mother was gone a lot and describes their relationship as “strained.” Fortunately, she had a very close relationship with her grandmother. Deborah described some heartfelt memories of growing up in her grandmother’s home and the difficulties of not being close with her mother:

We were closest to grandma and I especially remember her cooking. She was raised on a farm so everything was home cooked. We had real homemade noodles and it was all so good! I remember her in the kitchen cooking a lot—and making everything from scratch [which] takes a lot of time so she would spend the whole day in the kitchen cooking meals. My mom—because she was single and young—she’d go out at night and we wouldn’t see her until morning. I have never had an awesome relationship with my mom—it was just life—and we had our grandmother there for us.

Deborah met her husband, Bill, when she was a senior in high school. They dated for five years and Deborah went to college before they married:

We started to talk about having kids right away, but when we met with his doctors we learned that he probably couldn’t have children because of his [chronic

disease]. And so we went into the marriage knowing that having children was not really a possibility.

Bill has a sister who is adopted and Deborah describes the situation as “disastrous.” It was because of his experiences of being raised with an adopted sibling that prevented Bill from initially considering adoption. His sister was diagnosed with an FASD as an adult, and still has problems taking care of herself. At that point, Deborah shared that she had to come to terms with the fact that they may never have any children, biological or adopted. She tearfully recalled:

That was rough, because all around us—all of our friends were having babies—and we’d all hang out together and they’d all be breastfeeding and chit chatting. I’d be like, “I’ve got to go—I forgot—I have a meeting.” It was a lot of hurt and a lot of frustration because I didn’t want to sit there and watch it go on. It was very painful. I eventually got a job as a nanny and the little girl was adopted from Kazakhstan. Since their house was under construction I would bring her home with me. So that’s when she met Bill...and she had him twisted around her little finger so fast! I think that opened him up to the prospect of adoption.

Deborah continued to describe how they went through a period of time debating on whether to adopt or to try in vitro fertilization:

We eventually chose adoption because Bill’s insurance company didn’t cover a penny of IVF, and then we started doing research for domestic or international [adoption]. Bill didn’t want a situation where we adopted a child and then years later the birth parents come looking. So, he really wanted international, so that’s how we started.

Rob.

Rob is a 56-year-old Caucasian male, married to Nicole, and they have five children, four adult biological sons and one adopted son, age 15. Rob has been a special education teacher for 31 years and lives in a rural farming community in Indiana. Rob described having deep roots in the area going back several generations:

I have an older brother and I was number two, and then I have a younger sister and younger brother. Dad was a mail carrier and mom stayed at home, except for summers—she was a 4H leader for 28 years. We were all in 4H—very active—we showed cattle. By the time I was 14, I had 25 head [of cattle] of my own. We had a garden and we all did whatever had to be done. You had chores to do—no time for football, basketball, and things like that. I met my wife when we were freshmen in high school and we dated for six years before we married. We've been together for 42 years, married for 36.

Rob has a bachelor's in special education for mild, moderate, severe, and multiply and physically handicapped. He talked about his early years teaching special education, the defining experiences of working with children with severe intellectual disabilities, and how those experiences eventually shaped some of his hopes and fears of becoming a parent:

I was a teacher's aide in a welding class and we had two boys with Down syndrome. The teacher told me, "Just leave them alone, they don't know what they're doing, they're not capable of learning." By the end of the day they had second-degree burns on their arms and they had to be taken to the hospital. I think

it scared me a little bit. I once had a student die in the classroom. That was very difficult, and it still haunts me today. I was only two weeks in as a student teacher—she had a seizure—and we called the ambulance within three minutes but they got stuck in traffic. And then it was up to me to explain to the rest of the kids what happened. I actually used clown makeup and painted on fake tears, since a lot of [the kids] didn't understand grief; we talked about the sadness and that kind of thing. And then I can remember when Nicole was pregnant with our first son...every night I'd pray, "Lord, now just because I have a degree in special education does not mean you're giving me a child with special needs."

Rob and Nicole's first child was born when they were in college. He described becoming a parent at such a young age:

It was overwhelming and a lot of responsibility; we ended up getting married in student housing and I worked three jobs to support us and also went to school full-time. Eventually I got a better full-time job and we bought a house.

Several years later, one of his biological sons began having some emotional and educational challenges, so Rob quit his full-time job and worked part-time so he could help his son. He recalled: "That changed [my son]. He knew Dad was there and that he was important."

About six or so years ago, a boy named M, joined Rob's class. M had recently moved into the area after being placed in a therapeutic foster home in their town. Rob recounted the circumstances that led up to he and Nicole adopting M:

He was about nine and had been in 12 foster placements before he moved to the area. When he joined my class, he had this entourage—14 people came for his

conference at school. His [therapeutic foster parents] paid no attention to adoption. He eventually went to live with a pre-adoption family and that was a disaster. They were always calling the police on him and during the holidays, they put him into respite because they didn't want him with the rest of the family, even though they were going to adopt him. [Eventually] they decided they were tired of it; they were going to put him into an institution. I pulled the CASA (Court Appointed Special Advocate) worker aside and said, "you need to go back to the judge—I think we will become his foster family. He does not deserve to go [to an institution]." So 15 days later, just after Thanksgiving, we had our foster license. By March, we told them we were going to adopt M. They said that I was the closest thing to a relative that he had ever had, so they just considered it a relative adoption.

Nicole.

Nicole is a 55-year-old Caucasian woman, married to Rob, and they have five sons, four biological and one adopted. Nicole grew up in rural Indiana, the middle child in a sibship of three girls. Her father was a pastor, and they grew up heavily involved in their family church. Nicole was tearful when she recounted her growing up years:

I don't remember a whole lot as a little, little girl. When I hit middle school, I was the black sheep of the family and my mom and I clashed head to head all the time. Dad was pretty much never available. I don't remember it being painful [back] then; I think I do now more so than I did back then. I don't ever remember feeling

like he wasn't there. I always felt like I could go to him, but we knew he had other things and maybe [I] just didn't feel like a priority.

Nicole has a bachelor's degree and has worked at a university in budgeting and management for 36 years. She shared: "I'm reaching the point where I'm ready to retire. I've worked really since I was, let's see—I babysat through my summers from sixth grade on, so, I've worked since about age 12." Nicole was 19 when she started having children:

J was born in '82, A was born in '85, A was born in '87, and then E was born in '92. The two middle ones—they were just 21 months apart. They were just so close in age, and I was trying to work full-time, and it was tough.

When her children were older, Nicole said that fostering was something that was often discussed, but not adoption in particular: "We'd always kind of talked about fostering...in general terms, when the boys got older. But, it really started to hit home with Rob, especially because of his teaching." Nicole described her journey in the early stages of adopting their son. Her decision was, in part, due to her husband's work experiences but also because of her faith. She recalled the time when her son, M, joined her husband's special education classroom:

[Rob] always had a heart for M and he would come home and tell me stories, and he would [say], 'there's something about this kid.' When the situation with M presented, with knowing that he wasn't going to have a home and that the likely next step for him was an institution...when that failure started to happen with that adoptive family, and our youngest was moving out of the house, it just felt okay. It just felt right. It was just—a kind of peace and absolutely [about] faith. I feel like everything in our lives has really brought us to this point.

Results

Five super-ordinate themes and associated component themes emerged from the data, including Fantasies vs. Realities, Something is Off, Systems, Trauma and Isolation, and Seismic Shifts. What consistently emerged from the data were the participants' unconscious fantasies concerning adoption, including hopes and fears. The results show that some of their fantasies did indeed become reality; however, many participants experienced daunting and sometimes traumatic experiences leading up to and after their child Fetal Alcohol Spectrum Disorders diagnosis. Each of the super-ordinate themes contains some associated component themes, as noted in the following table:

Super-Ordinate Themes	Associated Component Themes
The Process of Adoption: Fantasies vs. Realities	
Something is Off	<ul style="list-style-type: none"> • Early Concerns • Putting the Pieces Together • Like a Bomb, But Now We Can Name It
Systems: The Good, The Bad, and The Ugly	
Trauma and Isolation	<ul style="list-style-type: none"> • Constant Vigilance & Chaos • Grief & Loss
Seismic Shifts	<ul style="list-style-type: none"> • Advocating • Connections • Meaning-Making • Moving Forward

Super-ordinate Theme I: The Process of Adoption—Fantasies vs. Realities

This section of the results looks at each of the parents' subjective journeys of adopting their child. Here they share their subjective experiences, including some of their early fantasies, of what adopting a child would be like. Many parents talked about their experiences with various adoption agencies, and some recounted the first time they saw

their child in a photo or video. Most also shared some of their early underlying worries about adopting a child, some of which originated from families and friends experiences, in addition to what they read about adoption on the Internet and in print. There are even points of time early on that some of the parents wondered about Fetal Alcohol Spectrum Disorders, as will be mentioned in the following narratives.

Elle.

When Elle and her husband decided to adopt, they were told that they were too old to adopt a healthy newborn baby in the United States. They knew that they wanted to adopt a child younger than their toddler son. However, they were told by a U.S. adoption agency that most children available to adopt within the U.S. would be older or have a known severe disability. Here Elle describes that conflict and the process of moving forward:

We didn't know if we were up for that. So, I started meeting with a couple [of] people who had done adoptions internationally and we kind of just thought...why not Eastern Europe? That's where [my husband's] family is from and so we did. [The adoption agency] was through a group up in Minnesota that did Russian adoptions and we were excited! We had done a little research—I was more afraid of some of the reactive attachment stuff at that point. That was more on everybody's radar screen at that time—more so than fetal alcohol.

She further described the home study experience as “grueling,” and it took over 9 months. Elle's experience with the individuals who were conducting the home study was predominantly negative. Here she recalls feeling affronted by the process:

There was a lot of paperwork from [the adoption agency] but it was [the local agency] that tripped me up—the workers came to interview us and I think I said too much [because] I talked about some of my anxieties about having a girl—and they wrote me up! “We don't know if she's a good potential candidate.” I felt really offended because I had probably 15 years [experience] on some of these people and I thought, “You're not listening to what I'm saying!” My lesson in that was just to keep your mouth zipped.

After passing the home study process, Elle and her husband received a video of an infant girl at a Russian orphanage. During the viewing of the video they consulted with a pediatrician who was an adoption specialist. This was the beginning of the process of how Elle grappled with the earlier fantasy of her future adopted child and the reality of what it may be like—from excitement to conflict to hope:

The first video that I remember was this child that just looked limp—it was terrifying! [She was] maybe five months old—but lifeless—she was so skinny—she really looked malnourished. At the same time, we were supposed to be making a decision on if we are going to take this child or not. The conflict was horrible! I felt so guilty about not taking a child that needed a home. Well, her grandmother came back into the picture and took her, so she was off the table for us. [When] we got [our daughter's] video—here's this 6-month-old baby [with] huge cheeks! She was behind in developmental milestones, of course—she couldn't flip herself over and she wasn't crawling yet. But, the nurses had put a rattle out in front of her and she wanted that rattle—and she just kept going for it and going for it and going for it. I was like, oh my gosh, she has some persistence

in her! We showed the video to [adoption specialist pediatrician], and he said, “She's a good one, take her.” He's clear, he said, “You know there are a lot of things at this point that we cannot tell, but she has none of the facial features [of FAS] and there's something in her that has some drive and some determination.” And so we said, yes!, and that was that.

Greg.

Greg also described his experiences with the early process of viewing the videos. As he was describing this time in his journey, he also talked about how impressed he was with [adoption specialist pediatrician], feeling very supported. Even early on, we see Greg's sense of hope at the time when he first saw the video of his daughter:

The first video that was sent, the [family] changed their mind, so then it was the second video that was of our daughter. I just remember that she had a real sense of inquisitiveness, curiosity—maybe even an indomitable sort of spirit, because, here she is in this orphanage and she was attracted to things in her surroundings and seemed stimulated by them. [We] took the video to [adoption specialist pediatrician] and we're watching the video together and I wondered about fetal alcohol syndrome and he said, “You cannot tell by looking at the video.” I also remember he said [about FAS], “There are certain things that I would look for and I'm not seeing those things.” I think even if she would have been diagnosed at that time, we still would have gotten her, but I think we would have been better prepared in terms of what to deal with.

Victoria.

Victoria and her husband began to consider adoption when their biological son was about 3 years old. It was at that time that she started to look through the Internet for adoption agencies who worked with Poland, her country of origin. Because they were not financially ready for adoption, they waited several years to begin the actual adoption process. During those years, Victoria did a lot of research, so she felt ready when the time came to find an adoption agency. She describes a difficult experience, working with uncompassionate adoption workers, some of whom were swindlers.

We found an adoption agency in [suburban Chicago] and we did a home study and they gave us approval. But, the Polish adoption authorities refused to accept our paperwork because they needed a placement agency. It wasn't the [suburban Chicago] adoption agency's fault, it was the Polish director that gave us false information, including certain requirements that we were not told about. So we lost money and we lost time. Then we found another agency in Georgia, but they were very dishonest. They took money from us and didn't tell us that they were under federal investigation and suspended from being able to provide services. By the time I found out [through the Internet] that they were suspended, it was too late. So, again, we lost time and money.

Similar to others in this study, Victoria and her husband had many ups and downs, hopes, and disappointments. They finally found another agency in New York and one that assured them that they were not having any issues with the government. Unfortunately, she described the experience with them as "horrible" due to poor communication and "zero compassion." Because so much time had passed, they had to do another home

study, which entailed more time and money. They eventually found an adoption advocacy agency that worked closely with Poland and she learned that, because of her Polish heritage, they could likely get a referral from a Polish adoption agency within a few weeks. Although this part was a relief and very exciting, Victoria describes how she had feelings of disappointment when the referral came through:

The director of the Eastern European adoptions advocated for us and we got a referral within two days, on Mother's Day! I was initially thrilled, but then disappointed because we were hoping for a boy—the referral was for two girls. We were hoping for two children and at least one boy since my husband was a professional soccer player and we thought it would be good adopt at least one boy—a brother—for [our son]. They sent two blurry pictures and there was also a statement in the paperwork that one of the girls was bottle-fed alcohol by the [birth] mom and also that the [birth] mom is an alcoholic. I thought that's going to be Fetal Alcohol Syndrome for sure. So, I called our main adoption agency in New York, and they said, "No, she's healthy—look at her picture—there's no diagnosis." I'm like—hmmm—the picture's unclear—I think they are playing games with me. Then they say to me, "You don't want them, okay, no problem." I think, No! I just want more information about these children. It took them a month to get me [more information], but it was just a letter that stated, "the girls are so sweet, they play, and they can dance!" There was no other information, and we were stuck with [the agency] because of my paperwork. I have no clue how such uncompassionate people can work in that field—it's just horrible. It's a business you know, they wanted to be done with us. Adoption is really difficult.

