

Adoptive Parent Perspectives on Placing an Intercountry Adopted Child with Disabilities in Out
of Home Care

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This dissertation is dedicated to the more than 400,000 (and growing) intercountry adoptees that survived the journey to families in the United States. You have not been forgotten.

Abstract

In the past seven decades over 400,000 children born outside the U.S. have been adopted to U.S. citizens through intercountry adoption (U.S. State Department 2014, Evan B. Donaldson, 2002). Many of these children experienced trauma, malnutrition, abuse, neglect, prenatal exposure to alcohol and other drugs, and institutionalization and nearly eight percent of intercountry adopted children under 18 in 2010 had at least one intellectual, developmental or mental health disability as according to the U.S. Census (Kreider, 2014). Some adoptive parents choose to place their child in out of home placement including residential treatment center, foster care, group home, or even another adoptive home as a result of their child's disability.

Research on the decision-making process of adoptive parents that placed their intercountry child either temporarily or permanently in out of home care does not exist in the current literature. Using a qualitative, constructivist grounded theory methodology (Charmaz, 2006) perspectives of adoptive parents who placed an intercountry adopted child in out of home placement due to the child's disability were explored. Nineteen parents representing 16 families living in West Coast, Midwest and Mid-Atlantic states participated in this study. Findings reveal that adoptive parents begin the intercountry adoption process with specific constructions about disability and intercountry adoption that impact the choices the parents make regarding the reasons they adopt, the services they choose (including out of home placements), and whether or not they consider dissolving their adoption. Additionally, adoptive parents experienced financial, social, relational and personal costs related to the choices they made in parenting their children and respond by making behavioral or emotional changes in their approach to parenting, leading them to re-define their concept of disability and adoption.

These findings from this study highlight the importance of developing training programs for both adoption agency staff as well as prospective adoptive parents on adopting children with intellectual, developmental and mental health disabilities. Policy recommendations include

requiring an increased minimum standard of training for adoption agency staff and prospective adoptive parents on disability content, better data collection on intercountry adoptive families, as well as a shift toward child welfare as the standard focus of intercountry adoption policy.

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Introduction

Chapter Overview

On April 8, 2010, Torry Hansen, a single mother from Tennessee, placed her 7-year old adopted Russian son on a plane headed to Moscow along with a letter stating her son was “violent and has severe psychopathic issues” and that she no longer wanted to parent her child (Levy, 2010). The public and professional response was swift. Within days Russian officials froze their intercountry adoption program, criticizing the United States. Many in the general public were outraged that Hansen had abandoned her son of six months, and particularly criticized the fashion in which she acted on her decision to dissolve the adoption. Others defended Hansen because of the child’s alleged psychological problems, which Hanson claimed were undisclosed prior to the adoption. Hanson’s decision to “return” her adopted child was one of the first of a series of public media reports about adoptive parents terminating their parental obligations to an intercountry adopted child because of the child’s disability, culminating in the investigative report conducted by Reuters in September, 2013. In *The child exchange: Inside America’s underground market for children*, journalist Megan Twohey introduced the public to the practice of “re-homing” – the dissolution of an adoption through the placement of one’s adopted child into another family. While re-homing is not a new practice, the convenience and availability of online technologies and social media has enabled adoptive parents to quickly connect with potential adoptive parents to whom they can hand over the child independent of agency or legal oversight and without repercussion. The Reuters’ investigation made this quiet practice public. One thing that struck the public’s attention: of the 261 children advertised for re-homing by their adoptive parents on one online forum, at least 70% were intercountry adoptions (Twohey, 2013).

Along with the Hansen case, the Reuters investigation into re-homing drew attention to an uncomfortable fact: sometimes intercountry adopted children with disabilities are placed with adoptive families that are unprepared to parent a child with disabilities and these parents seek out

others to care for the child. Intercountry adoption is the legal and physical transfer of a child born in one country to a parent(s) with citizenship in a different country (Miller, 2005). The availability of data on the number of internationally adopted children with experiences in out of home care after their adoption finalization in the United States is limited for many reasons (Schuman & Flango, 2013). Since the 1940s, over 410,000 foreign-born children have been adopted to the United States (U.S. State Department 2014, Evan B. Donaldson, 2002). According to the 2010 Census, almost 8% of internationally adopted children under 18 years old in the U.S. have at least one physical, developmental, intellectual and psychological disability (Kreider & Lofquist, 2014). Sometimes these disabilities are known to the adoptive parents prior to the adoption but often the disability is unknown, undiagnosed, or sometimes even concealed from prospective adoptive parents. As this study found, in the U.S. parents sometimes choose intercountry adoption specifically to avoid adopting a “special needs” child from foster care. Yet the pre-adoption experiences of intercountry adopted children and youth are strikingly similar to those of youth in U.S. foster care and often include a history of abuse and neglect, trauma, poverty, multiple placement disruptions, institutional neglect, prenatal issues (exposure to alcohol and other drugs, lack of prenatal health care), low birth weight and prematurity (Jenista, 2005; Miller, 2005; Rutter, 2008). In addition children may be placed in out of home or alternative care in their country of birth because of a physical, emotional, intellectual or developmental disability (Jenista, 1995, 2000; Miller, 2005).

Efforts to promote and facilitate adoption without considering what families need to support stability of the adoption after the finalization places already vulnerable children at further risk. In order to lay the groundwork for future research plans to examine factors that lead adoptive parents to displacement and dissolution across adoption types (foster adoption, international adoption, private infant adoption), I sought to first understand the phenomenon from the point of view of those who have lived the experience, that is, adoptive parents and

internationally adopted persons. I chose adoptive parents as the first focus of study to understand the reasons for and ways in which these children come to be in the United States in the first place. In addition, adoptive parents are the ones who make decisions about out-of-home care for their child.

Throughout their lives, adoptive parents work with multiple systems, ranging from their pre-adoption work with adoption agencies in the United States and their child's country to social service and mental health organizations after finalizing the adoption. My practice and community experiences certainly inform how I understand the reasons adoptive parents might choose out-of-home placements for their intercountry adopted children but I argue that conducting a comparative or prevalence study without first undertaking this foundational research would result in a study reliant upon researcher assumptions and biases about adoptive parent experiences rather than grounded in the lived experiences of the parents themselves.

This chapter will introduce and provide an overview of my dissertation study which explores the decisions adoptive parents make when considering out of home placement experiences for an intercountry adopted child with a mental health, intellectual or developmental disability. I will begin with a description of the study. Next, I will provide information on the study background, and statement of the problem. I will then describe the research questions I sought to answer followed by an overview of the historical contexts of adoption, special needs adoption and international adoption. The chapter will conclude with a brief overview of the remaining chapters.