Although ambivalent, Victoria and her husband moved forward with the process.

Victoria talked about how she was hoping for a boy and for healthy children but was constantly worried because both of the girls had a physical appearance that was “very suspicious.” When a local agency worker did an updated home study, Victoria said she “put more flame into my fears.” The home study worker—looking at the photos—said, “Yes, they both look like they might have issues [and] since the mom is still alcoholic there is a huge, huge chance that there will be some issues.” Victoria shared:

I was freaking out, I was scared, I was angry with this mom that fed her baby alcohol. She put wine in their bottles—wine or beer. That’s crazy! [Polish Social Services] asked her and she told them she did it because it helped them fall asleep and stay quiet. And this was written in the paperwork! I wondered, how much is not written? We knew that we didn't want a child with Fetal Alcohol Syndrome because someone told us that the brain is not able to rebuild. But, we didn't have the diagnosis, so we didn't know. And I still didn't feel any connection; it’s not what I expected. I saw these two girls—one was sucking her finger another was giggling—and both of them looked like they have issues.

For Victoria, faith was a big part in moving forward with the adoption process, despite her feelings of ambivalence and fear. She talked about praying to God and asking for guidance, eventually reading some passages in the bible, which she felt were telling her a story. Here she describes that internal shift—from fear to hope:

I eventually felt like God is telling me through this story, “You should go and adopt the one that I have chosen for you and just trust me.” This time God changed my whole perspective. I thought, is this a crazy ride or is this something

that we can handle? At that time, I knew that we would adopt them—I really knew deep inside. So we both went into it with open minds. We wanted [our son] to come with us to meet the girls, so we all went to Poland. And at that point, I was really curious to see them, curious to meet them.

Deborah.

Deborah and her husband knew they wanted to adopt an infant, but had a long and painful journey dealing with the process, including three separate countries over the course of eighteen months. Here she describes the beginning stages of the process:

I went online and started looking for an agency—I was looking for a country that had younger infants for adoption because I really felt like I needed an infant. So we found [adoption agency] that had a program in Nepal, and we started the application process. But then they announced that they were closing down adoptions because it turned out that some of the children [who were available for adoption] were being kidnapped or sold. We totally agreed! That would have been a nightmare for me to have a child and realize that my child had been kidnapped for the purpose of adoption. So, [at that point] we were almost a year into the process.

During that first year, Deborah read a lot of books on adoption, took all available online classes, and made sure to turn in all the required paperwork. Once she and her husband found out Nepal's adoption agency had closed down, she described feeling "in limbo." They eventually got a few referrals from Guatemala, but received very little information in both instances:

I emailed them asking to get more information on the child, but then we received a message that the child was no longer available. So, then we received another referral for another infant in Guatemala and we were in the process with her and I received a call from the adoption agency stating that the birth mother changed her mind. So, then it was back to square one! It was heartbreaking because we had a picture of her, we were making plans for bringing her home—so, it was hard.

Because of their experiences with Nepal and Guatemala, the adoption agency pushed Deborah and her husband ahead of everyone else waiting for an adoption referral in Russia. But at that time, Deborah recalls that they were opposed to adopting from Russia because they had heard so many stories about children with Fetal Alcohol Syndrome and attachment problems. Here Deborah conveys her experiences with feeling pressure to choose, but at the same time they were still grieving:

The day we received [our daughter's] picture was the same day that they told us that the other birth mother [in Guatemala] had changed her mind. We were still in the process of grieving the other child, but we knew we had to make a decision fast because agencies don't want to wait a long time for you to decide, so there was some fear in making the decision. At this point, we were thinking what is wrong with this agency? This is the third country now that we are trying and this is our third referral. So, at the point when we accepted [our daughter's] referral, we were at the point like, "let's just get this over with so we can be done with these people." I was so fed up with them.

Ambivalence during the adoption process continued, in particular when seeing first photos of her child, an 11-month-old girl from an orphanage in rural Russia. This is also

layered with Deborah's not having adequate time to process the grief and loss of the child she thought she would be adopting. Further, Deborah's first experience seeing a photo of the child [who would become her daughter] is another example of how the fantasy does not match the reality:

The first time I looked at the pictures I thought, "This is not my child," especially because we were still thinking of the other one. But, as we started getting into the process and praying that this one actually worked—we started to feel more and more that she was meant to be ours. But, the first time I looked at her I was like, hmm—I'm not feeling it. It was rough. I think [my husband] had an even harder time; he had already started to adjust to the other one and he absolutely refused to allow himself to get sucked into the anticipation because he didn't want to feel that heartbreak again.

We see Deborah's shift over time—from grief to worry to acceptance—but then only to get the rug pulled out from under her once again:

Well, we weren't done with our ride yet. Shortly after we accepted the referral for [our daughter], a woman in Utah murdered her children that she had just adopted from Russia. [As a result] Russia put a temporary ban on adoptions until further investigations could be made.

Rob.

Rob described how he and his wife decided to adopt. He had recently retired, his four adult children had all moved out of the home, and there was a boy, M, in need of a family. M had been in over twelve foster homes, several of which were pre-adoption

homes that failed. Rob was M's teacher in a classroom for children with severe emotional problems. He saws something in M and told his wife about him over the course of several years. When they decided to foster M, Rob talked about the day they asked him to be in their family. It was at a Christmas dinner, just a month after starting to foster M. The family was gathering to take a group photo, with the whole family and close family friends. Rob showed me the family photo while describing the experience:

This picture here is how we asked M if we could be his family. While we were getting ready to take the photo, all the family got together, and there was an empty chair in front. So, we asked M if he would fill the chair and become part of our family. He sat there and bawled and cried for a while. My friend, who was there and who knew M and his background, said to me, "Now [Rob], this is the best Christmas you could ever have." See here [in the photo]—it's all of us; my parents, kids, all the grandkids, and our new son, M. Soon after that we adopted him.

Rob further described how his family and friends would often question their decision to adopt and how his faith was one crucial factor that helped affirm the decision. But, even though there was peace in the decision, he admits that it has been an arduous journey, especially in the beginning:

They'd say, "Are you sure you're ready? They're already leaving the nest— they are all ready to go—now you're going to have your time." And I would say, "yes, but because of our faith, the Lord is telling us to do this, and if I turn my back and walk away, then I'll never have peace." It was rocky and, of course, my wife had never dealt with anything as intense as what M could be. It was 3 years later that

our bedroom door could be closed. For 3 years our bedroom door had to stay open because he wanted to make sure we were still there. And he had night terrors for all those years.

Nicole.

When M came to live with Nicole and Rob, she knew there would be challenges. She talks about the intensity and the reality of M's complex issues and also touches on how she felt, in the beginning, that love would be enough:

When we started to kind of bat around the idea of fostering M, it never really was a scary thing for me until probably the day he came home—and his first rage at home. That's when I was like, "I'm not sure I can do this." This child is so intense—I had never seen a meltdown quite like that with a child. I mean, my kids got mad, they stomped off, did whatever—but I had never had seen something like this in my life. And that's when I realized, wow, this is intense. Still though, in that dream world of mine, [I think] love is going to be enough. I still have that dream sometimes.

Nicole also shared how she developed a love for her son and how her faith was also a guiding factor for her:

I fell in love with him almost right off the bat. I guess I'd fallen in love with him just from talking to Rob about him. The day that we decided we're going to investigate this further—things just started to click. It was just like, "Okay God, I surrender—we got this, and it's in your hands... not a thing we can do but follow the path that you set for us."

It seems that all of the participants had difficult starts in the process of adopting. Through their narratives, we learned of their early fantasies of what they first envisioned and how those hopes were broken down and sometimes shattered throughout the process. There was also a common thread on how some of the adoption agencies and related systems were dishonest or had a lack of compassion for the adoptive parents. Many parents even admitted that they had early worries about FASD, yet their fears were either minimized by professionals or outright dismissed. The internal conflicts were intense and each participant talked about their own experiences moving forward with adoption: shifting from fear—to ambivalence—to hope.

Super-Ordinate Theme II: Something Is Off

Another major theme among all of the parents was that they felt like something was off with their child after the adoption was finalized. All had some minor concerns before the adoption, and some even anticipated there might be some complicated issues. However, what emerged from the data was that every person noticed that there was something more profound going on with their child; something other than issues stemming from things like early neglect, attachment problems, typical learning disorders, or even emotional and mental health issues. There are three associated component themes in this section, including Early concerns, Putting the pieces together, and Like a bomb—But now we can name it.

Early concerns.*Elle.*

After returning from Russia with their 10-month-old daughter, E, Elle and her husband brought her to [adoption specialist pediatrician] for an evaluation. They were told that E looked “pretty good,” but it was too early to know some things; they would just have to see how she developed over time. Elle poignantly described how even after that first appointment with the pediatrician, they felt that something seemed off. She talked about how things early on with E were so much different than the early experiences they had with their biological son when he was an infant:

The first thing we noticed was that [during the day] she was completely silent—and I just attributed that to shock. The other thing that we noticed was she had night terrors; she would wake up screaming bloody murder! I've never heard a sound like that before and it continued for years. We would go in to try to comfort her—and if we picked her up—it made it worse—she did not want to be held, which was scary! It was a lot of sadness—there was also a lot of joy, but it was so different than with [our biological son].

During the time leading up to the adoption and after bringing their daughter home, Elle was in several groups with other adoptive parents. During playgroups, she would compare her daughter's development with other adopted children, and it was then that she noticed the lag. This led Elle to explore testing options in addition to finding a preschool that would be the best environment for her daughter:

Some of the people that I had gotten to know who had also adopted internationally—their kids were blossoming—and mine was lagging. By the time

she was 2 she started to say a couple of words. And then, I decided I am going to get her screened. I told them that I don't have any deep background in child development, but it just feels like something's off. They did their tests and said, "Oh no—she's fine, she's fine." Eventually, we tried a couple of different preschools. One was a more play-based preschool, which we thought would be good, but it was completely over-stimulating for her; it made her an anxious wreck! So, we thought maybe something with more structure; so, we put her in Montessori. But cognitively she wasn't doing what the other kids were doing—she wasn't able to keep up.

Elle shared how she began to develop an almost gnawing feeling—that something was really wrong. Not only was her daughter struggling in overall development, but also in academics and with peer relationships. Here Elle explains some of those early occurrences:

I knew she wasn't able to keep up but what shocked me—I mean—it wasn't like there were vast differences. I just could kind of feel or sense when I watched the other kids—some of the developmental lag. I kept thinking, "Well, that's okay—she went through a rough first year of life; this is all going to be a little behind track." It was the first time that I felt like this is territory that I don't understand. I mean, I can understand learning disabilities, but I started to have an awareness that we were in a really weird territory that I didn't get. At that point, there were a lot of things that were stimulating anxiety for her. Social relationships certainly started to be a part of that even more so, because everybody else is getting their little best friends, and she didn't have any little best friends.

Greg.

For Greg, he talked about how his early fantasies of what things would be like were not matching the reality:

We've helped E, but it's certainly very different from what I imagined it would be... I'm sure what I have was kind of an idealized image of that. But it was a challenge from the very start. She had these night terrors every night for years, and we couldn't console her the way we could with her brother. When we got her in school—she just didn't do well. My experience is, I think there is a whole other life for her that we aren't aware of.

As with some of the other study participants, Greg's frame of reference stemmed from the positive experiences he had parenting his biological son. In the following segment, Greg compares some of those differences and how the hope he had for his daughter was eventually crushed:

What we were hoping for was the kind of experiences that our son had: no trouble making friends, teachers really liked him, and he did well [in school]. I thought it would be, sort of what my parents did for me, I thought, we're going to give her this opportunity and she's going to flourish. I think my idea of flourishing was different than what eventually happened. Not to say she hasn't flourished, but that idea, my original idea was very, very different. I think that early on—that image was being shattered. Early on, when she was in kindergarten, she didn't have any friends—the kids would ostracize her, they would bully her, and she was the one kid that didn't get invited to birthday parties. Her brother was just the opposite.

Victoria.

Victoria and her husband went to Poland to adopt two girls. She remembered meeting them for the first time and was struck by the fact that both girls seemed much younger than their chronological age. The older girl, A, would later be diagnosed with an FASD, but both girls had some significant delays after they were brought home to the United States. Similar to Elle and Greg, Victoria's baseline was somewhat determined by her biological son's successes and on-point development. In the following segment, Victoria described what it was initially like after the girls came home, reflecting that she felt disappointment that it wasn't as she imagined or hoped:

It was such a difficult year with them—the first year. I did homeschooling and didn't see any results. It was just so frustrating—I was very naïve. I was really hoping that we'd be able to overcome. [My biological son] is doing so well at school—he's an honor roll student and so I felt like I have the tools, I have the books, I have my degree, it's going to be a happy ending. It really hit me hard when I learned that it's deeper than whatever I first thought.

Because of the frustration and profound impact that something was off, Victoria started to think about getting the girls evaluated, but that was prohibitive due to financial constraints. Over time, it wasn't just academic performance that was lacking with A; it was day-to-day memory problems—and with things that seemed very basic to Victoria:

We had them in swimming lessons and the teacher was teaching A how to do the backstroke—and the next day she goes in the water she doesn't remember anything. I was like, "What?" I just couldn't believe that she could not remember even simple moves. Things like that happened over and over—it was just so hard.

Deborah.

Deborah described her daughter, G, as a “well-behaved” child, even from the time they returned home from Russia. Early on, G never cried and would rock in her crib. This concerned Deborah: “She was so quiet, she never talked or anything. Even when we transitioned her to a toddler bed, she never got herself out of bed.” It wasn’t until years later—around age five—that G would get out of bed on her own. For Deborah, G’s quiet nature, the rocking behaviors, and some of the issues around attachment were particularly difficult:

I thought it was sad because I think that in the orphanage there weren’t a lot of caretakers at night. It’s my understanding if [a child] woke up in the middle of the night and cried, no one would come to them or comfort them. We just figured she rocks herself because that’s all she knows. I even remember having a rocking chair in her room, and I would try to rock her to comfort her—and she was so stiff—because she didn’t know she was supposed to relax—that was sad; she didn’t know what it was like for a parent to rock her in a rocking chair. That was hard because I’m that kind of person that wants to cuddle, especially since she was the size of a 6-month-old when we brought her home. Even though she was a 19-month-old, she was still the size of an infant. It was heartbreaking, and it was hard.

After G turned two, they began attending a mommy-child preschool together. Deborah noticed that G was lagging in some other areas, including with fine and gross motor skills. Deborah also talked about how G was still very small in stature. Because of

her size, many people misjudged G for being a younger age: “It was a little hard to see that lag.” As G started getting older, her emotional development was more noticeably delayed, which has continued through the years.

Rob.

Rob’s experiences of learning about his son, M, began several years before adoption. He was aware of M’s history of complex trauma, multiple foster placements, and challenges with learning. With time and the development of a trusting relationship, M started to show some vulnerable emotions, such as sadness, when he was with Rob. Rob talked about how he knew that M wasn’t the extensive laundry list of diagnoses that was in his child welfare chart, including Oppositional Defiant Disorder and Bipolar Disorder. However, Rob started to get a feeling that there was something more than developmental trauma, something he couldn’t quite put his finger on, as described here:

I knew he wasn’t a bad kid—he could be the best little kid there ever was. But, I also knew there was something deep down that was wrong because there were days he could read and he could do other things, and then the next day he would have no idea how to even spell his last name. I saw that early on, and I knew that there was something deeper down going on. On good days, M can add clear up to 10,000. On a bad day he’s counting to four on his fingers. I always called it the *Swiss cheese effect*. It’s like there was a giant piece of cheese and he’s fallen into a hole that day and he can’t crawl out.

Putting the pieces together.

The next associated component theme is Putting the Pieces Together. Over time, parents began to start doing their own research in trying to figure out what was happening with their child. Some had their child tested, often with extensive evaluations. Others began to dig for information on the Internet. There is undoubtedly an element of isolation during this process, in addition to seeing failures within various systems. The following excerpts also show the parents' perseverance.

Elle.

After several years of expressing concerns to teachers and doctors, Elle and Greg decided that their daughter needed further testing. Here Elle touches on that experience:

By second grade I said, "I'm done—I can't." It was so obvious to me that something was really off. So, we went to [university] to the communications department and they did a couple days batteries of tests. You know what they said at the end? They said, "Wow! There's really a lot going on here—and we don't understand how it all fits together." That was both good news and bad news.

With the results from the comprehensive testing, Elle felt some justification in her concerns, yet there was still the unknown diagnosis. The evaluators did help advocate for some of E's school accommodations. But, not having a definitive diagnosis was isolating—yet it propelled Elle into researching on her own:

Overall, I didn't really have a frame of reference—I was just kind of like floating out there in the dark. Then, when our lives were falling apart, I learned to get on the Internet and start doing research. That's when I came up with [developmental

neuropsychologist's] name, and it dovetailed with an article that we had read in Newsweek or Time that included him. And that's when we then took her out to him for testing.

Greg.

Greg's early experiences with his daughter were similar to Elle, yet he talked a bit more about the overarching hope to be able to help her, which loops back to his early fantasies of adopting a child in need and providing a better life for that child. He admitted not having as big of a role as Elle in the research process, yet his experience with not knowing what was going on—or how to help his daughter—was just as painful:

Early on there were so many challenges with her; getting her tested, trying to figure out what was wrong, and what was going on—so that we could help her. The whole idea was not to make her into this perfect child—we just wanted to help her. I think that has been one of the hardest things to deal with and, despite everything that we have done, I don't know how much we've really helped her.

Victoria.

Victoria's experience with research began long before she went to Poland to adopt her daughters. From very early on, she had a sense that something was off. However, the adoption agency and the orphanage tried to squelch her concerns. Here Victoria recounted those experiences, including initial fears, hopes, then feelings of despair:

I first started [researching] when we got the referral, but then when we met the girls—the people in the orphanage who knew them were so optimistic. I kind of

let the optimism take over for a while. I think a month after we came home from Poland, I started searched the Internet again, researching Fetal Alcohol Syndrome—and everything matched. It was late at night and the kids were sleeping, my husband was working night shift, and I was with my iPad crying in my bed. It was just so hard. At that point, I kind of hit a wall again and I thought that if it is [an FASD], it means huge damage [to their brain]—and there's not a way to fix that kind of damage.

Deborah.

Deborah recalls feeling lost in her concerns and unsupported or invalidated by their family doctor, which further fueled her drive to research more:

When we first brought her home, we didn't have a pediatrician, so we just took her to our family doctor. He examined her and said, "You know, she's beautiful, she's healthy, congratulations!" But over time we were concerned about her rocking, among other things, so we kept going to the doctor and saying, "What is this? Is this an autistic quality, is this self-soothing?" And he kept saying, "She's fine, there's nothing wrong, she's fine, not a big deal, she just likes music." I'm like, there's no music playing while we're eating dinner, that doesn't make sense to me.

Deborah admits that she started to research Fetal Alcohol Spectrum Disorders over time. She noted that she often wavered between wanting to figure it all out and not wanting to know:

I started doing research about [FASD] when things seemed off. She was still young and we were not really seeing a lot of the things that you would normally

see. But as she started to get older, we started to think, “oh yeah, yeah, that, mm-hmm, yeah, that’s it, that’s what they call it, *Swiss cheese memory*,” where she would know something one day, and then the next day she would not. That was an indication, like oh, okay, now we’re beginning to see some of that. Also her emotional behavior was not quite what you would expect for her age. In the beginning we didn’t see it, or maybe we didn’t want to see it—I don’t know. But I just began reading a lot and then it started to click.

Rob.

Rob started to talk to his wife about concerns with his son M. He noted that, as a special education teacher, things were different with M than he had seen with many of his other students who had a history of trauma:

That’s when I told Nicole, “There’s something here,” and I brought up fetal alcohol—I’m not sure why. And then she started doing a lot of research. She loves to [do research] on the Internet, including on social media. We eventually found and had communication with his biological mom and biological grandmother. And that’s how we found out that his birth mom drank and did drugs during her pregnancy.

Nicole.

Nicole described needing to find out more about M; in particular, so that she could advocate for him:

I needed to find out everything I could find out about his background. It was almost like it was a burning desire that I had to know what happened to this kid... to understand who he was before so I could help him. I unturned everything that I could—we had gotten some adoption papers, some background information. So with those names, of course with the Internet now, you can search a lot. I had family obituaries that I had gone through and I had pulled people from people and looked at them on Facebook and tried to piece that together. I reached out to his grandmother on Facebook, kind of anonymously and eventually talked to her on the phone. I got to know her a little bit to the point where I was comfortable asking some questions. And that was eye-opening!

Nicole recalls being surprised at how much M's grandmother shared, and was also deeply concerned about what she had learned, including the following:

She was pretty forthcoming; at that point, on the drugs that [M's] mom was into, the fact that his mom and dad were second cousins. So it started to make me understand a little bit more where M was coming from. I started to, I guess, maybe, in some ways, pity him more. And pity may not be the right word. But I certainly had a deeper understanding of where he might be coming from. It wasn't just this child that was fighting to fight or being defiant to be defiant. There were circumstances that had certainly led him there.

During the research process, some parents found information about Fetal Alcohol Syndrome that further raised their suspicions, which led to eventually finding professionals who had expertise in diagnosing and treating children with FASD. The next associative component theme, *Like a Bomb—But Now We Can Name It*, is about the time

at which parents' finally learn about their child's diagnosis. As laid out in this section, the experience for all parents was two-fold: a shock and relief.

Like a bomb—But now we can name it.

Elle.

Throughout the interviews, Elle described how they worked so hard to get their daughter tested and to get to the bottom of why she was having such significant struggles. Finally finding an expert in a clinic on the east coast of the United States helped them to get a firm diagnosis. Elle emotionally recounted what it was like for her at the time they received the diagnosis:

It was her sixth-grade year and [developmental neurologist] did this full battery of tests. He just sat us down afterwards—she wasn't in the room with us at that moment—and he said, “Well, she's got Fetal Alcohol Syndrome, and I'm going to go over some things that I think you can do to help assist her in her learning process, and we're going to look at this all together. But the one thing I'm going to tell you is if you do not get her out of this public school system, and immediately, she's not going to make it through high school.” I remember feeling like—socked in the gut—and tears were just rolling down my cheeks. But at the same time it was really comforting, because somebody was telling me that they knew what was going on.

While describing this experience, Elle's emotions again became visible as she continued to describe more about that day:

He proceeded to talk about his five or six adopted children from Eastern Europe, one of whom struggled with [FASD] and was still at home. I felt like, okay—so this feels real, this feels right, but I was shell-shocked. Then he proceeded to sit down for a day with us and go over everything; about all the different kinds of information that came out of the testing, implications for academics, family systems issues. I live in intensity and handle things like that pretty well, but I was creamed by the end of this day! It felt like way too much to digest, but it also felt like okay, the marching order is—get her out [of her school].

Greg.

Greg touched on his experiences following the diagnosis, once again reflecting on some of his regrets and disappointments through the years:

After the [FASD] diagnosis, I remember reading this book...we tried to learn as much as we could, and not much has worked, to be honest. I mean some things have—but we've not ended up where we had hoped. [Before we knew the diagnosis] we were all trying to help her, and I was helping her—probably helping her too hard and expecting too much of her. But over time, as we knew more about her, we learned a little bit more about how to better help her with her disabilities. But that was hard, you know, to start.

Victoria.

For Victoria, the experience of learning of her daughter's diagnosis brought up a range of emotions. In this quote, she describes how learning a definitive diagnosis

brought some relief, while also sharing the helplessness she felt due to not being able to “fix” it, since an FASD has a lifelong impact:

[After the diagnosis] it was kind of like a relief, to some degree, because I started to read again... and the stuff that I read about [FASD] helped me understand—it started to come together: *This is what I'm facing*. Before [I knew the diagnosis] I was full of emotions, blaming myself, “if I could do better, if I could do more.” You look at this child and you don't want this to be the reality. You want this to be something that you can fix. So [learning diagnosis] was good for me although I wish it could have happened earlier so I could be more like—this is my solid ground, I'm standing on [FASD], let's see what can I do now.

Deborah.

While describing the time leading up to a diagnosis, Deborah expressed her frustration in knowing something was off while her family physician brushed her concerns off for several years:

Finally, when she was 4, the doctor had enough of me talking about her rocking, so he said, “You need a neurologist, but you'll see, there's nothing wrong with her.” I was like, wait a minute—you're sending me to a neurologist to tell me there's nothing wrong? That didn't make sense to me.

Deborah brought her daughter to the neurologist who completed an evaluation.

During the feedback process, the neurologist nonchalantly gave her diagnostic impressions, which is described here:

[The neurologist] says, “She has sensory processing disorder. I’ll write you an order for an occupational therapist. By the way, did you know she has Fetal Alcohol Syndrome?” Like a bomb, right there! I was like, “What?!” And she says, “Yeah, she’s got all the facial features.” So that was a shock. It wasn’t so much a shock because—wow, we didn’t expect this—but a shock like how come no one has told us this sooner? Our doctor has been looking G in the face for four years—how has he not said anything? When we scheduled a follow-up appointment with him and told him what the neurologist said, he stated, “No, I don’t see Fetal Alcohol Syndrome, I see a beautiful Russian girl.” And then he said I wouldn’t be too quick to label her because some parents can get weird when you start labeling their kids. But knowing everything will allow us to get her the help that she needs. After that we left that doctor.

Rob.

Over time, Rob also had a suspicion that M had an FASD. Like Deborah, he experienced a lot of frustration and anger about the attitudes and unresponsiveness of many of the professionals. When an expert in FASD finally evaluated his son, Rob was able to shift gears to meet his son’s needs:

Once we adopted M, we had weekly counseling for him and family therapy. For three years, I kept bringing up fetal alcohol to his child psychiatrist and she would just blow me off. That was around the time [my wife] was doing research, and we had kind of a gut feeling that something’s different—[we knew] it wasn’t autism, and they wanted to call him autistic. I just kept saying he’s not autistic, he’s

something else, I think he's fetal alcohol. And then they wanted to argue. We finally got a Fetal Alcohol Syndrome diagnosis—and they did the full measurements, they did everything, and he has full-blown FAS. Now Nicole and I had to learn a different way of parenting M when we got the diagnosis.

Nicole.

Nicole emotionally recounted the experience of learning the diagnosis: “It was two-fold; a relief but sobering because it's a life-long thing that we're dealing with.” The diagnosis further changed much of what she initially envisioned when adopting her son:

It was kind of like, Yes, we've not failed! All of the parenting strategies that we've known aren't working [and] there's a reason. But, this isn't just a phase or a trauma thing that we can counsel out or work through. That's not going to happen. We thought were going to have him in our home for five years... by time he's 18 or 21 he'll be out of the house and independent. But he's not going to be out of the house and gone by the time he's 21, so we had to start some different life plans because of that.

The diagnosis was important in more ways than one. About a year after the diagnosis, M was in trouble with the law and was subsequently placed in a residential treatment facility. Nicole describes here how the diagnosis was important for M's court hearings:

I'm so thankful that we had the diagnosis of [FASD] before he went to court because this could have been a whole different scenario. We dug deep. I mean, we have scoured books, and seminars, and listened, and scoured the Internet on so

many different things to try and find things to help him, to teach them [court officials, residential treatment staff] what fetal alcohol is and what it does, and what it can't do.

For all the parents in this study, there was a period of time of sensing that something was off with their child's development. Because most felt isolated in their concerns, most began to conduct their own research to find answers. The research all led the parents to professionals with expertise in FASD, which resulted in a conclusive diagnosis for their child. For all, there was both shock and relief in the knowing.

Super-Ordinate Theme III: Systems—The Good, The Bad, and The Ugly

Parents described myriad positive experiences and challenges that they have had with various systems. From schools to adoption professionals, medical and behavioral clinicians, to closer-knit systems like families and friends. This next super-ordinate theme describes parents varying experiences within all systems... the good, the bad, and the ugly.

Elle.

Elle shared many of her negative encounters with the schools over the years, describing how there were inconsistencies, incompetent teachers, and refusal to make adequate accommodations for her daughter, even after the diagnosis:

I talked to the teachers about our concerns; they'd acknowledge that she was a little behind, but we had nothing to worry about. Then I get to the final evaluation during the end of year conference when she's 4 years old, and her primary teacher

at the final conferences said, “I have to tell you, I’m so worried about E. I don’t think she should go on to kindergarten.” I was like...What!?! They had never approached me about this... and this has been the history—people keep saying—“oh, she’s fine—she’s fine, she’s normal, she’s normal”—and I don’t even like that word, but, all along they’re thinking *there’s something kind of off*, and then, Bam! Shit hits the fan! And then I’m left spinning, not knowing what to believe. I want support for our child, but nobody’s really coming forward with ideas of how to support her.

There are certainly bad experiences within systems, including schools. It is within some of these experiences that many parents find a stronger voice, in order to advocate for their child. Here Elle talks about a particularly awful experience with a teacher, and how she fought to protect her daughter:

In third grade she had a horrible teacher who had a history of just humiliating children, period. Not just my kid. She humiliated my kid, but she humiliated a lot of children. I kind of went on a crusade and I pulled all my credentials out and I made a case for the fact that [she’s] a real problem here. And actually, she ended up getting pink slipped, which I was very glad for, because she was doing so much harm. But that was like a lost year for E, just a lost year. It was awful.