Brief Study Description

While research on placement stability for children adopted from foster care is abundant in the literature, there are limited published findings of empirical research on the placement stability for intercountry adoption children. This study is an exploratory, grounded theory examination of the experiences of adoptive parents that have placed their intercountry adopted children in out of

home care due to their child's disability. Nineteen adoptive parents participated in semi-structured interviews. I asked parents to describe their families including how they came to adopt their child; what disability means to them; their access and use of services for their child; and the impact of their child's disability and out of home placement on the family. Using a social construction lens (Burr, 2003; Gergen, 2009), I explore how adoptive parents construct and define disability, and intercountry adoption. From an ecological systems theory framework (Bronfenbrenner, 1979), I sought to understand the interactions between the parents and other persons, organizations and institutions across the family's micro, meso, exo and macrosystems. Drawing from disability theory I explore the ways in which the families navigate the medical model, social model, and Siebers' (2008) concept of "complex embodiment" for persons with disabilities.

The purpose of this study is to contribute to a better understanding of why and how adoptive parents choose out of home placement for an intercountry adopted child with mental health and intellectual/developmental disability. In addition, this study aims to inform practice, policy, research and practice and begin the discussion of the gaps that exist between the systems that govern intercountry adoption and the public child welfare systems in the United States. The findings of this study suggest that the adoptive parents in this study felt overwhelmed in the parenting journey and struggled to find the appropriate services for their child. The parents in this study also reported a lack of pre-adoption education and preparation for parenting a child with one or more disabilities. Finally, while parents experience their own grief, loss and secondary trauma related to their adopted child's disability and out of home placements, they were also able to identify ways in which parenting children has benefitted their lives.

Definition of Terms

For this thesis I use the overarching definition of disability as defined by the Americans with Disabilities Act (1990, amended 2008), which defines disability as “a physical or mental impairment that substantially limits one or more major life activities of such individual” (Americans With Disabilities Act, 1990).

Specific types of disabilities as well as other key terms are defined as below:

- *Child welfare services.* Programs and services that ensure the safety, permanency and wellbeing of children. Child welfare services may include (but is not limited to) child protection case management, mental health case management, developmental disabilities services, out-of-home placement (see below), and adoption.
- *Intercountry adoption.* Intercountry (also called international or transnational) adoption is the legal adoption of a child from a country other than that of the parent’s country of residence and/or citizenship. The application for an intercountry adoption is approved by the government of the child’s country of citizenship and the approval of an immigrant visa application for a child for the purpose of adoption in the United States is regulated by the U.S. State Department. Usage of the term “intercountry adoption” became more widespread after the implementation of the Hague Convention on the Protection of Children in Respect of Intercountry Adoption was drafted in 1993. The term intercountry will be used in this thesis except for quotes from a participant or citation.
- *Intellectual/developmental disability.* The Administration on Developmental Disabilities (ADD) defines developmental disability as “severe, life-long disabilities attributable to mental and/or physical impairments which manifest themselves before the age of 22 years and are likely to continue indefinitely” and include limitations in at least three of the following: self-care, comprehension and language skills (receptive and expressive language), learning, mobility, self-direction, capacity for independent living, economic self-sufficiency

and/or ability to function independently without coordinated services (continuous need for individually planned and coordinated services (ADD, 2010). The definition of intellectual disability as defined by the American Association on Intellectual and Developmental Disabilities (AAIDD) is "...characterized by significant limitations in both intellectual functioning (reasoning, learning, problem solving) and in adaptive behavior...[that] originates before the age of 18" (Shalock, Luckasson & Shogren, 2007). Developmental disabilities (DD) may include (but are not limited to) cerebral palsy, Autism Spectrum Disorders (ASD), Attention Deficit Hyperactivity Disorder (ADHD), Fetal Alcohol Spectrum Disorders (FASD), and intellectual disabilities (ID) (Grace, 1997).

- *Mental health disability.* Mental health disability is also commonly referred to as a mental illness or mental disorder. According to the National Institute of Mental Illness (NAMI) "a mental illness is a medical condition that disrupts a person's thinking, feeling, mood, ability to relate to others and daily functioning" (NAMI, 2013). The DSM-V defines mental disorder as "a syndrome characterized by clinically significant disturbance in an individual's cognition, emotion regulation, or behavior that reflects a dysfunction in the psychological, biological or developmental process underlying mental functioning" (American Psychiatric Association, 2013).
- *Out of home placement.* Out of home placement refers to a child's temporary or permanent residence some place other than that of his/her parent(s) and may include placement with a relative or in a shelter, foster care, group home, residential treatment center, juvenile detention facility or hospital or other institution. (Child Welfare Information Gateway, n.d.).
- *Post-adoption services.* Post-adoption services include programs and services for adopted children, youth and their parents after the adoption has been finalized. Post-adoption services may include adoptive parent support groups, social or support groups for adopted children and youth, respite care, continuing education through workshops and conferences, heritage

- camps for transracially or internationally adopted children and youth, newsletters, warmlines, referrals for mental health or clinical services, homeland tours (for international adoption), and search and reunion assistance.
- *Special needs.* The term “special needs” in the child welfare context is used to describe a child that has one or more characteristics that place the child at increased risk of not finding an adoptive placement without adoption assistance. The federal definition of “special needs” may include “ethnic or racial background, age, membership in a sibling group, medical, physical, or emotional disabilities, risk of physical, mental, or emotional disability based on birth family history or any condition that makes it more difficult to find an adoptive family (Child Welfare Information Gateway, 2009). The definition of “special needs” varies by state.
 - *Special health care needs.* The Maternal and Child Health Bureau defines special needs as: “chronic physical, developmental, behavioral or emotional conditions that also require health and related services of a type or amount beyond that required by children generally” (McPherson, et. al, 1998).

Study Background

According to the most recent estimates approximately 153 million children considered around the world are considered orphans, defined by UNICEF as a child that has lost one (half orphan) or both parents (full orphan) (UNICEF, 2010). In addition, children may be without parental care due to abandonment, abuse or neglect by a parent or caregiver (Miller, 2005). Children with disabilities are particularly vulnerable to maltreatment and abandonment (Crosse, Kaye & Ratnofsky, 1992); and children without parental care often end up in institutional care or become homeless and are particularly vulnerable to trafficking for sex or labor (UNICEF, 2011).

The deleterious effects of institutional care on child development are well known. Children raised in institutions have been found to have developmental delays, difficulty forming

attachments, and other medical, medical and psychological difficulties due to congregate care limitations including low individualized attention, low stimulation, high caregiver turnover rates, lack of appropriate or routine medical care, neglect and/or abuse (Bowlby, 1969; Miller, 2005; Rutter, 1998; Tizard 1979). Children raised in foster care also experience developmental impairments due to multiple caregivers and placements and lack of stability (Berry, Propp & Martens, 2007). For children without parental care, adoption has been conceptualized as the intervention that best provides the opportunity for a child's maximum potential development (van IJzendoorn & Juffer, 2005).