There are also examples of when systems or individuals within systems are positive, and make a difference in the lives of their children. Here Elle recounts how another teacher had a very positive impact on her child and what enhanced the learning process:

And then in fourth grade she had a really great teacher. He was like all into experiential learning, and so they built cardboard box towns...and he loved E. He got that she was different, but he didn't mind that. He kind of liked it. And he supported her. So I was so grateful for Mr. P. And again, she continued to get some supports.

Victoria.

For Victoria, her experiences with the clinic that diagnosed her daughter were positive, despite the devastating diagnosis of [an FASD]. As illustrated in this quote, Victoria shared some of the details of that experience:

I think working with the team of people at [Chicago pediatric clinic] was very helpful because they gave me tools, books, and resources. It was really, really helpful. Because with my child it's not only [an FASD], it's also neglect; it's ABUSE with upper case ABUSE. Working with [the therapist] was also very helpful. She worked with A in a relational way, understanding the impact of FASD and neglect. I think the therapy helped A immensely, like she felt she had a voice, she could speak, and [the therapist] could understand her. And that was really important. I cannot imagine my life without that.

For Victoria, she recalled her own processes with understanding how and why the therapeutic interventions helpful for A and for herself:

[The therapist] named A's emotions, like "Oh, this baby is crying. What do you think? How is the baby feeling? Is the baby sad?" And now we talk about emotions, and now A is better able to name her emotions. [My own] therapy was

also helpful, in particular with understanding why A wanted to play with the baby all the time. Therapy helped me to understand that it was okay to let her be the baby. Because as a mom, you want to say “Hey, you are almost 10, you skip it, let’s do something else, let’s read.” And she’s like, “No, I want to be a baby.” I think she is replaying her past, what she missed.

Deborah.

Here Deborah describes her frustrating experience with a teacher who refused to learn more about Fetal Alcohol Spectrum Disorders:

I think they understand more, but they have never been working with a child with Fetal Alcohol Syndrome. And I even offered the teacher this documentary, “Moment to Moment,” and she refused to watch. Can you believe that? She told me that she’s very busy; she doesn’t have time to watch because she has already read about FASD, and she knows what she needs to know. That was horrible. Horrible.

Rob.

Rob’s involvements with various systems included schools, mental health professionals, child welfare agencies, and juvenile justice. Throughout the interviews, Rob recounted what some of these experiences were like:

You would think that if you are a residential treatment center, for youth with development disabilities and autism, that you would have a little bit more sense of what things are about. And I would think that the probation and the court system

would have a little more idea of fetal alcohol. But even the therapist who just got his master's in therapy from [university] was clueless on how to deal with a child with [an FASD].

Nicole.

Nicole talked about a particular experience with the juvenile court system:

The court is looking for consistency, but with fetal alcohol, you're not going to get consistency. That's the whole problem. And we've tried to teach them it's similar to traumatic brain injury. But, because he was born with [FASD] it's not an injury, so they [his counselors and others] make this big distinction on that. Of course the chief deputy prosecutor was ruthless with him on the stand—how he should just be locked away. She said, “I will fight for him to be on the sexual predator list because he's an animal, he's out of control all the time, and hurting people, and he'll never be able to be trusted.”

Over time, things in the court system began to shift for the better, some due to connecting to people who understood FASD. Nicole feels like it was in part to faith that led to the most recent turn of events:

In what can only be events that were God-ordained, the chief deputy prosecutor was absent from court that day and the head prosecutor was there. We submitted into evidence the neuropsychological test results and a letter from [evaluating doctor]. As things progressed, we quickly learned the head prosecutor is a psychologist by training and he trained under [evaluating doctor]! He asked the judge to send M home where he could receive the help he needed. The head

prosecutor told the judge and probation officials that M's issues were due to his brain damage and that placing him at Department of Corrections would only victimize him. The head prosecutor advocated for M, so we brought M home that day! The next day, we learned through a close friend in the legal system, the chief deputy prosecutor that originally handled M's case had been fired, the last straw being her handling of M's case.

All of the parents in this study faced a range of experiences within their various systems—from family to friends to larger systems like adoption agencies, clinicians, schools, and even juvenile justice organizations. Some poignantly spoke of how they were eventually able to identify *the good* systems, those who offered steadfast support through the most difficult of times. The parents also shared interactions with *the bad* and *the ugly* systems—which ultimately led to trauma and isolation, described in the next super-ordinate theme.

Super-ordinate Theme IV: Trauma and Isolation

All the participants described how their experiences of parenting a child with FASD was very isolating and on many levels and sometimes, even traumatic. Within this super-ordinate theme, two associated component themes emerged: *Constant Vigilance & Chaos and Grief & Loss*.

Constant vigilance & chaos.***Elle.***

Early on, Elle recognized how parenting her daughter began to activate many other aspects of her life, some of which she addressed in her own therapy:

I had gone back into therapy nine months into being E's mom, because I was having stuff get kicked up; there was my original mom stuff [ambivalence of being a parent], but then there was my [positive] experience with my [biological son] and then there was this: I wanted to be close to her and she didn't know how to be close. She couldn't talk and I could feel us just functioning in two separate worlds. She just couldn't stay attentive to anything—except kicking the ball—and I could only kick the ball so much. With my little boy it was it was relational—that was my frame then. Now I have a child that I want to connect with and it just felt like everything was a mess. That's what it really felt like—it was like a tangled ball of yarn.

A neighborhood kid sexually abused Elle's daughter, E; the abuse was discovered because they noticed E stealing and acting out behaviorally. E eventually admitted that she was being abused. Unfortunately, the school focused only on E's behaviors; they dismissed the fact that E had been victimized. Because Elle's child is so vulnerable due to the FASD, there is a constant worry about her safety. While describing this experience, Elle became visibly emotional:

I was so scrambled. We have to protect her from this school; we have to get her out of this school. I have no idea what's happening with our child other than the fact that she's been sexually abused. But now the sexual abuse came in the wake

of a trusting relationship—and she doesn't get social relationships; she doesn't get cues and she can be manipulated completely. This wasn't the first time we had seen that she was way too trusting—that she could be manipulated because she was so desperate for love and affection. I thought we were a pretty loving, affectionate family, but... anybody who showed her the least... [*choking up*] ...the least bit of kindness, she would be vulnerable. So, that's the biggest fear...that somebody's just going to take complete advantage of her.

Greg.

Greg also talked about *living on the edge*. Here he discusses his daughter's history of stealing, describing the painful changes they had to make in response, and what he ultimately learned was indicative of something much deeper than willful behaviors. Greg also recounted concerns about these behaviors resulting in something more serious in the future:

There was a pattern of stealing when she was younger...it was primarily from her brother. We actually had to put a special lock on his door, which was absolutely horrible. But we had to draw the line and it lasted for a long time. I had to actually go out and buy a whole new door with a special lock and then fit it in. Then there was some stealing behavior at school, too. But that was different. The stealing behavior at school was a cry for help because there was an unfortunate thing that had happened at that time. What are we going to do if it continues and there's something really bad [that happens] in the future, like if she ends up in jail?

Now, I mean, this is horrible to say, but I really—I trust her very little. And she consistently proves to us that, you know, you can't really trust her.

Victoria.

Victoria shared her experiences with the ups and downs of parenting her daughter who has an FASD, including hope, frustration, and guilt. In addition to an FASD, Victoria's daughter also has significant intellectual delays that cause her to need day-to-day attention:

I think for me as her parent, going through all of these different stages. The people in the orphanage, they gave me a lot of hope, they were telling us how kids in the orphanage have many delays: "You just have to deal with it and give her time, give her attention, she's going to improve." So I was doing that, and there was no improvement. I kind of blamed myself, you know, maybe I need to do more story time, maybe I need to read more, maybe I have to be more patient and keep smiling. Sometimes you just face this child and you kind of feel speechless because she cannot remember, she cannot learn, and it's just overwhelming. My husband was in denial for a long time, but he like, "We're going to work it out—give her time, give her time." And he just wasn't supportive at that time. Like even in going to [the Chicago clinic] he was like, eh, you know, give her time, she's going to be fine. I'm like, I don't think so. He eventually became very supportive and totally on board. He became just as much of an advocate as me.

Deborah.

Deborah shared her most frustrating experiences over the years, in particular, the constant battles with the school system and feelings of heartbreak over her daughter's struggles with peers:

It's difficult because [the school] is not seeing the evidence. I've even had teachers come to me and say I don't understand why you say that G doesn't act ten because when I see her with her classmates, she acts just fine. I'm like yeah, because she's at school, and she wants to fit in with her peers. But when she's at home that's not the case. I also want to say, "Why is she not invited to any of her friends' houses to play? How has she not been invited to any birthday parties?" That's kind of an indication. She's got some kids that she's friendly with, but she's not invited to their houses to play.

Rob.

For Rob, parenting M was a shift, even though he has expertise in working with children with emotional, behavioral, and intellectual disabilities. Here he shares some of his experiences and the impact on his family:

I don't think people understand the magnitude until they go through it. You know, I've got a master's degree and I've done this for 32 years. I never realized that it's a 24-hour-a-day job, seven days a week. Our middle son has been affected by what's happened. So, I had to make sure that [he knows], "you're our son and he's our son." I have to do what I need to do as a dad and as a grandfather. But, it's really put a strain on the relationship. Our middle son feels like you just "beat

them with a 2 x 4 and you lock them away.” And a lot of that is because of what he sees at the prison and being a prison guard. He’s softened a little, but I’m not sure that that relationship that we had before will ever be there.

Nicole.

Nicole shared some of her journey in parenting M on a daily basis, shifting from how she parented her biological sons:

When he would start to go into a meltdown or a rage, my instinct was, number one, let’s either talk it out or I’ll tell him go to his room. It took me a long time to get that you don’t confront him right then. If he’s doing something and he’s out of control, now is not the time to talk about it. Where with my other boys, I could talk about it in the moment. So it was a learning curve for me, a big learning curve. I would say it’s probably only been in the last year that I’ve really, really learned that, the hard way, because I’ve made him blow up many a time when I shouldn’t have. I now realize that his brain just didn’t work that way.

Nicole also described the day-to-day struggles and constant vigilance:

Nobody could have ever prepared us for that. And people, even our closest friends—even our family, really, they don’t really understand the stress and the dynamics of living with someone who can literally one moment be absolutely fine—a sweet, coherent kid—and never know what might trigger the aggressiveness or what might trigger the next mood. A lot of people describe it as a form of posttraumatic stress disorder for the parents because of all of the ups and downs. I certainly wish that I was stronger than that, but at the end of the road, if I

were stronger, I wouldn't be as effective, maybe, in understanding some of the things he goes through. That feeling that I get in the pit of my stomach when I hear the phone ring, thinking it's about M. But that's nothing compared to what he goes through...so I try and look at it that way. The day in and the day out is a lot harder than just seeing it on paper or having someone tell you. It's just almost indescribable to someone that hasn't lived it in the trenches.

Grief & loss.

Elle.

There are stories of grief and loss interwoven throughout the parents' narratives. Some of the loss is due to loss of close relationships because people don't understand. Here Elle poignantly described her experiences with loss of friends:

I felt like [*choking up*]*—it was hard for me to continue to get together with [friends] because I just couldn't talk to them. I think this is about the general sense of isolation—over the years—it started back then but it has really continued.*

Victoria.

Victoria talked about her experiences with her family and how there has been some disconnect due to their not understanding:

I think the most I suffered was with my mother-in-law, who totally doesn't understand them. There was a time when she was staying with us because she broke her arm, and the girls were misbehaving. But if you have a scale from zero to ten, and ten is the worst, they were at a five. But, she just couldn't take it. She

said, “If you’re going to behave like this, you’re going to go back to the orphanage.” I told her, “Mom, we don’t talk like this. This is really serious and they are with us forever. We’re not going to threaten them like this.” She stopped but she’s not inviting us over and we’re not inviting ourselves to her house. She’s still upset with me and this has put some stress on my relationship with my husband. I think he wouldn’t mind her living with us, but I’m like No—that would be unnecessary stress for me and for the kids because she has no clue how to talk to them. So, I think some people have no clue. They don’t know how to talk to kids who are adopted. I think people are kind of speechless, you know?

Rob.

For Rob, he talked about his experiences of loss at many levels, including family, friends at work, and in his church community:

I lost a lot of friends, you try to get them to understand that M doesn’t intentionally do a lot of these things; it’s part of the disability. And yeah, he’s a good-looking kid, and yes, he could hold a surface conversation with you and you would have no clue that he’s got a disability—it’s an invisible disability—that’s what we’ve struggled with at school. That’s where I lost a lot of my teacher friends. They just thought he was a smart aleck. They just thought he was a bad kid. And a deacon at church has told us that we should just turn our backs and walk away.

Parenting a child with a neuropsychological deficit like an FASD may result in living in a vortex of chaos. Moreover, many people misunderstand children who have an FASD, subsequently leading to the loss of some family, friends, and communities. For

many of the parents in this study, the loss of former close relationships resulted in an overwhelming sense of grief and mourning. However, many found some eventual *meaning-making* and peace, which is described in the next super-ordinate theme.

Super-Ordinate Theme V: Seismic Shifts

All the participants talked about how their lives shifted after receiving their child's diagnosis. The final super-ordinate theme, Seismic Shifts, focuses on the life changes that unfolded after that critical turning point. Four component themes are Advocating, Connections, Meaning-making, and Moving forward.

Advocating.

Advocating was a strong common thread, something that all of the parents have come to know. For some, it was defined as something that they had to do because of challenging systems. For others, advocating is experienced as a positive force that comes from within. For many of the parents, both of these reasons are part of their experiences in advocating for their child... and the knowledge of the diagnosis was a kind of power.

Elle.

Elle's experiences as an advocate for her daughter have spanned over 18 years. Here she describes a particular time shortly after receiving the diagnosis:

We started that process of getting her out of her school and into [a therapeutic school]. But the school district, they didn't want anything to do with that because it's \$40,000 a year for them, plus an admission that they can't educate her. And

the long and the short of it is—I felt like something had been unleashed in me, and I had had it up to here with all of the different systems that didn't want to really learn about how to take care of my kid. And it was during that period I felt like I became this fierce warrior on behalf of my child. I had been fierce, but not like this. I wasn't going to take it anymore, because I've got an awareness that unless I got her help, the kind that she needed, it was going to be over.

Deborah.

For Deborah, the school systems have been the hardest challenge in getting her daughter's needs met. Even though they moved to another State for better schools, the difficulties still linger and she finds herself continually advocating for her daughter:

That's why we moved out of Chicago, because the school wasn't really working for her. I wasn't even looking for somebody who would specialize in FASD, but I was looking for more attention and for more direct kind of interactions. And that was the reason we sold the house and we moved to a different school. Now I'm trying to be hands-on. I worry about, you know, like I try to tell people: when she's 16, but she's acting 12, are we going to let her get her driver's license? No. When she's 18, graduating from high school, but she's acting 15, are we going to let her move away to go to college? No. She doesn't have the skills necessary, or she won't. Like we don't know for sure, but that's kind of like what I'm trying to describe to people.

Victoria.

Victoria's experiences with advocacy began early on and, in some ways, advocating also means having constant vigilance:

You know, being an advocate for her, it's just like you have to predict stuff and you have to be proactive before something will happen. After we returned from Poland, I found a Polish theater group called Little Stars and I didn't know what to think about A and her problems at [the theater]. So I had to go and talk to this woman and I said, "Listen, she was adopted, she has a lot of issues. Please keep an eye on her and tell me how I can help."

Another piece to advocating is sharing information in more general terms. For instance, Victoria sees her role as not only advocating for her daughter but also for others who may be experiencing the same struggles in regard to adoption. Yet, sometimes knowing how much to share is a challenge:

What's also difficult [about being an advocate] is to figure out how much sharing is too much sharing. So, when I talk about adoption, and we've recorded different stuff—some has been broadcasted—and I have to be honest. So I say "it's not easy with my child. It's not easy with special needs." But do I need to tell everyone everything? I don't know. I really question this—how much do I need to tell everyone?

Rob.

Rob recounted several incidents of how he must advocate for his son, especially now that M is in a residential facility:

Just recently a boy [at the residential facility] slugged M and bruised his face and he fought back—so they put him in solitary. And he beat the wall until he broke the bones in his hands. [The residential staff] called us when they were leaving the hospital four days after it happened. That really set us to a new level of advocacy, and now nothing goes unnoticed, nothing goes unturned. This is my son. I'm fighting for my son. I'm advocating for my son.

Rob further describes his anger over the lack of communication from the residential home staff, in addition to their inability or unwillingness to understand M and his needs:

They said, "Well, why didn't he just tell us to begin with?" I tell them, "because he can't verbalize that to you because he doesn't feel safe around you." That's when I also said, "because you're always badgering him, you're never telling him he's doing a good job."

Nicole.

Nicole recalled a recent incident when her son was involved in the court system for assaulting a residential home staff member; something that Nicole feels could have been prevented if the staff member had listened to her about M and his needs:

I cannot tell you how many times we have told them you cannot come up behind him and do anything. You absolutely cannot. I can't come up and touch him without saying something. You just can't. So, [the residential facility] was short on staff. Well, a new staff member came up behind him because he was getting angry with a new kid who was going berserk. She came up behind M and put him

in a bear hug. He flipped her over his shoulder, just—[*Nicole snapped her fingers*]*]*—and broke her rib. So now he’s on a crisis watch and if he hurts anybody else, they’re going to send him to [Department of Corrections]. They’re going to remove him and he’ll have to start all over someplace else. He’ll go through the whole thing again because those people won’t listen.

Connections.

Parents also shared the times that they’ve felt special connections with their children. In many of these moments, what is described is a kind of bonding to some—and to others—an important part of co-regulation that is critical for children with FASD. Parents also identified other variables that helped their child’s self-esteem. This section covers all of these moments of interpersonal connections.

Elle.

Elle touched on how certain things made a positive impact on her daughter, both in sports and during family trips:

In terms of gross motor skills, once she got kind of on balance and started to develop physically—some of her gross motor skills were like bam! Such strength! So, we literally ran with that. She loved playing with balls, she was kicking—playing soccer by the time she was three. She was known as the kid who could kick the ball half way across the soccer field and she was a lefty so everybody loved her. It became really evident early on that she was going to be an athlete.

We took great comfort in that because it was arena where everybody felt good, she was at her best, and we could feel as though we could just relax a little bit.

Family vacations were also a strong part of Elle's family feeling more cohesive, and a break from normal routine where they had opportunity to experience joyful moments together:

Through the years, we took the kids to Costa Rica and to the Dominican Republic. We skied innumerable times up in Canada, which, I look back and I think, wow, we could buy a house with all that. But, it was the best time. It's really what held us together. Even K and E would get together at those times, because she couldn't steal his stuff, and because we were just being a family together. Those times together, in addition to school, her basketball program, and her therapist, I felt like we were finally starting to get the support together that she needed. And with that, we didn't feel so alone.

Greg.

Greg fondly recalled the moments of connections with his daughter:

Early on, I would read a book to both kids and we would act it out—I have a lot of good memories of that. She was also incredibly athletic, unlike her brother, and so that was another point of connection for the two of us. We'd go out and she first liked soccer, so we'd play soccer together in the yard and then eventually youth soccer leagues. Just like I did with her brother, we'd go to games together and sometime go out of town, just the two of us. So, athletics was a big point of connection for us.

Greg also shared about his experience of having an adopted child, which seems to reflect the early bonds that were created:

To this day, I'll talk openly about her being adopted but it still seems almost surreal at times to say she's adopted because—not that I don't remember—I do remember going through the whole process. But, she just became part of our family so for me it's hard to articulate a real difference. Yes, she's adopted and K isn't, but from the very start, it just always felt like she was part of the family.

Rob.

Rob and his son M go fishing a lot; it's their unique bonding activity together and also a time that allowed M to feel safe to tell Rob about his traumatic history:

After we would go to therapy he and I would go across the street to [a river] and we'd go fishing to kind of give him down time. And as that has progressed throughout the years, that's when he would let his guard down and tell me things. It was regulating for him and it was therapy for him. I just usually would sit there and just not say much, and then he would start unloading.

Meaning-making.

Through the years, the parents all had a range of experiences in meaning-making. For most, the process began early on and continued to present day. Meaning-making circles around to some of the reasons they chose to adopt and also to making sense of an often chaotic journey in parenting their child, including going through a grieving process and even acceptance.

Elle.

Elle talks about how she had come to make sense of her daughter's disability from the prenatal alcohol exposure. Ultimately, she has shifted her thinking in order to better help E function now that she is living outside of the home:

In E's scrambled brain—the older that she's gotten—there are ways in which she has become so much more capable. But, in terms of how she understands what's going on in relationships, how people relate to each other, the ability to communicate clearly, all of that is still a train wreck. And that's the thing that's gotten sharper and sharper for me in the past couple of years. She went off to school and we thought we had the accommodations piece in place—I built a structure [for her] and I was going down there almost every day as a touch point and over time it seemed like she was stabilizing a bit. I was providing all of that executive functioning for her.

Unfortunately, things started to spiral, despite all of the supports that were put in place and despite all of the years of perseverance in building accommodations from therapists, schools, and family:

For a child who has learning disabilities the way she has, the eight ball that she was suddenly behind was unconquerable. But we kept trying to conquer it. And she kept getting crazier and crazier. She did not have me as the external brain so impulsivity reigned, bad judgment reigned. People were interpreting her behavior as just bad kid behavior. I felt like we were back to square one again.

Greg.

This excerpt from Greg's interview touches again on the fantasies that were present early on and how things are in reality. For Greg, there is some acceptance that developed over time:

You know, I think I was pretty idealistic when we talked about adoption. We knew that we were faced with some challenges because of kind of that laundry list of medical problems that she had, allegedly had, that came from the orphanage. But I guess even before that, I just thought that we were going to give somebody who needed an opportunity, that opportunity. And I think that what we were trying to envision for her is kind of what we were seeing with other kids at the time. She'd go to school and have friends and make some choices. She'd go to prom and start dating and get involved in sports. And some of those things happened, but they didn't happen in the ways that I had imaged.

Victoria.

Here Victoria talks about grieving in addition to feeling helpless about not being able to help her daughter:

I think it's like going through grief, like you grieve the childhood that your child lost, you grieve the life that this child could potentially have but doesn't because of the damage that was done. For a parent, you have to face your fears and you have to also be open-minded about options, like what's the best option for my child. There are hard moments—like this one time, A was on the stage, and she's supposed to grab a blue flower, but for her, blue, red, pink, whatever—she grabs

pink. And this child who's supposed to have a pink flower, she doesn't have a flower. So they're performing on the stage dancing, this child is running behind the stage looking for her pink flower, and she missed the performance because of my child. You know how I felt? Horrible. And I knew, because I was there watching them, that A grabbed the wrong color. But this child wasn't flexible enough to go and grab another one. So, I think we'll have a lot of moments like this when things will go wrong.

Nicole.

Nicole's experience of making sense of it all comes down to faith and resolve, as she describes here:

Knowing that above all there's a purpose for what we're going through. Knowing that we feel like we are placed here for M, for whatever reasons that we were chosen for him, to be his parents, has helped us to see that through to an end and to strive to do the best that we can do for him. I think it was a culmination of our whole lives, really.

Moving forward.

This last associative component theme is one that looks at how the parents are making plans for the future, how they find some peace in helping others, including writing about their journey of parenting a child with an FASD. For many, even talking about the process, in general, felt cathartic. This was part of what supported their yearning to help others by sharing their stories.

Elle.

Elle's experiences of raising her daughter have resulted in her hopes of writing a memoir. During our interviews, Elle mentioned her experience of talking about her journey was healing in some ways.

Advocating for E to get into a therapeutic school was the beginning of my memoir, because while I wasn't really writing a memoir, I was writing all these notes out for the lawyer about different stuff that had happened, and the whole sequencing of it. It was really my first experience of writing about it and feeling a catharsis in that. [*Tearing up*] I haven't been emotional about this in this way for a long time. I've got so much to say—it's jogging a lot of memories that I haven't pulled up in a long time.

Greg.

Greg's daughter is now a young adult, which brings about new concerns about her future in addition to worries about her relationships due to her vulnerabilities and poor executive functioning. He talked about a recent meeting with an FASD professional, who suggested that a special type of mentor might be a good option for his daughter:

He described what a mentor is, what he had in mind; and it's not like a typical kind of mentor. He suggested somebody who's a little bit older than she is and somebody who can be—this is really crass—but like a paid friend. When he said that, it made a lot of sense to us. It would have to be somebody that we respect, that we would want her to interact with, and pay this person to hang out. Because

she has this tendency—she’s always attracted to somebody who shows her some interest. And I think that’s because it’s really hard for her to make friendships.

Victoria.

As illustrated in a previous quote, Victoria expressed that her education and work experience prepared her for adoption. Here she further describes how her background and experience have laid a foundation for her to help others:

I know how to find help, I know how to name the stuff, I'm not afraid to talk about it, I'm not afraid to admit that this is hard. Even now, at this stage, I really feel compassion for the kids who are left in the orphanage, so I became a board member of an organization that helps orphanages in Poland. I can advocate for the people who are tiny and live in orphanages. I really feel like that's my calling and I'm happy to talk about those issues because, as a parent, I think that for specific disorders that you need clear communication, clear guidelines, what to do and what not to do. I feel like mission accomplished because more kids will find homes and when you think in the long term—where would the kids be without a parent?

Deborah.

Deborah described a local organization that provides activities and networking for children with special needs. She explained how she sees a future connection with this organization, for herself and her daughter:

There is an organization here for children with special needs. Maybe eventually if I get a little more involved I might find something there that I can do, either as a volunteer or something. But, it's a fairly new organization, so they're still young yet. When they first started, they just worked with children with Down syndrome and now they're starting to expand to children of all different special needs. I also think it's important for G to be involved with these organizations because the more she works with them and understands them then later in life, it'll be easier for her to maybe work in a field with kids with special needs. I'm not doing it so she can feel superior; I'm doing it because I want her to grow that tender heart.

Rob.

With his background in special education and connections to people in the field who have been supportive, Rob's plans are to create a network and agency that will help people with similar experiences. Here he talks about how those plans developed over time:

Someone made a comment to me that we struggle because there's nothing out there for us. I finally decided to do something about it, quit wallowing in self-pity and let's move on and do something about it. And so that's what we've done. That's why we have started this. That's why we're in the process of getting it all together. We have a group of people who really wanted to make it work and we're doing it for Michael because we want to be able to provide a place, even if it's a job where he's the janitor when we get the facility. That's the ultimate goal, is that he will have a place that he can call his own.

We're going to start out with just the support group. But we have people on board from [university], from the special ed department. Some students are going to come in and provide a support group for parents. We'll have physicians come in who are accepting of FASD, who can do the sensory because you don't have any of that here in this area. We don't know who to go to. We don't know who we can count on that is going to be understanding of the child when they go to a meltdown in the dentist's office or the doctor's office. And then to be able to provide just a network where I can call you, you can call me when things are getting too tough. To know that this person has gone through it, seen it, done it.

Nicole.

Nicole talked about the future and coming to terms with what that means for her family. Here she recounted a vision of what that may be like:

We're putting things in place so that there will be a trust fund set up for him. What we'd really like is to be able to get a little house that he could stay in separate from us but still here, because he's never going to be able to do money or even remember to go to a doctor's appointment. Those things are just going to be beyond him. We really want to get things in place, though, so that he can have some kind of a job or at least something that he can have success at on his own outside of us, so that he has some independence.

Summary of Results

For the six adoptive parents participating in this qualitative study, five super-ordinate themes emerged from the data. First, they shared their subjective experiences of early fantasies of adoption and how those fantasies compared to realities over time. The next theme that emerged was when parents began to notice that something seemed off with their child's development. This section also encompassed parents' early concerns, the process of researching for answers, and to eventually learning about their child's diagnosis of an FASD. The third super-ordinate theme was about positive and negative experiences with various systems, including macro, micro—and even within close personal circles. Next, the phenomenon of trauma and isolation emerged, which was also a common thread for many throughout the years. Lastly, in the final super-ordinate theme, Seismic Shifts, parents shared those experiences that encompassed a drive to be a fierce advocate, the transformation of their way of knowing and understanding their child, the moments of connection with their child, and the various ways that they are moving forward personally and in ways to help others.

Chapter V

Findings and Implications

Introduction to Findings

The aim of this study was to learn about the lived experiences of parents who unknowingly adopted a child with a Fetal Alcohol Spectrum Disorder (FASD). Six adoptive parents participated, each revealing an in-depth narrative about their individual struggles, resiliencies, hopes, and realities of parenting their child. This chapter presents a description of the study's conceptual model, followed by a summary of the theoretical perspectives used to analyze the data, including attachment theory, neuropsychological, and psychodynamic perspectives. Next, the findings include a review of the five superordinate themes that emerged, each assessed through the various aforementioned theoretical frames. Finally, there is a discussion of the validity and limitations of the study, implications for clinical social work practice, and suggestions for future research.

Findings in the study revealed both similarities and differences with other qualitative research conducted on this topic. Similar emergent themes include: school issues and need for supportive services (Phung, Wallace, Alexander & Phung, 2011), feeling like something's not right and the experience of receiving a diagnosis (Sanders & Buck, 2010), the future (Michaud & Temple (2013), and lack of services (Nelson &

Friesz, 2015). Different themes also emerged, including hopeful fantasies of what it would be like to adopt a child and the experiences of paradigm shifts following their child's diagnosis and through the years.