Children are adopted domestically in the United States through three types of processes. The first is through private arrangements between the adopted child's birth family and adoptive family, mediated through adoption agencies, adoption facilitators or attorneys. Most children adopted through private arrangements are infants and the adoptive parent typically finalizes the adoption in family court soon after the child's birth. Because accessible adoption data on private adoptions are limited it is unknown exactly how many children are adopted through these private facilitators, agencies or attorneys but Pecora, Whittaker, Maluccio, Barth & Plotnick (2009) estimate over 50,000 private agency-facilitated infant adoptions and over 25,000 private, attorney-facilitated adoptions take place in the U.S. each year.

Children are also adopted domestically in the U.S. through the foster care system. When children are removed from their families of origin due to abuse and/or neglect and the child's birth parent(s) are unable or unwilling to maintain the safety, permanency or well being of the child, then a court may terminate the parent's legal rights to the child. The state then seeks permanency, defined as adoption or legal guardianship, if reunification with the birth family is not an option. Relatives and foster parents adopt the vast majority of children adopted from foster care. In 2013, "new resource parents" (adults that did not have a previous relationship with the child they adopted) adopted 26 percent of children adopted from foster care in the U.S. (U.S.

Department of Health and Human Services, 2014). Children adopted from foster care tend to be older and have often experienced years in out-of-home placement (Barth, 1991). In 2013 over 50,000 children were adopted from the foster care system in the U.S. (U.S. Department of Health and Human Services, 2014, p.5). The third type of adoption is the adoption of a child by a relative or stepparent. Relatives or stepparents adopt an estimated 53,000 children each year (Pecora et. al., 2009). There is some overlap in data as some relatives were also considered the foster parent for the child prior to the adoption (U.S. Department of Health and Human Services, 2014).

Children are also adopted through intercountry adoption and the U.S. receives the majority of the children adopted each year through intercountry adoption (Seleman, 2012). As with children adopted from foster care in the U.S., children adopted through intercountry adoption may have been removed from their biological family of origin due to abuse or neglect, family instability, poverty, or as a result of parental death or disability (Miller, 2005). In some cases the child may be relinquished for adoption due to government family planning policies as in China or Romania, or due to stigma against single motherhood as in South Korea (Miller, 2005; Seleman, 2012). The U.S. and other countries in the global North have conceptualized intercountry adoption as a child welfare intervention for children without parental care, particularly for countries that have little or no developed in-country child welfare or adoption programs, based on the premise that intercountry adoption is a better alternative for the healthy development of a child than institutional care within the child's country of origin. Although intercountry adoptions have been continuing since the 1940s, specific policies regulating intercountry adoption in the U.S. have only been in place since the 2000 Intercountry Adoption Act. The Intercountry Adoption Act of 2000 was the U.S.'s response to the Hague Convention on the Protection of Children and Co-Operation in Respect to Intercountry Adoption (hereby Hague Convention), an international treaty signed by the U.S. in 1993 but not fully ratified until 2008 (Hollingsworth, 2003). The U.S.'s implementation of the Hague Convention is crucial. Receiving

countries such as the U.S. have a great deal more economic and political power compared to the sending countries from which the majority of the children are adopted. In addition, the disparity between the intercountry adoption fees adoptive parents pay (up to \$40,000 per child) and the low per capita income in the child's country make the adoption process vulnerable to unethical practices including kidnapping and trafficking children for adoption (Freundlich, 2000; Hollingsworth, 2003; Roby & Ife, 2009; Roby & Maskew, 2012). The Hague Convention establishes guidelines and protocols for governing the ethical implementation of the intercountry adoption process.

Problem Statement

Internationally adopted children with intellectual and/or developmental disabilities experience multiple vulnerabilities: they are children in a society where adults make decisions on their behalf, often without considering the child's expressed needs or desires (Petr, 1992); they are adopted in a society that privileges biological relationships and connections (Kressiere & Bryant, 1996; Wegar, 2000) they are often placed in environments that lack representation of their racial, ethnic, religious, linguistic and social customs from their birth countries (Lee, 2003; Raleigh & Kreider, in press); and they have a disability in a world that stigmatizes and discriminates against people with disabilities (Cousins, 2009). Intercountry adopted children with disabilities experience what Grace (1997) refers to as a "double whammy," a "two-fold impact as the adoption and the impairments influence his/her growth and development" (p.77). Although adoptive parents often struggle to find competent post-adoption services for their intercountry adopted child there is no evidence that intercountry adopted children are routinely "returned" to their country of origin. It is more likely the child will end up involved in local public child welfare systems, placed in alternative or out-of-home care, or transferred to the care of other adults in legal or illegal placements.

Adoptive parents often have difficulty navigating the public child welfare system and disability systems for an intercountry adopted child. The child welfare system, disability system and the intercountry adoption system do not naturally have overlapping services or goals. The intercountry adoption system consists of agency partners in both the receiving country and sending country, along with respective government agencies if the countries are signatories to the Hague Convention. Since adoption itself has largely been conceptualized as the intervention, agency post-adoption services for the intercountry adoption community thus far are minimal and largely focus on services to support positive adoption and cultural identity such as peer group activities, culture camps and mentoring programs. When families experience more difficulty or need to address a child's disability, private agencies must refer to outside services. Parents may be unaware of the disability services available through their county or state agencies and the public child welfare service system is geared toward providing services and interventions for children that are more parent-focused than child-focused. When adoptive parents of intercountry adopted children seek services from their county they may be told, as Janet in this study shared with me, "We don't have money for this, we don't have resources. How dare you bring this child from [country] and expect us to take care of him?"

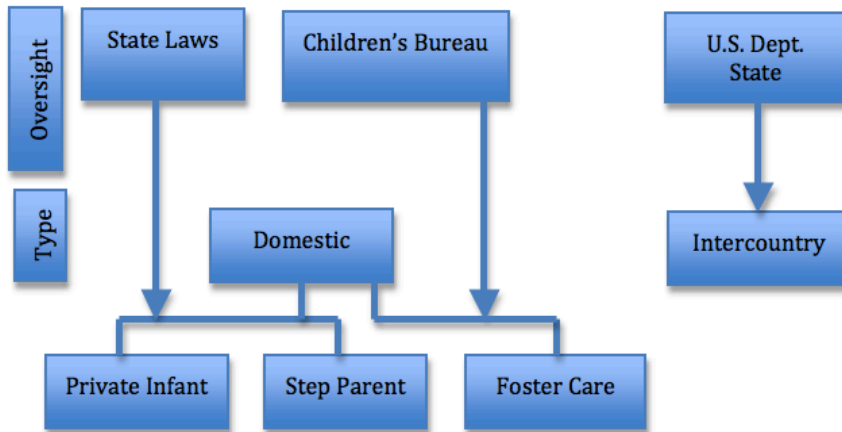
Problems Related To Data

Historically the adoption of children in the United States has been segregated into separate and distinct silos of policy, research and practice (see Figure 1). This has created a system in which the private adoption system, child welfare system and intercountry adoption system are regulated by different governmental agencies. As a result no national clearinghouse for adoption information and data exists. As Shuman & Flango (2013) point out, through previous research we have come to understand much about adoption except for the most basic

information, the raw number of children adopted each year. Complicating the availability of adoption data is the lack of inclusion and integration of adopted children in disability data.

Over the decades a few researchers have made attempts to generalize adoption data. The 2003 National Survey on Children's Health included 2,903 adopted children in their randomized sample of parents in the U.S. (Bramlett, Radcliff, & Blumberg, 2007). The CDC followed up with the National Survey of Adoptive Parents based on a randomized sample of 2,089 adopted children including 781 adopted through private adoption, 763 adopted from the foster care system and 545 intercountry adopted children (Vandiver, Malm & Rader, 2009). In 2000, the U.S. Census included a question on adoption for the first time (Simmons & O'Neill, 2001). According to the most recent 2010 Census just over two million adopted individuals are living with their adoptive parent(s) including 1.5 million under the age of 18 (Kreider & Lofquist, 2014). The most robust body of research on adopted children is of children adopted from the U.S. foster care system due to the requirement that county and state entities collect and submit data in order to receive federal Title IV-E reimbursement. Domestic private adoptions are finalized in family court and as there are no mandates to report numbers of finalizations to any federal entities, the only way to begin to understand the number of private adoptions (including infant and stepparent adoptions) that occur in the U.S. would be to contact every district court in each state and ask for the number of finalizations that they approved. Even if such an undertaking occurred, court jurisdictions define and count adoptions differently (Shuman & Flango, 2013). Intercountry adoption statistics are limited to the number of incoming adoptions entering the U.S. tracked by the number of visa applications approved by the U.S. State Department (2014). As a result, the little is known about intercountry adopted children in general and even less about those with disabilities and their long-term placement stability.

Figure 1. Types of adoptions in the United States



In addition, the child welfare system has not differentiated between internationally adopted children and other children who enter the child welfare system. In 1993 Congress enacted the PL 103-66, the Statewide Automated Child Welfare Information System (SACWIS), a case-management tool used to collect data on children involved in the child welfare system. The implementation of a SACWIS system is not mandatory, thus not every state has this mechanism for data collection. As of April, 2015, 13 states did not have SACWIS systems in place (U.S. Department of Health and Human Services, 2015). Currently a child's name, birth date, social security number, among other identifying data, can be entered into the state's SACWIS system. However there is no universal mechanism to include whether a child was adopted, the year of the adoption finalization or country of birth for an intercountry adoption. After a child is adopted their name changes and a child that enters the child welfare system is entered under their adoptive parent's name. As a result, as a researcher it is difficult to obtain the specific number of adopted, let alone intercountry adopted, children that enter the child welfare system, have disabilities, receive services, experience out of home placements, or end up in dissolution in the U.S.

Because private adoption, child welfare adoption agencies and disability service organizations work in separate systems, social workers working in each of these separate systems may not know what services are available to families across systems. Families who adopt from

the foster care system may be eligible for adoption assistance, a monthly subsidy intended to help the adoptive parent pay for special needs services for their child. Adoption subsidies do not exist for families who have adopted children internationally. When intercountry adopted children receive a diagnosis of a disability that was unknown or undiagnosed prior to the adoption, parents may be disappointed to learn that their agency is unable to offer or provide the more intensive or clinical or therapeutic post-adoption services the family needs. Parents of children adopted from the foster care system typically have some familiarity with the child welfare system as children with disabilities adopted from foster care often have some information regarding their medical, developmental and social history and may have received services for their disabilities prior to or at the time of the adoption.

The worst-case scenario for an intercountry adopted child is that they experience another placement disruption through abandonment or abuse by their adoptive parent. While adoption is marketed as finding “forever families” for children 10-25% of foster care adoptions disrupt or dissolve (Berry, 1997, Coakley, 2008; Festinger 1986, 2001). It is unknown how many intercountry adoption disruptions and dissolutions occur in the U.S. but other countries report intercountry disruption rates between 0.8% to 2.8% (Berástegui, 2003; Elmund, Lindblad and Hjern, 2006; (Hoksbergen,1991; Palacios et al., 2006). Multiple placements hinder placement stability; a child that experienced adoption dissolution is less likely to find another “forever family” (Barth, 1991; Barth & Berry, 1988; Festinger, 1990; Rosenthal & Groze, 1990).

Anecdotal stories of intercountry adopted children returning to out of home care abound but to date there is limited empirical data on the phenomenon. I first learned that some intercountry adopted children did not remain in the adoptive family when I met Korean American adults that had been in foster care, group homes, residential treatment, or re-adopted by another family after being placed in an adoptive family in the U.S. As an adoption worker for a public child welfare agency I became aware that adopted children sometimes come back into state

guardianship for a number of reasons including abuse and neglect by their adoptive parents, as well as a result of the child's behavioral needs for safety or treatment. If intercountry adoption is to be an intervention for children without parental care, adoptive parents must be equipped to parent the children they adopt and provide the placement stability these children need.

Research Questions

Adopted children do not just “show up” in a family; unlike children who enter a family by birth there are multiple processes that adoptive parents must complete in order to be chosen by an adoption facilitator or agency to become a parent. Whether a child enters a family by birth or by adoption, there exists some measure of risk that a child may have or develop a disability. Because the adoption process itself is, as Ellen Herman (2008) states, “kinship by design” (p.1) adoptive parents may sometimes believe that by choosing a child they may also be able to choose a non-disabled child or choose the level of severity in terms of risk of a disability or actual disability. Adoption agencies and facilitators may intentionally or unintentionally lead prospective parents to believe that through their matching process, the risks of adopting a child with a disability are minimal or non-existent.

In order to begin understanding the placement stability of intercountry adopted children with disabilities, I chose to explore how these children entered into their adoptive families and how the parents managed the challenges of maintaining placement stability. Thus, my overarching research questions for this study were “Why and how do adoptive parents choose out of home placements for an intercountry adopted child with an intellectual or developmental (I/DD or mental health disabilities?” In addition, a number of sub questions were posed:

- What was the parent's understanding of mental health, intellectual or developmental disabilities prior to adopting their child?
- How does the parent construct disability?