Conceptual Model Developed

The methodology utilized in this study was interpretative phenomenological analysis (IPA). The authors of IPA (Smith et al., 2009) suggest that, "qualitative research...tends to focus on meaning, sense-making, and communicative action (p. 45)." Phenomenology is a qualitative research method that is transcendental and emphasizes subjectivity and discovery of these *essences of experiences* of individuals. According to Creswell (2007), a phenomenological study explains the lived experiences of a concept or phenomenon for individuals. Namely, the focus is on participants' experiences and/or understandings of a particular phenomenon.

Phenomenology has a strong philosophical component as conceptualized and described by Husserl (Zahavi, 2003), who suggested that "adopting a *phenomenological attitude* involves and requires a reflexive move, as we turn our gaze from, for example, objects in the world, and direct it inward, towards our perceptions of those objects" (Smith et al., 2009, p. 12). Husserl proposed that bracketing, also known as *Epoche*, is a method to ensure that the researcher is suspended of any judgment regarding the true nature of reality. Bracketing allows the researcher to "put to one side, the taken-for-granted world in order to concentrate on our perception of that world" (Smith et al., 2009, p. 13).

Epistemology examines the nature of the relationship between the knower and what can be known. Gringeri, Barusch, & Cambron (2013) define epistemology as,

“theories of knowledge that justify the knowledge-building process that is actively or consciously adopted by the research” (p. 55). The interpretive epistemology is one of subjectivism, which, based on real world phenomena, does not exist independently of our knowledge of it (Grix, 2004). This type of methodology is a form of reflection, which is “an examination of our own knowledge formation process” (Gringeri, et al., 2013).

Reflexivity, which is central to epistemology, requires that the researcher develops a critical awareness of the social inputs that shape the production of knowledge and is imperative for strengthening the validity or knowledge claims in all research” (Gringeri et al., 2013, p. 56). Epistemology and reflexivity are essential components of qualitative methodology. So, in choosing this methodology for my study, I was able to examine real world phenomena through critical awareness of the participants lived experiences. These processes were also imperative for reinforcing the validity of the study.

Theoretical Frame

Various theoretical perspectives, including attachment theory, neurobiological, and psychodynamic perspectives, will be interwoven throughout the discussion to aid in an in-depth understanding of the parents’ experiences. As described in the literature review, attachment theory is one framework that enhances our understanding of the dynamics of parent-child relationships. Attachment influences a child’s development in various ways, early on in life and throughout their lifetime (Cozolino, 2002). The attachment system is also a safety-regulation system that, when activated, allows an individual to seek proximity with a secure other (Zimmerman, 1999).

From a psychodynamic frame, we know that children with FASD may have disrupted internal working models (IWMs), thus inhibiting the development of a healthy or secure attachment with their caregiver(s) (Pietromonaco et al., 2000). According to Zimmerman (1999), internal working models within an individual must be developed for higher adaptation to be assumed. Zimmerman also posits, “IWMs of attachment regulate emotional communication within individuals, as well as between individuals and attachment figures” (p. 293). As outlined in the previous chapter, most of the parents in this study have faced a range of challenging experiences due to their child’s impaired IWMs, including communication, emotional and affective regulation, and the development of a secure attachment.

Some of the more recent neuropsychological research emphasizes how children with FASD experience an over activation of the limbic system, creating a constant fight or flight response and, consequently, inhibiting the development of a secure attachment (Palicka, Klecka & Przybyło, 2016; Schore & Schore, 2008). Moreover, prenatal alcohol exposure is also known to damage the prefrontal cortex, the area of the brain that mediates executive function (Lemche, Giampietro, Surguladze, Amaro, Andrew, Williams, Brammer, Lawrence, Maier, Russell, & Simmons, 2006). Since these areas of the brain are critical in the formation of emotions and for the ability to form attachments, children with FASD are at risk for developing an insecure attachment with their caregivers (Palika et al., 2016). Cozolino (2006) asserts, “Early successful attachments set the stage for social regulation of biological processes throughout life” (p. 115). Further, emotion regulation and the ability to feel empathy for others are foundational to the development of healthy attachments (Schore, 2012). From another neurobiological perspective, even

parents who have their own secure attachment patterns may struggle greatly with attunement to their child who has an FASD, since that child may have a disrupted capability to form a secure attachment.

Parents raising a child with an FASD shared the challenges they faced with professionals and systems, particularly those who have little awareness or knowledge about FASD. The macro- and micro-level experiences are a few of the major issues that consistently came up during the interviews, in addition to the strengths and resiliencies that enhanced their experiences in parenting their child. The following discussion of the results will further explore these and other issues, all of which are tied to the five super-ordinate themes that emerged.

Findings

Throughout the interviews, the parents' lived experiences were shared with the principal researcher and often with strong emotions. For some, the interview process was the first time disclosing these personal experiences to someone other than family members. Throughout the interviews, there was mention of how it was cathartic talking about these experiences, which can be a common and positive consequence in qualitative research. Hutchinson, Wilson & Wilson (1994) supports this notion suggesting, "As qualitative researchers, we respect the value of peoples' stories and the varied meanings they have. We recognize the transformative power that telling a story has and the benefits that accrue" (p. 164).

The scope of this qualitative study explored the longitudinal life experiences of each of the parents, including the life experiences of their own childhood—to the point in

time when they decided to adopt a child—to their present day subjective realities. It is important to note that all of the adopted children of the parents in this study have also suffered some form of environmental trauma after birth, including early neglect, physical and sexual abuse, and witness to violence in the home. Unfortunately, few studies have focused on the effects of co-occurring prenatal alcohol exposure and environmental trauma on children (Henry, Sloane & Black-Pond, 2007). The authors of a recent systematic review and meta-analysis examined studies on children with this type of dual exposure, noting “Children with FASD and/or a history of trauma often present with common neurobehavioral disorders (such as ADHD) it is necessary to better define any differences between type and magnitude of neurodevelopmental impairment from different exposures” (Price, Cook, Norgate & Mukherjee, 2017). While the phenomenon of dual exposure is important to keep in mind and is relevant for future research, the focus of this study is specific to the experiences of parenting a child with an FASD. Nonetheless, some of the environmental traumatic experiences of the children are interwoven throughout the results and discussion.

Within the phenomenon of parents raising an adopted child with an FASD, five super-ordinate themes emerged:

- The Process of Adoption: Fantasies vs. Realities
- Something is Off
- Systems: The Good, The Bad, and The Ugly
- Trauma and Isolation
- Seismic Shifts

The process of adoption: Fantasies vs. realities.

As discussed in the literature, we know that adoption is commonplace, with an estimated five to six million adopted individuals at any given time in United States alone (Kreider & Lofquist, 2010). The Evan B. Donaldson Benchmark Adoption Survey (1997) portrayed the enormous scope of adoption, estimating that 6 out of every 10 adults have had some personal experience with adoption as a birth parent, an adoptee, or as an adoptive parent. The literature on adoption is abundant, with most studies focusing on the adopted child. Conversely, the psychodynamic literature on parents' experiences of adopting a child is limited. In her 2010 article on *Adoption as a developmental milestone*, Wade asks:

With so much at stake, why don't we know more about parents' pre-adoptive experience? Has no prior analytic writer observed that the sorrows of infertility and the demands and uncertainty of the adoption process do not inevitably impede attachment; rather the struggle may engender its own incubation period which the intensity of longing and disappointment. ...The psychoanalytic literature has hardly considered this question is ironic given that the law requires couples or individuals wishing to adopt to have their lives dissected by social workers in home studies before they are deemed up to the job of parenting (p. 26).

This study explores the lived experiences of the adoptive parents and their entire adoption process. It also looks at the nuances of parenting a child who is later diagnosed with an FASD. Among children who are adopted, it is unknown exactly how many of those have been prenatally exposed to alcohol in utero. However, based on a meta-analysis by May & Gossage (2001), the rate of FASD in the United States alone is

approximately 1% of all births. Further, *The National Task Force for Fetal Alcohol Syndrome and Fetal Alcohol Effect* estimates that one in every 1,000 children has FAS and one in every 100 presents with the milder effects of prenatal alcohol exposure (Weber, Floyd, Riley & Snider, (2002).

The participants in this study all began their interviews describing their own childhood experiences in addition to sharing their fantasies of someday becoming a parent. All six parents described altruistic reasons for adopting, even if infertility was an initial motive for pursuing adoption:

- Helping a child was important to us.
- There is value of helping someone in need.
- We wanted to give a child an opportunity for a better life.
- We're older and we have room in our house now that our biological kids are grown.

Three of the six participants cited their faith as a strong driving force to adopt:

- I eventually felt like God is telling me [to adopt] through this story [in the Bible]: "You should go and adopt the one that I have chosen for you and just trust me."
- He was created for us and we were chosen for him.

The various reasons that led parents to adopt were consistent with the literature findings (Blum, 1983; Kraft et al., 1980; Daniluk et al., 2003; Fisher, 2003). Of the six parents, three in this study began their adoption process due to infertility:

- It's too painful to go through [a miscarriage] again.

- All my friends were having babies—and I felt sad and left out... it was very hard.

It is common for individuals to experience a period of mourning between infertility and the decision to adopt. Santona & Zavattini (2005) concluded, “the exhausting process of mourning...allows for the painful transition...to the creation of the mental space for accepting a child born of other people.” D’Amato (2007) also reflects on the process of adoption as it relates to grief and loss:

Adoption is a journey that begins with loss. The loss provokes fantasies that impact every participant in the adoption process ... and psychoanalysts believe that unresolved and unrecognized feelings are not eliminated but instead become repressed and thereby reside in the unconscious...all members of the adoption triad deal with the emotions adoption arouses in one way or another (p. 54).

From a psychodynamic perspective, infertility can be a form of object loss. Benovitz (2006) writes about the “shame and a sense of failure associated with infertility” further asserting, “In not being able to conceive couples are faced with mourning the child they could not have and the loss of the fantasized child” (p. 14). Bowlby’s internal working model is the internal system that describes how parents may eventually adjust and work through this and other high-stress situations.

Even in the beginning of the adoption process, most of the parents had some concerns about adoption. Of the five who adopted internationally, all expressed worries about adopting a child with an attachment disorder or a child who has experienced institutional neglect. These worries are certainly justified since there is an abundance of literature on adopting a child with severe attachment disorders (Selman, 2009; Hughes,

1999; Johnson, 1997). Some parents did mention that FASD were of concern prior to adopting, but it was not at the forefront of their worries in the beginning stages of the process.

It was also striking that all of the participants experienced a challenging adoption process. Some noted that they were offended and angered by the insensitivity of adoption workers. Two parents talked about how they lost large sums of money and one was even reported feeling “swindled” by an unscrupulous agency that was later learned to be under investigation. In relation to this phenomenon, Benovitz (2006) writes:

Couples...are often dragged through the process of being investigated and screened by the adoption agency. This kind of process gives rise to anxiety, confusion, and helplessness, and further erodes the parents’ confidence, planting seeds of doubt about their right to be parents at all (p. 15).

The parents in this study all seemed in sync with one another in terms of having a fantasy of what adopting a child would be like, which, early on, was mostly positive. Nevertheless, all admitted to having some inner conflicts as the adoption came to fruition, especially those who adopted internationally (five out of the six parents). For these five parents the first time seeing their child was either on a video or in photos. For two of these parents, the initial reaction to seeing their future adopted child was negative:

- I saw photo of [her] and thought, I don’t like [her]...[she] looked like she has issues.
- When I first looked at the photo I felt “this is not my child”...I just was not feeling it.

For the two other parents who adopted internationally, they described feeling some hope when first seeing their child on a video:

- I just remember that she had a real sense of inquisitiveness, curiosity—maybe even an indomitable sort of spirit, because, here she is in this orphanage and she was attracted to things in her surroundings and seemed stimulated by them.
- I was aware of the caretakers in the video—they were interacting with her and she was tracking with them—and I thought, oh, that's good!

In the first super-ordinate theme, the process of adoption, parents shared their personal journeys, which presented a range of positive and negative experiences. Adoption itself can be a trying experience in many ways, whether it's overcoming loss from infertility or dealing with adoption systems that are sometimes insensitive or even misleading. For many, there were moments of hope and excitement, which often allowed for diligence in the process. When the adoption process was complete, parents shared their experiences of how the fantasies of their adopted child and parenting their adopted child turned out to be something different. Despite knowing their child's early life and the potential challenges that may arise because of it, the next section describes how the parents' began to have new concerns, as described in the next super-ordinate theme, *Something is off*.

Something is off.

Fetal Alcohol Spectrum Disorders are often referred to as *invisible disabilities*, since most individuals who are prenatally exposed to alcohol in utero have significant structural and functional changes within their brain, but do not have overt physical facial

dysmorphology or significant growth retardation (Mattson et al., 2001). Many children with an FASD often develop co-occurring secondary disabilities, including mental health problems, sensory processing disorders, school-related problems, trouble with the law, and inappropriate sexual behaviors (May, Keaster, Bozeman, Goodover, Blankenship, Kalberg, Buckley, Brooks, Hasken, Gossage & Robinson, 2015; Jirikowic, Olson, & Kartin, 2008; Streissguth et al., 1996).

Because of the abovementioned issues, children with FASD are often misdiagnosed. Many of these children receive a range of other diagnoses by clinicians who are not knowledgeable in FASD (Chasnoff et al., 2015; Gahagan, Sharpe, Brimacombe, Fry-Johnson, Levine, Mengel, O'Connor, Paley, Adubato & Brenneman, 2006). These matters, in addition to the parents not receiving adequate historical and medical records for their adopted child (an unfortunate yet common phenomenon in adoption), resulted in many difficulties before and after adoption was finalized. As shown in the results chapter, the parents in this study all experienced a range of negative feelings associated with these issues, including:

- Anger at birth parents.
- Not wanting to get sucked in and then let down.
- Anticipation of heartbreak.
- Things you read terrify you.
- It's hard not knowing.

Yet, despite the negative aspects mentioned above, some of the parents in this study described having hope and an overall sense of peace during the process of adoption, despite their fears and doubts, which allowed for their continued perseverance:

- We saw her [in the video] and it gave us hope.
- She had persistence!
- We wouldn't have peace if we didn't adopt him.
- The orphanage gave me hope that she was okay.
- I felt prepared to adopt because of my profession in education.

What also emerged from the interviews was a picture of the difficult journeys that took place prior to their child receiving an official diagnosis. Some parents did have a suspicion that their child had an FASD, yet many professionals would minimize their concerns, which is consistent with studies that revealed there is a lack of professionals who understand FASD (Elliott, Payne, Haan, & Bower, 2006; Gahagan et al., 2006). Here are a few of their noted emerging frustrations and concerns:

- It's not clicking for her.
- She could not remember things from one day to the next.
- It's hard to witness—I have no frame of reference for this.
- He's complexly traumatized but there's something more.
- Things aren't matching up—she functions more like a child half her age.