- What was the parent's experience with accessing and utilizing services related to the child's disability?
- How has this experience impacted their life?

Historical Context of Adoption in the United States

From the earliest recorded histories to modern times, there have always been some children who find themselves separated from their biological parents as a result of death, abandonment, war, or social-political causes (Boswell, 1988). Solutions for caring for parentless children have been as varied as the reasons for being parentless and historically have depended on the cultural and social contexts of any given society. The only thing that can consistently be stated about adoption is that “it has existed in both formal and informal ways because who adopts, who is adopted, and how adoption is culturally constructed changes both across cultures and even within the same culture over time” (Cole, 1990, p. 44). In the U.S., adoption is conceptualized as a replacement parent-child relationship in which the relationship of the child to his or her biological parent(s) must be severed in order for the adoptive parents to have full legal recognition and responsibilities for the child. Other countries and cultures do not necessarily require a termination of parental rights in order for an adoptive relationship to be recognized (Cole, 1990; Roby & Ife, 2009).

I argue that early adoption in the U.S. was conceptualized less as child welfare and more for labor and population control. Adoption, according to Cole (1990), “was intended to suit the political, religious and economic needs of the adults” (p. 44). The first U.S. law legally recognizing adoption as a parent-child relationship was the 1851 Massachusetts Adoption Law and Minnesota's adoption law in 1917 set the standards for other states regarding closing adoption records to the public and setting the first requirements for an investigation of the prospective adoptive home (Herman, 2008).

Prior to the 1900s, “sentimental” adoption was rare; rather, adoption was seen as a reciprocal act of caring for another family’s child in return for the child’s labor (Zelizer, 1985). As an alternative to orphanages or poor houses, many of the earlier placing out or fostering programs focused on the “problem” of impoverished children. Charles Loring Brace, a Protestant minister and head of the New York Children’s Aid Society, began the orphan train movement as a solution to eliminate the large numbers of poor, urban, immigrant children in New York. In *The Dangerous Classes of New York*, Brace argued that these immigrant children would become society’s future criminals and indigent population unless they were civilized. Brace believed rural farming families offered the most wholesome environment for learning the American values of hard work and Christian faith (Brace, 1872). In the last decades of the nineteenth century until 1929 an estimated 200,000 urban, mostly immigrant and Catholic children were by train to rural areas of the Midwestern United States to be placed in foster and adoptive homes in farming communities. The term “put up for adoption” originated with the practice of placing children on train stations for inspection by potential foster and adoptive parents. Some of these children were orphans but many were not; their parents were either too impoverished to provide for their basic needs or were unable to provide supervision due to work (Holt, 1992). The children were not adopted for sentimental reasons but to provide farm and domestic labor for the families that took them in (Holt, 1992; Zelizer, 1985).

During the same time period as the orphan train movement, the U.S. government began a program of systematic, forcible removal of Native American children from their homes. As many as one in three or four Native American children were placed into government and religious boarding schools across the United States (Crofoot & Harris, 2010). The purpose was to assimilate Native Americans into the dominant white culture through the elimination of native cultures, which boarding school advocates (as well as government and civil leaders) believed was most successful conducted by assimilating the children. At the boarding schools, children were

prohibited from speaking their Native languages and practicing their traditional spiritual rituals and were given Anglicized names (Herman, 2008). Additionally, Native American children were singled out for an adoption program sponsored by the Child Welfare League of America from 1958 – 1967 with the intended goal of the assimilation of Native American children (Herman, 2008). The 395 Native American children adopted through the Indian Adoption Project were purposely placed in white adoptive homes.

These forms of adoption, as practiced historically in the U.S., were more an effort by white Americans to “civilize” immigrants and Native American communities than to protect the safety and wellbeing of children (Cole, 1990, p. 46). Social work professionals have and continue to participate in private and public adoption work and were active in both the orphan train movement and the Native American adoption programs. Social workers also professionalized what was once considered the domain of religious charity organizations in adoption and child welfare practices (Kunzel, 1993). It was professional social workers that raised concerns about the lack of background studies of prospective parents and oversight of the child’s placement during the orphan train movement and their advocacy successfully ended the practice (Holt, 1992). The social work profession turned toward adoption as a separate sphere of practice during the Progressive era after taking over operation of maternity homes for unwed mothers (Kunzel, 1993). The Child Welfare League of America began publishing guidelines for adoption practice in 1938 and over the years published revisions reflecting current changes in practice such as promoting or discouraging sealing adoption records and open adoptions, transracial adoption and “special needs” adoptions (Herman, 2008).

Social work as a profession was also at the forefront of creating the “sentimental market for adoption” in which prospective adoptive parents, in particular mothers, were recruited as a manifestation of Progressive Era maternalism, an extension of the motherly response to nation building (Ladd-Taylor, 1994; Zelizer, 1985). The majority of the children placed for adoption

came from the children born to women in maternity homes, who were white and often middle to upper class and for whom pregnancy outside of marriage was considered shameful (Kunzel, 1993). According to Zelizer (1985), this shift from labor to sentiment as a focus of adoption coincided with a general societal shift of valuing children for their emotional contributions to the home instead of only on their economic contributions for white, middle class families. Promoting adoption as a means of finding a child for parents looking to have a family grew after World War II (Cole, 1990; Herman, 2008). Following the return of the service men and women after WWII, a culture of family building and domesticity prevailed and adoption became marketed as an option for families struggling with infertility (Herman, 2008). In this period of formalized adoption social work, child welfare workers emphasized the importance of placing a child in a home where they looked as if they could be born to the adoptive parents. This emphasis on matching was in part an effort on the part of adoption professionals to provide a specialized “service” that, as Berebitsky (2000) suggests, other non-social work professionals, such as doctors and lawyers, were not able to provide. Child development experts, psychologists and social work professionals heavily focused on the adoptive parent as the client and created a body of assessment tools used to ensure that the child placed into the adoptive home would match the parents so seamlessly – in terms of physical features, religious background and (estimated) intellectual functioning – that those outside the family would never know the child was not biologically theirs, a process Herman (2008) calls “kinship by design.”

Historical Context of “Special Needs” Adoption in the United States

Children with “special needs: in child welfare. Children with disabilities are more likely to be maltreated than children who do not have disabilities (Bruhn, 2003). Maltreatment rates for children with disabilities are between 1.7 and 3.4 times higher than for children without disabilities (Crosse, Kaye & Ratnofsky, 1992; Sullivan & Knutson, 2000). In a study of

maltreatment of children with disabilities, Crosse et al. (1992) reported that 47 percent of the children with disabilities experienced maltreatment due to the disability. Children with disabilities were 2.1 times more likely to experience physical abuse and 1.8 times more likely experience sexual abuse than children without a disability in the study.

Children in the child welfare system are also more likely to have disabilities than children who have not experienced involvement in the child welfare system. Maltreatment was the cause of a child's disability for more than 14 percent of children in the Crosse et al. study (Crosse et al., 1992). Coyne's study of children under state guardianship found that 36 percent of the children had disabilities, of which 40.3 percent were diagnosed with both intellectual and developmental disabilities (Coyne, 1997). The Child Welfare Information Gateway (n.d.) estimates 30 to 50 percent of children in foster care with a permanency plan for adoption have developmental disabilities.

These disparities continue to exist among children who are adopted. Compared to their non-adopted peers, adopted children are more likely to have special health care needs, including physical, developmental and learning disabilities, and mental health disorders (Bramlett & Radel, 2008; Bramlett, Radar & Blumberg, 2008). Adopted children are five times more likely than their non-adopted peers to be diagnosed with a developmental delay or a physical impairment. Altarac & Saroha (2007) found that adopted children had higher rates of learning disabilities (20.4 percent) compared to their non-adopted peers (9.3 percent). In summary, children with disabilities in the U.S. are more likely than their peers without disabilities to experience maltreatment and intervention in child welfare services, and these disparities continue to exist among children who are adopted.

Demand for "healthy" babies for adoption. Most prospective adoptive parents in the United States sought to adopt healthy infants, and adoption professionals have gone to great measures to ensure that children being placed for adoption were healthy, both physically and

mentally (Cole, 1990). During the orphan train movement it was not uncommon for the foster and adoptive parents to select the strongest and healthiest children from the group and send the others back on the train to the next stop since the child's ability to provide labor was one of the criteria for adoption for many of the parents (Holt, 1992). Part of this demand for healthy children was due to a dual philosophic and practice model for children – that children could be a solution to a couple's infertility at the same time a couple was the solution to a child's need for parents. Adoption professionals thus had two sets of clients, parents and children, and simultaneously sought "children for families" and "families for children" (Nelson, 1985).

Former Child Welfare League of America chair Joseph Reid (1957) wrote that the prejudice against adoption was so negative that social workers were challenged to find prospective parents willing to take in a child who was not biologically related to them in part because of the concern the child would have a "defect." As a result, adoption social workers practiced "kinship by design" to assuage prospective parents that "adopting a child was a far less risky procedure than having one normally" (Reid, 1957, p. 30). Dissolving an adoption because it was discovered a child had a disability from a pre-adoption condition not made known to the adoptive parents was considered acceptable (Bussiere, 1990). In a 1985 study, the most common reason an adoptive parent sought a dissolution was due to a "defect or abnormality of the child" (Carroll, 1985, p. 155). In some cases, parents even sued for damages after discovering their adopted child had a disability (Bussiere, 1990).

After the 1960s, a number of societal factors converged that changed adoption policies and practices. Improved access to contraception, the legalization of abortion and lessened social stigma around women having children outside marriage meant women had more control over their childbearing decisions (Solinger, 2001). The numbers of "healthy, white infants," most in demand by adoptive parents, decreased (Cole, 1990). At the same time the number of "special

needs” children in foster care who were older, from communities of color, and those with disabilities needing adoptive homes grew (Billingsley & Giovannoni, 1972, Roberts, 2002).

Adoption of U.S. born children with disabilities. Until the 1960s adoption was not considered for children who were older or had disabilities. The current pathways to adoption for children in the United States with mental health and developmental disabilities are largely determined by which system of care they enter – the child welfare system or the mental health/Developmental Disabilities (DD) system (Coyne, 1997). Children who are designated for adoption as their permanency plan typically come through the child protection system while those placed in care (foster care, group home or institution) through the mental health/DD system via voluntary placement by their parents are rarely adopted and the parents retain their legal parental rights (Blatcher & Bromle, 1990). To the child with a disability, the two systems of care may look similar but in the latter case, the child’s biological parent(s) are legally allowed to maintain a relationship with the child. That is not always true for the child in the child welfare system. For children in institutional care or out of home care via the mental health/DD system, the out of home placement is the intervention. For children in out of home care via the child welfare system, “permanency” is the intervention (Coyne, 1997).

Historically parents were routinely advised to institutionalize a child born with a disability (Blacher & Bromley, 1990). During the 1950s-1960s, a growing public attitude against institutionalizing children with intellectual and developmental disabilities occurred along with a move towards de-institutionalization in general. The shift toward recommending adoption over institutionalization or foster care placement was slow. Some parents wanted to maintain a connection with their child and adoption would require severing ties to their child (Blacher & Bromley, 1990).

Adoption agencies, who once “patrolled the borders of adoption, now campaigned to open them” and began to implement recruitment strategies and practice changes with the aim of

placing children who were formerly considered “non-adoptable” in adoptive homes (Herman, 2008, p. 196). In a 1956 letter to the editor in the journal *Pediatrics*, Dr. Paul Beaven called on adoption agencies to actively recruit homes for children with intellectual disabilities, writing:

When I first became interested in this important area of child welfare, only a child nearing 2 years of age with a good genetic background and a practically perfect score, physically and mentally, was considered acceptable for adoption...we decided children with correctable pathology, such as club feet, harelip, and surgically remediable heart defects, should be given to adoptive parents. We have recently placed in adoption children with incorrectable defects, such as deafness, blindness, and certain types of cerebral palsy...If we believe that all children, legally free for adoption, who can benefit from family life should be adopted, then these retarded children should have the benefit of a search for the legal home for them” (Beaven, 1956, p. 971).

Although change came slowly, children formerly considered “hard to place” because of their disabilities, race, or age, became “children with special needs;” a term used to soften the negative connotation of being “unadoptable” (Cole, 1990, p.44). In the 1970s and 1980s, legislative policies such as the Child Abuse and Prevention Act of 1974 (CAPTA), the 1975 Education for All Handicapped Children Act and the Adoption Assistance and Child Welfare Act of 1980 (AAACW) began to focus attention on children with “special needs” and in particular the AACWA provided adoption assistance for families that adopted children with special needs (Barth & Miller, 2000; Cole, 1990; Coyne, 1990). The first adoptions across difference however were not about finding parents who sought to adopt across difference. Rather they were prospective parents that agencies deemed to have “eligibility disadvantages” such as being older or having other children in the home (Herman, 2008, p. 197). “Blue-ribbon babies” continued to be placed with “blue-ribbon” parents (Gailey, 2010; Herman, 2008).