The findings also revealed how isolated many of the parents felt before an FASD diagnosis, which was augmented when clinical professionals and “experts” would brush off parents' continued concerns. For many, not getting answers from professionals was a launching point into conducting their own research:

- I just need to understand so I'm digging into the Internet, reading everything.
- I'm thirsty to learn.

- As soon as you find something new—you research and find more—it's just endless.
- I needed to know—is this [FASD]?

On a positive note, conducting their own research led many parents to find experts in the field of FASD, which ultimately lead to a concrete diagnosis for their child. As mentioned in the findings, this experience for every parent was difficult, yet paradoxically it offered some sense of relief:

- It was two-fold... like a progressive regression.
- It was a shock—why didn't anyone tell us sooner?
- Our doctor looked at her for four years and he didn't have a clue.
- Now we know there's a reason...but it's sobering because it's lifelong.
- These are not willful behaviors—and now we know that we cannot use normal parenting ways.
- It all makes sense now.

As mentioned before, individuals with FASD are at risk for developing secondary disabilities, which can include learning disorders, emotional and behavioral dysregulation, poor judgment, impulsivity, trouble with stealing, and a myriad of other mental health problems (May et al., 2015; Jirikowic et al., 2008; Streissguth et al., 1996). Experts agree that early identification, interventions, and caregiving stability are all correlated with a reduction in the development of secondary disabilities (Streissguth, Barr, Kogan & Bookstein, 1996). Unfortunately, for many parents, it is often years before receiving an accurate diagnosis.

When the parents in this study finally learned of their child's diagnosis, they all described going through a kind of paradigm shift with how they understood their child and how they had to consider moving forward. All parents described fears of what challenges may arise in the future, including a need for guardianship when their child turns 18, potential financial burdens and the need to put off retirement, and the need to constantly oversee and protect their child due to the known vulnerabilities that come with FASD.

From a psychodynamic perspective, parents who have healthy internal working models (IWMs) can improve their way of understanding and experiencing relationships (Pietromonaco & Barrett, 2000). However, when their child has a neurocognitive deficit like FASD, the child's IWMs are likely disrupted, thus impacting the development of secure attachment. This phenomenon may result in parents feeling de-skilled in their ability to calm and soothe their child, which further impacts a healthy attachment connection. Warshaw posits,

The powerful needs and fantasies, both conscious and unconscious...may also set the stage for formulations, projections, and preoccupations that impact significantly upon the parent's attunement to the child's experiences...[ultimately] impacting the development of the child's core experiences of self and other (p. 80, 2006).

In this study, some of the parents talked about these types of struggles and worries, in particular around their continuous efforts to connect with their child and how the inability to do so at a deep level increased their feelings of being ineffective in parenting.

Systems: The good, the bad, and the ugly.

Throughout their longitudinal life experiences, parents in this study all discussed their range of experiences within various systems; from agencies to clinicians to schools, and even within their close interpersonal circles. With respect to adoption agencies, the following were some of the common threads around some of their experiences of feeling supported, understood, and guided:

- They taught us that it was okay to advocate for our child.
- He gave us hope and it was important that he really knew our child.
- The therapist was relational and made a human connection—that was critical.
- [The school] just got her— they recognized her way of learning.
- The support group was powerful.
- He was open, kind, honest, and supportive—he gave us hope.

On the other hand, all six parents described the difficult times they had with various systems, often leading to feelings of isolation and anger. Some talked about their frustration with adoption professionals and their lack of basic understanding of FASD or other neurocognitive deficits, poor communication, and an overall lack of compassion:

- There was little to no communication and we were often left hanging.
- Some wanted to sugar coat everything – they were not truthful.
- Therapeutic foster homes are not therapeutic, they're re-traumatizing.
- They have no compassion.
- They only care about money.

Another common thread within this emergent theme was frustration with those who refused to work with them to help their child after the diagnosis of an FASD:

- They don't even try to understand even though we gave them the evaluation.
- They were not open to learning about FASD—we had to fight with a lawyer to get accommodations.
- They just see him as a bad kid, a troublemaker, and they treat him that way.
- The therapist just doesn't get it—behavioral therapy does not work.

Parents also talked about smaller systems, including their extended family members and friends. Many spoke of loss and the pain of losing those who turned away during times of need and crisis:

- We now are seeing who they really are.
- We feel abandoned.
- Some friends and family will never understand—they just see him as a bad kid and don't understand that it's not willful behavior.
- We just had to separate the wheat from the chaff.

Despite the painful losses within smaller systems, most parents also shared their experiences that brought about positive change. Some described having developed an even closer connection with some of their loved ones and close friends because of their responses and support during difficult times:

- The small few we can count on support us through good and bad.
- Those who stuck with us.
- Some of the connections became deeper.

Psychodynamic theory allows us to understand the interactional milieu between parents, their close friends and family, and within a larger social context. From a self-psychology perspective, self-objects are experienced subjectively and help organize and

strengthen the self. Further, Kohut (1984) asserted that the self-object needs are fundamental to the human experience and are essential for self-cohesion. To maintain a cohesive self, the parents in this study sought out those who were supportive, all the while working through experiences of feeling powerless and inadequate. Finding close connections, especially when others have been lost, has been critical for the parents in this study, which is supported by Palombo (2016) who states, “The maintenance of the capacity for self-cohesion depends on the availability of others who provide these functions...[and] isolation from others or loss of contact endangers the sense of self and threatens the loss of this capacity (p. 90).” When a loss of this capacity happens, parents are more vulnerable for experiencing *trauma and isolation*, as described in the following section and super-ordinate theme.

Trauma and isolation.

Another common emergent theme in the parents’ experiences of raising their child with FASD was trauma and isolation. Parents described having constant worries, guilt, shame, and sometimes living in a vortex of crisis. During the interviews, there were many moments of strong emotions, sadness, and constant worries that were expressed:

- We are barely surviving.
- It’s like a roller coaster—sometimes we think everything is going to be okay and then we are spiraling out of control again.
- I’m just waiting for the next bad thing to happen—how are we going to manage?
- One minute we’re angry, the next minute we’re crying.

- It's a form of PTSD—we are living in the trenches every day.

In describing some experiences of constant vigilance, many parents circled back to how the reality of raising their child is different from their earlier fantasies of adoption:

- I was naïve—I hoped that there would be a similar connection—like the one I have with my biological child.
- Sometimes I let optimism take over and then I hit another wall.
- We thought that love could fix it, but it can't.
- Early on, she would rock herself—and she was very quiet, she never cried—and she wouldn't want to cuddle. That was very hard.
- It's heartbreaking...it's not what I thought.

For some, trauma and isolation was compounded by many years of experiencing grief and loss, from the beginning of their adoption journey, which began just after experiencing infertility. For others, there was profound grief over the loss of the fantasy of what they had hoped it would be. Warshaw (2006) writes,

Parents' experiences of both infertility and the negative experiences often generated by the adoption process itself contribute to parental feelings of damage...thus, personal experiences of loss may serve as sources of distortion as well as points of identification for parents and child (p. 79).

For most of the parents, the early fantasy of their adopted child was shattered, which resulted in feelings of guilt, sadness, and self-blame:

- We had hoped for a healthy child but it's not how we imagined it would be.
- We are not happy; it's a difficult life.
- Maybe I'm not doing enough.

- Did I contribute to the problems?
- I want to fix him so bad.
- Sometimes I blame myself.

This phenomenon is illuminated from psychodynamic perspectives, including Brinich (1980) who wrote about self- and object representations associated with adoption. He maintains, “The adoption of a child is, in human terms, always a painful and potentially traumatic event (p. 107).” Freedgood (2013), who is also an adoptive mother, wrote, “Adopting parents are caught in the illusion that their love will heal all (p. 28).” She further suggests that there are layers upon layers of dynamics that may become barriers to a successful adoption, including positive and negative influences from the child’s biological and environmental history.

A child diagnosed with an FASD adds on another layer of difficulties for parents, most of whom try their best to help their child, wanting their child to have a happy and fulfilled life. Further, for the parents in this study who also had experiences raising a biological child, the baseline of parenting was oftentimes not sufficient enough for parenting their child with an FASD. Palombo (2016) sufficiently summarizes this phenomenon, in addition to some of the other challenges that parents may face when raising a child with a neurocognitive deficit:

Parents are often in the dark about what the child requires. Some caregivers respond intuitively. Through their empathetic capacities, they can fill in the child’s neurocognitive deficits. In fact, these parents, if they have had other children, recognize the differences in the child and feel they must respond as they do or cause the child serious distress. When parents either cannot or do not

complement the child's deficits, the child suffers. The reason for the child's distress is seldom evident early on. Parents often feel much puzzlement and guilt as they assume that they are the cause of the problem (p. 154).

The parents in this study also discussed how their own childhood experiences might have impacted the experiences of parenting their child. Blum (1983) suggests, "Intergenerational conflicts impact adoptive parents' attainment of parental identity, attachment, and confidence in their rearing of the child" (p. 161). This statement supports the importance of having an understanding of insecure attachment patterns, how they emerge, and how they impact relationships. As a child with an FASD develops, disrupted attachment patterns can lead to fear, mistrust, and withdrawal tendencies—all of which impact a child's ability to make and keep friends. For the parents, this was often a painful and helpless reality to witness. These feelings and experiences led to a kind of *shift* for the parents, all of whom took various forms of action to protect their child, in addition to seeking out ways that could help their child live a happier life.

Seismic shifts.

For the parents in this study, the challenges of parenting their child was described as overwhelming at times. Despite the challenges faced, all described some of their own personal strengths that emerged from chaos, including found resiliency and becoming a strong advocate for their child. Perhaps this can also be referred to as a form of posttraumatic growth, which refers to positive psychological change experienced as a result of the struggle with highly challenging life circumstances (Tedeschi & Calhoun, 2004):

- I need to protect her because she is vulnerable, so I became a fierce warrior—something unleashed in me.
- I fight for what's right—I'm fighting for him.
- I have to protect my child—I am her external brain.
- This is my fight—I am helping her get what she needs because she learns differently.

After the diagnosis, all parents talked about the sense of relief in knowing. Yet, the newly understood diagnosis was often a moot point when dealing with others who did not understand FASD. Here we can see the parents' experiences of trying to get others to understand their child and the FASD diagnosis, which was often described as the most frustrating of all their battles:

- I am teaching others about kids with special needs—I'm just hoping that more people will develop more understanding and empathy.
- I am making sure that others understand FASD, but there's always another battle.
- We need to educate his teachers, his lawyers—because of his FASD he's more like 7 than 15.

Some discussed their experiences of ambivalence about what or how much should be disclosed to others:

- How much should I share with others?
- She's desperate for love and affection but she's so vulnerable—so how do I keep her safe?

Parents also shared many of the positive occurrences throughout the years, which were described by many as moments that created shared experiences of love, joy, and hope:

- She's so athletic—it's something we share and enjoy.
- We fish together—and those are the quiet time when we are together and he feels safe.
- Our family Christmas was his first encounter of what family is all about.
- People don't know she is adopted and say that we have a resemblance—it's our joke together, and it's another way we connect.

Most of the parents discussed how they envision the future of raising their child with an FASD. Before the diagnosis, some parents reflected how they had once looked forward to their retirement years. Now many have had to shift their plans, since FASD are lifelong disabilities in which the child will have dependency, even in adulthood:

- Where to draw the line—how to draw the line—what boundaries do we need in place?
- I wish we would have known about guardianship options before she turned 18.
- She is going to always need support—I feel so helpless.
- We want him to be successful but he also needs to be sheltered and protected, so we are developing a trust fund.

Some parents' shift was developing a new sense of purpose, of helping other parents and families who may be experiencing similar struggles:

- Let's do something about it—let's help others.
- I want to make connections and protections for these kids.

- I hope to find others who are also dedicated to make it work.
- I want to do something positive so I am writing a memoir.
- I want to share my story—it's cathartic.

What also emerged from the interviews were heartwarming stories of strength and of hope. Despite the challenges of disrupted attachment and deficits due to FASD, relationships can be strengthened, especially through the process of rupture and repair. These kinds of experiences also lead to *meaning-making*, which is the process of how an individual makes sense of life events, relationships, and the self (Ignelzi, 2000). The following are some of the moments when the parents' pride and joy were palpable, as they spoke of their child's positive qualities:

- He's loving, giving, and wants to make others happy—he can be such a delight.
- She's very social and not shy.
- She's athletic and strong—she loves running, gymnastics, dancing, and performing—these are all things that help her focus and make her happy.
- She is natural at sports and is at her best when playing sports—everyone loved watching her, which helped her to gain confidence and have increased self-esteem.
- She's bright, loving, kind, and funny... she's a joy to be with.
- Now I'm learning to let go... letting her be where she is and being okay with that. It's freeing.
- We go above and beyond with the little things that bring connections and joy.

The experiences of the parents in this study portray the subjective journeys of raising a child with an FASD. These included the difficult journeys that led to adoption as well as the tumultuous moments that occurred once the adoption was finalized. Each

parent had frustrating and sometimes infuriating experiences with systems, at both the micro- and macro-level. Some of these sequences of events lead to parents becoming fierce advocates for their child, and even brought some of them to a place of wanting to help others with similar experiences. Each parent in this study explained one or more significant shifts that they experienced through the years. Wade (2010) provides the following poignant summary, which seems to appropriately describe the experience of raising an adoptive child with an FASD:

These are intense emotional dramas, not infrequently involving false starts, plans that change, and adoptions disrupted before or after placement. Well-meaning friends may tout the myth that adoption offers a simple solution to infertility, but it is rarely an easy route to parenthood (pp. 26-27).

Conclusion

The adoptive parents in this study all shared their longitudinal journeys that led up to the point of adopting their child—from being a child in their family of origin—to their present-day lived experiences of raising a child with an FASD. The data revealed, the often, painful adoption process, including grief and loss due to infertility or, for some, the arduous and long-term processes of adoption and adoption professionals who showed lack of compassion or indifference.

For most of the parents in this study, the hopeful fantasies of adopting a child were eventually thwarted due to subtle or, at times, more overt indications that something is off with their child's development. Many described feeling unsupported and helpless, which propelled them to conduct their own research to find answers— independently and in

isolation. For all, this process eventually steered them to professionals who had expertise in evaluating and diagnosing FASD. The concrete diagnosis of an FASD created a two-fold reality for most of the parents—both earth shattering and intense relief in the knowing.

After the diagnosis, many parents expressed they finally had the information they needed to become a fierce advocate for their child. Nevertheless, there were still struggles with some family, friends, and broader systems that did not understand FASD or the common secondary disabilities often associated with FASD. This paradigm launched some parents into developing deeper connections with those who remained supportive and took the time to develop a better understanding of FASD. Some parents were even compelled to take their experiences to find ways of helping others.