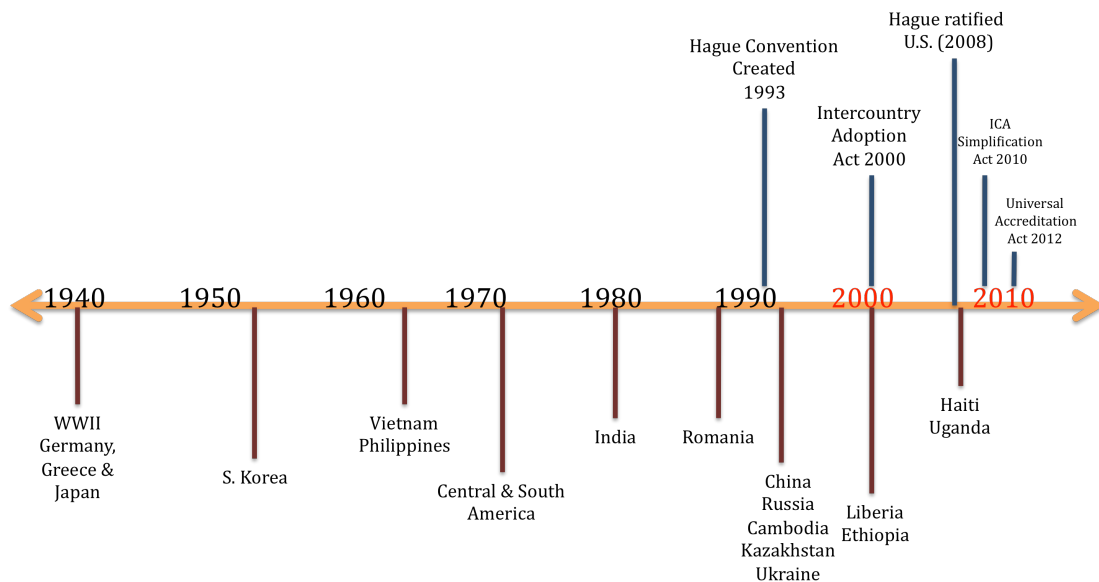
The current context of foster care adoption is one that equates children in foster care as having special needs. Maza (2014) suggested it is time to eliminate the term “special needs” as

the data on children currently in foster care awaiting adoption shows nearly all meet the criteria for having “special needs.”

Historical context of intercountry adoption

A timeline of intercountry adoptions to the United States, as well as significant legislative policies governing intercountry adoption is shown in Figure 2 below.

Figure 2. Timeline of intercountry adoption to the U.S.



The first sizable cohorts of intercountry adoptions to the U.S. occurred following the end of World War II when U.S. citizens adopted children from Germany, Greece, and Japan. An estimated 5,814 children from Europe and more than 2,000 children from Asia, most from Japan, were adopted to the U.S. between 1948 to 1953 (Miller, 2005). At the time, the United States did not have policies that specifically regulated the transnational exchange of children from outside of the country for the purpose of adoption. In order to adopt a child from outside U.S. borders prospective adoptive parents used existing immigration and refugee laws in order receive an

approved visa application for their intended child (Herman, 2008). The Refugee Relief Act was one such law used by prospective adoptive parents (Altstein & Simon, 1991).

From the 1940s through the 1960s, the number of intercountry adoptions remained low, however the longest running intercountry adoption program began in this time period. In the mid-1950s, following the conflict in Korea, the U.S. began facilitating adoptions from South Korea to the U.S. and an estimated 100,000 to 150,000 children have since been adopted from South Korea, the largest number of adoptions from any single country (Bergquist, 2007; Seleman, 2000). Adoption from Vietnam began in the 1970s in the midst of the Vietnam conflict. The “Operation Babylift” program ordered by President Ford evacuated children from Saigon, many of whom were adopted to the U.S. and other countries and is known for a tragic 1975 plane crash that killed 178 people including 78 children. Adoptions from several Central and Latin American countries began in the 1970s and 1980s including (but not limited to) Peru, Paraguay, Brazil, Mexico, Guatemala and Colombia as well as small adoption programs from the Philippines and Taiwan.

In the early 1990s journalists from the U.S. went undercover in Romania and discovered children living in neglect in squalid, overcrowded orphanages, a result of Romania’s pro-natal family reproduction policies (Rutter, 1998). As a result of this media attention, intercountry adoption to the U.S. increased sharply as American families adopted children from Romanian orphanages (Seleman, 2000). Two of the biggest intercountry adoption programs also opened in the 1990s. China, also experiencing a crisis of abandoned girls as a result of the country’s family reproduction policies (in this case, a one-child policy), began allowing intercountry adoption in the early 1990s. Since adoptions from China first began, over 70,000 children have been adopted to the U.S., the vast majority of which are girls (U.S. Department of State, 2014). Following the breakup of the Soviet Union, Russia opened up an intercountry adoption program. Over 46,000 children from Russia were adopted by U.S. citizens by the time Russia closed its adoption

program to the U.S. in September of 2013 (U.S. Department of State, 2014). Other Eastern European countries opening up intercountry adoption programs in the past twenty years include Ukraine, Bulgaria and Kazakhstan. Intercountry adoption from African countries began in the 2000s, most notably from Liberia, Sierra Leone, Ethiopia, Uganda and the Democratic Republic of Congo. Although adoption from Haiti had been occurring since the early 1990s, the earthquake in 2010 spurred renewed interest in adoption.

As the numbers of intercountry adoptions to the United States, Canada, and Western European countries dramatically increased in the decades leading up to the peak in 2004, so did evidence of baby selling, kidnapping and trafficking of children in sending countries to fill the demand for adoption (Roby & Ife, 2009; Roby, Rotabi & Bunkers, 2013). Countries in which allegations of fraudulent and coercive adoption practices by U.S. adoption agencies have occurred include Cambodia, Haiti, Guatemala, Ethiopia, Samoa, Vietnam, China, Uganda and the Marshall Islands. The Hague Convention on Protection of Children and Cooperation in Respect of Intercountry Adoption (hereafter referred to as the Hague Convention), a treaty created in 1993 to enhance the UN Convention on the Rights of the Child, was the first international effort to protect children from unethical intercountry adoption practices (Parra-Araguren, 1994).

The United States became a signatory on the Hague Convention in 1994, moved to ratify in 2000 through the Intercountry Adoption Act and completed all of the necessary requirements for implementation including establishing a Central Authorizing Agency (through the U.S. State Department) to oversee all intercountry adoptions in 2008 (U.S. Department of State, 2014a). U.S. adoption agencies facilitating adoptions between the U.S. and other Hague Convention countries must currently meet specific accreditation standards. However, it is important to note that adoptions between countries that have not signed, ratified or implemented the Hague Convention is not prohibited and several of the top sending countries that American parents adopt from, including Russia, South Korea, and Ethiopia, have not ratified the Hague Convention (U.S.