Validity and Limitations of the Study

In conducting qualitative research, there are particular methods used to provide internal validity of the results. For my study, I incorporated the following foundational elements to assess the validity of the results. First, as outlined in IPA methodology (Smith et al., 2009), I adhered to the principals of *commitment and rigor*. As I conducted the interviews with each parent, I did so with a great deal of attentiveness to what they were saying, including taking note of their affect and overall presentation. Further, I spent a lot of time with the data—listening, reading, and re-reading—along with in-depth coding, all to support rigor of the study.

Next, I conducted *member checking* by ensuring that all participants had an opportunity to read through their interview transcripts and provide feedback. This process

was also conducted to increase the validity of the data, and all feedback was incorporated into the findings. Finally, careful and frequent consultation occurred with an advisor to reduce the impact of subjective bias in the collection and coding of data. During this process, I was also able to share my own thoughts from my reflective journal.

I began this study due to former clinical experiences with children and families impacted by FASD. Although I listed my assumptions as part of the bracketing process, my prior knowledge of the topic may have influenced the emergent themes, which may affect some aspects of the validity of the study. In regards to limitations, this study may not be generalizable to all parents' experiences of raising a child with an FASD. The sample of participants was not only small, but also limited in terms of racial diversity and geographic location, even though the study was open to include anyone regardless of age, gender, race, ethnicity, or religious affiliation.

Implications for Clinical Social Work Practice

Many clinical social workers, in addition to other professionals working in the field of adoption, have limited awareness and understanding of Fetal Alcohol Spectrum Disorders (Wedding et al., 2007; Caley et al., 2008). The findings in this study support that FASD can profoundly impact a child throughout their lifetime and the effects on the child's parents and family can be devastating (Riley et al., 2005; Mattson et al., 2011). The data reveals a depth understanding of the multifaceted personal, familial, and therapeutic experiences of these parents.

This study highlights the need for clinicians to be more aware of FASD, especially when working with adoption and child welfare populations. What also emerged from the

data was the importance of looking for the unspoken, as parents were often reluctant to bring up some of the core issues because of feelings of isolation and shame (i.e., “no one cares,” “we haven’t been able to talk about this”). Clinical social workers and other professionals also need to anticipate some of the obstacles these parents face, before and after the adoption. For those providing psychotherapy for these parents, it is critical to continue to look for the unspoken, offer psychoeducation about FASD, and normalize their experiences.

Many parents in this study spoke of isolation, but the reality is there are many others with similar experiences. Unfortunately, individuals and systems are often in silos, which is another critical area to address at the micro and macro level. Overall, the results of this study demonstrate the profound and intense emotions experienced by these parents, which may offer valuable insights for clinicians treating individuals who are impacted by FASD.

Suggestions for Future Research

Some suggestions for further research include a larger and more diverse sample. Also, it is important to look for changing trends in adoption, especially international adoption to explore any changing trends in regard to FASD. Further, the impact on education and training of helping parents with earlier screening and support. Information on prenatal substances of abuse should be a mandatory part of curriculum for individuals in helping professions. Internationally, there are experts on FASD; however, many of these individuals and systems do not seem connected, or do not collaborate as much as

they could. Other areas of research include looking at the impact that FASD have on siblings, couples, and family systems as a whole.

Appendix A

Study Flyer



Are you an adoptive parent raising a child with a Fetal Alcohol Spectrum Disorder (FASD)?

VOLUNTEERS NEEDED FOR A STUDY ON THE EXPERIENCES OF RAISING A CHILD WITH A FETAL ALCOHOL SPECTRUM DISORDER

Purpose of this Study: This study will explore the day-to-day experiences of adoptive parents who are raising a child with Fetal Alcohol Spectrum Disorder. Participation in this study will include two 60-minute interviews. The interviews will take place in person, at a private and convenient location (of your choosing), and confidentiality is assured.

To Participate in this Study: You are an adoptive parent of a child who received an FASD diagnosis after he or she was adopted into your family. The date of the FASD diagnosis must be more than one year from the time of the first study interview. Finally, the location of the interview must be within a reasonable driving distance from the Chicagoland area.

Benefits of Participation: Your participation will contribute to an in-depth understanding of the experience of raising a child with an FASD.

Risks of Participation: There are minimal risks in participating in this study.

FOR YOUR TIME PARTICIPATING IN THIS STUDY, YOU WILL HAVE A CHOICE OF RECEIVING A \$20 TARGET OR STARBUCKS GIFT CARD.

This research is being conducted by PhD Candidate, Amy Groessl, supervised by Dr. Denise Duval Tsiolos and under the auspices of the Institute for Clinical Social Work (ICSW), 401 South State Street, Suite 822, Chicago, IL 60605. This research study has been approved by the ICSW Institutional Review Board. If you have any questions, please contact Amy Groessl at 773-991-3655 or agroessl@icsw.edu. You may also contact Dr. Duval Tsiolos at dduval@icsw.edu.

TO VOLUNTEER, PLEASE CONTACT AMY GROESSL:

773-991-3655

Appendix B
Recruitment Letter

Amy Groessler, MSW, LCSW
agroessler@icsw.edu
773-991-3655

Dear Provider,

My name is Amy Groessler and I am a Ph.D. candidate at the Institute for Clinical Social Work (ICSW) in Chicago. I am conducting a study on parents who unknowingly adopt a child with a Fetal Alcohol Spectrum Disorder (FASD). I am looking for parents who were not aware of their adopted child's prenatal exposure to alcohol before the adoption was finalized. Also, there should be at least one year since their child's FASD diagnosis and the time they would participate in this study.

The purpose of this research study is to gain an in-depth understanding what it is like to adopt and parent a child with an FASD. By taking part in this research study, parents will have an opportunity to share the struggles, resiliencies, hopes, and realities of parenting their child. There will be two in-person interviews that will be scheduled at a convenient time and location. Complete confidentiality will be maintained at all times, protecting parents' identities in all data and reports. Parents participating in this study will have a choice of receiving a \$20 Target or Starbucks gift card after each interview, as a small gesture of appreciation for their time involved. Participants who choose to cease interviews at any time will still receive a gift card.

I am a licensed clinical social worker with many years of experience working with children and families impacted by FASD. I am conducting this research for my doctoral dissertation at ICSW and my proposed research has been reviewed and approved by the Institutional Review Board. I hope you will take this opportunity to pass along my information to parents who may be interested in participating in this study. I can be reached at 773-991-3655 or agroessler@icsw.edu to learn more about the study. Parents who contact me will not be obligated to participate. Gaining perspectives and experiences of parents who are raising a child with an FASD is not only important for professionals working with these families, but also for the individual family members who are impacted. Thank you for your interest.

Sincerely,

Amy Groessler, LCSW
PhD Candidate

Appendix C

Phone Interview Script

Prospective study participants will call or email me to set up phone interview, which will include the following:

Hello, my name is Amy Groessl and I am a PhD candidate at the Institute for Clinical Social Work in Chicago. I am conducting a research study about the experiences of adoptive parents who unknowingly adopt a child with Fetal Alcohol Spectrum Disorder. I have a brief survey that will take about 5 minutes of your time to complete. Your participation is entirely voluntary, you may skip any of the questions that you don't want to answer, and I am not collecting any identifying information. Because I am looking for specific aspects to study, the following questions will see if you are a good match to participate.

- a. *Have you adopted a child? (If yes, go on to b; If no, thank them for taking the time to call).*
- b. *Has your child been diagnosed with an FASD? (If yes, go on to c, If no, thank them for taking the time to call).*
- c. *Was your child diagnosed at least two years ago? (If yes, go on to d, If no, thank them for taking the time to call).*
- d. *Would you be willing to participate in two interviews (in-person) and a follow-up phone interview? (If yes, ask for more contact information so that a PDF packet of information can be emailed, which will include the Formal Consent Document - Appendix E, detailing the study, including risks, benefits, confidentiality, and the consent process. The consent will be signed in-person before the initial interview begins. If no, thank them for taking the time to call).*

Appendix D
Formal Consent Document

Institute for Clinical Social Work**Research Information and Consent for Participation in Social Behavioral Research*****The lived experiences of parents who unknowingly adopt a child with a Fetal Alcohol Spectrum Disorder (FASD)***

I, _____, acting for myself, agree to take part in the research entitled: The experiences of parents who unknowingly adopt a child who is later diagnosed with a Fetal Alcohol Spectrum Disorder. This work will be carried out by Amy Groessl, LCSW (Principal Researcher) under the supervision of Denise Duval Tsioles, PhD (Dissertation Chair). This work is conducted under the auspices of the Institute for Clinical Social Work; at Robert Morris Center, 401 South State Street, Suite 822, Chicago, IL 60605; (312) 935-4232.

Purpose

The purpose of this study is to explore and discover the day-to-day experiences of adoptive parents who are raising a child who has been diagnosed with a Fetal Alcohol Spectrum Disorder (FASD). For the purposes of this research study, Fetal Alcohol Spectrum Disorder (FASD) is an umbrella term used to describe children who are exposed to alcohol during their birth mother's pregnancy, causing adverse effects. Medical and behavioral health specialists, including those that work in the field of adoption, are aware of the immense need for understanding and treating children and families who are struggling with the complex issues associated with FASD. Because FASD can profoundly impact a child throughout their lifetime and the impact on the child's family can be equally as devastating, the results of this research study aims to develop a more thorough understanding of the comprehensive needs of these children and their families.

Procedures used in the study and duration

You will receive two 60-minute, in-person interviews at a private and convenient location of your choosing; confidentiality is assured. A third 30-minute interview via phone may be added (if needed) to ask follow-up questions. The interviews will be audiotaped with an iPhone and I, the principal researcher, will transcribe the recordings. A false name of your choosing will be used with your transcripts. Transcripts of your interviews will be shared between my dissertation committee and myself. For your time participating in this study, you will have a choice of receiving \$20 Target or Starbucks gift card after each in-person interview.

Benefits

Your participation in this study will contribute to a better understanding of the experiences of adoptive parents who are raising a child with an FASD. The results of this research study aim to develop a more thorough understanding of the comprehensive needs of these children and their families. Results may also aid in helping develop more appropriate treatment strategies to strengthen children and their families as well as potentially serving as a measure of prevention.

Costs There are no costs associated with participation in this study.

Possible Risks and/or Side Effects

This study poses some risks, which may be in the form of emotional discomfort as a result of discussing personal information. You are encouraged to share only information that you feel is relevant and non-damaging to your emotional well-being and comfort. You reserve the right to decline any of my questions if they bring up feelings that are overly uncomfortable or upsetting. If you experience emotional distress following the interview, a list of resources, including psychotherapists will be made available.

Privacy and Confidentiality

Data from this study will include your chosen false name. Data from interviews will be stored on my private computer and transferred by email (only on an as-needed basis) to my committee chairperson's secured email account and computer. All audio files containing data will be permanently deleted upon final completion of the research study.

Subject Assurances

By signing this consent form, I agree to take part in this study. I have not given up any of my rights or released this institution from responsibility for carelessness. I may cancel my consent and refuse to continue in this at any time without penalty or loss of benefits. My relationship with the staff of the ICSW will not be affected in any way, now or in the future, if I refuse to take part, or if I begin the study and then withdraw. If I have any questions about the research methods, I can contact Amy Groessl at this phone number: 773-991-3655. If I have any questions about my rights as a research subject, I may contact IRB Chairperson John Ridings, through ICSW at: 312-935-4232.

Signatures

I have read this consent form and agree to take part in this study as it is explained in this consent form.

Signature of Participant

Date

I certify that I have explained the research to _____ and believe that they understand and that they have agreed to participate freely. I agree to answer any additional questions when they arise during the research or afterward.

Signature of Researcher

Date

Appendix E
Sample Interview Script

- Please tell me about yourself
 - *Age?*
 - *Gender?*
 - *Marital Status?*
 - *Where do you live?*
 - *Do you work? If so, what do you do?*
 - *What is your day-to-day life like?*
 - *What are your hobbies?*

- Please tell me about your current family
 - *How many children do you have?*
 - *How many are biological?*
 - *Adopted?*
 - *Do you have any step-children or foster-children?*
 - *Their ages?*

- Please tell me about your family of origin
 - *Where did you grow up?*
 - *What were your parents like when you were a child?*
 - *Would you please describe your relationship with your parents?*
 - *As a child vs. as an adult?*
 - *Were you closer to one more than the other? Can you tell me more about that?*
 - *Siblings?*
 - *Your relationship with your siblings?*
 - *Other extended family?*

- What were things like for you when you were a child?
 - *How did that feel?*
 - *What did you do?*
 - *Memories that stand out?*

Relationship history

- Please tell me about your marriage (if applicable)
 - When did you meet?
 - What was it like when you first got together?
 - Did you talk about having a family in the beginning of your relationship?
 - Did you both feel the same way?

Adoption

- Please describe to me what first motivated you to adopt a child?
 - *When did you first begin to consider adoption?*
 - *What was that like?*
 - *Did you have any concerns?*
 - *How did your partner/spouse feel (if applicable)?*

- Please explain more about how you came to the decision to adopt your child? (*Infertility? Altruistic reasons? Other reasons?*)

- Describe your fantasies/expectations of adopting a child?
 - *Is it how you envisioned it to be?*
 - *Is anything different than you expected?*

- What was your experience with the adoption agency or adoption workers?
 - *What was positive?*
 - *What kind of challenges did you have during the process?*
 - *What did you know going into the adoption (how was _____ described)?*
 - *What information did you have on _____ biological family?*

- What did you notice about [your adopted child] that prompted you to get testing?
 - *How old was he/she?*
 - *What kinds of things were happening that were of concern?*
 - *At home?*
 - *At school?*
 - *In community settings?*
 - *Anything else you can tell me?*

- Please describe your experience when you first learned about your child's FASD diagnosis?
 - *Who told you?*
 - *What did you remember feeling or saying when you learned about the diagnosis?*
 - *Would you please tell me how your life has changed since learning about the diagnosis?*
 - *Is anything worse?*
 - *Is anything better?*
 - *What do you imagine the future to be like?*

- What have things been like for you since _____ was diagnosed?

- How have you coped since the diagnosis?
 - *Personal care?*
 - *Professional?*
 - *Community/support groups?*

- What things, if any, have impacted others in your family?
 - *Your spouse/partner?*
 - *Other children?*

- Who has been available for you in a supportive role?
 - *Personal?*
 - *Professional?*

- How has the FASD diagnosis impacted your relationships with others?
 - *Can you share more about what that was like for you?*
 - *Both positive and negative...with your child?*
 - *Other children?*
 - *Spouse/partner?*
 - *Extended family?*
 - *Your child's school teachers/administrators/support staff?*

- Please tell me about your thoughts about your child's birth family.

- Is there anything else that you would like to add that has not yet been addressed?

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