Department of States, 2014a). Prior to 2012, U.S. agencies facilitating adoptions from non-Hague countries were not required to meet the accreditation standards, thus the protection of children's best interest in the intercountry adoption process did not extend to all intercountry adopted children. The 2012 Universal Accreditation Act, passed in 2012, requires accreditation for all U.S. adoption agencies facilitating intercountry adoptions, even if the sending country is not a party to the Hague Convention (U.S. Department of State, 2014c).

More than 400,000 children are estimated to have been adopted to the U.S. through intercountry adoption since the 1940s. The numbers of intercountry adoptions to the U.S. have declined each year since the peak in 2004 when over 22,000 children were adopted (U.S. Department of State, 2014). Many factors have contributed to this decline in adoptions including the closure of some country programs (sometimes by the U.S. and sometimes by the sending country) due to fraud and illegal adoption practices, change in political support for intercountry adoption in the sending country, and the creation of in-country child welfare and adoption programs in some of the sending countries.

Intercountry adopted children in out of home care. There are multiple pathways to out of home care for intercountry adopted children with disabilities. If adoptive parents have the resources, private placement in residential treatment settings, such as the Ranch for Kids, may be an option. Since 1990 over 300 adopted children, many of them intercountry adopted, have been placed at the Ranch for Kids, a residential treatment facility in northwestern Montana that specializes in treating intercountry adopted children. About 30 percent of these children do not go back to their adoptive families (Johnson, 2010; Rubin, 2008). However, many families, after spending upwards of \$30,000 or more for an adoption do not have the financial resources to pay out of pocket for residential treatment centers. Some families choose voluntary foster care placement through their local public child welfare agency. Unfortunately, an unknown number of intercountry adopted children run away or end up homeless or at long-term shelters such as The

Bridge for Youth (www.bridgeforyouth.org) in Minnesota, where one staff member shared that over the past few years the number of intercountry adopted youth using their services has increased (C. Call, personal communication, January 2010).

The child welfare system in the United States was created for the safety of children and the majority of the services provided to families are intended to address the parent problems that led to a child's abuse and/or neglect. In one sense, foster placement is considered the intervention for a child because it removes a child from an unsafe environment. The child is seen as the victim of his or her parent's behaviors, therefore removal from the parent *is* the intervention. Placement or residence is seen as *the intervention*, rather than as *the setting* in which intervention takes place (van IJzendoorn & Juffer, 2005).

Parent services and interventions, for example, address parenting, anger management, chemical dependency assessments and treatment, mental health therapy, domestic violence, Medicaid, and finances (employment, housing, and food). Services for children typically focus on placement unless specific needs (such as counseling) are identified (Pecora et al., 2009). Intercountry adoptive families, however, often come to the attention of the child welfare system because of the child's issues, not the parents. Families that place their intercountry adopted child in out of home care have to navigate a system focused on resolving parent problems. Thus, in this context, the child welfare system may be inadequate to assist the needs of intercountry adoptive families.

Overview of Remaining Chapters

In the chapters that follow I explain this study in more detail. Chapter 2 outlines the conceptual frameworks guiding my approach this study. In Chapter 3 I review previous research on intercountry adoption, adoption of children with disabilities, and adopted children in out of home placement. In Chapter 4, I describe the methods used to conduct this study. Chapter 5

provides the findings of the study and introduces the Adoption Displacement Decision-Making model. I also discuss the limitations of this study. Finally, in Chapter 6 I discuss the implications of the study's findings and the Adoption Displacement Decision-Making framework on the research questions and their relevance to social work policy, practice and research.

Chapter 2: Conceptual Frameworks

Chapter Overview

The purpose of a grounded theory study is to generate or develop a theory that emerges from the data. This means that rather than testing or validating an existing theory *a priori*, I approach the process of inquiry without attempting to fit the data into a pre-determined theory. However, I am of course influenced by some conceptual frameworks that served to guide and inform how I constructed this study, chose the methodology, developed research questions and considered the applicability of this study in terms of implications for policy and practice. This chapter will introduce the primary conceptual frameworks in which I ground my research study. First I will describe some overarching paradigms that influence my view of the world. Next I will describe the specific theories that influenced my analytic approach to this study including ecological systems theory, social constructionism, and disability theory as specifically conceptualized by Siebers (2008). I conclude this chapter with my goal in terms of using these conceptual frameworks to analyze data.

Overarching Frameworks

This study is grounded in specific overarching worldviews I hold about the nature of knowledge and reality and the purpose of research. I begin with the worldview that reality is constructed and that discourse is the method by which humans construct their reality. This study is informed by social constructionism, evident in the way I value the meanings my study participants ascribe to their experiences, particularly within their historical and social contexts (Charmaz, 2006; Creswell, 2007). Of particular interest to me are the ways in which adoptive parents define concepts such as family, adoption, parenting and disability before, during and after adopting. I also bring a feminist worldview to this study. While feminist theory has many diverse perspectives, a common aspect of feminist theory is seeking to understand women's lived

experience by examining their roles and rights in society (Dominelli, 2002b). This lens is evident in the ways I think about the particular experiences of the sixteen women in this study who largely figured as the main caretaker in their families and often were the target of violence from their adopted child. In addition, I bring a feminist lens to analyzing the similarities and differences in the ways mothers and fathers in my study cope with and/or manage the stress of parenting their child and to consider the ways in which gender participants' experiences with systems (Dominelli, 2002). I am also mindful of the ways in which the adoptive mothers in this study are also privileged in comparison to the biological mothers of their adopted children, particularly in terms of the resources they were able to direct toward these children because of their race, U.S. citizenship, and middle to upper socio-economic statuses. Considering that this study involves racial, ethnic, cultural and socioeconomic class differences between the adoptive parents and their adopted children, intersectionality (Crenshaw, 1991), anti-oppressive (Dominelli, 2002a), and decolonizing (Tuhiwai Smith, 1999) frameworks address the impact of power and privilege inherent in this form of family building and in the ways these internationally adoptive families are viewed by professionals and agencies providing services to the family as well as society at large.

Ecological Systems Theory

Adoption is often framed in terms of a relationship between an individual child and two sets of parents, all of whom at some point are "the client." However adoption is more than an exchange between individuals, it is also the interaction between systems – family systems, systems of care, and in the case of international adoption, between nations. Each system is composed of interdependent parts that interact with each other and it is this interaction that is the focus of systems theory.

Ecological systems theory developed out of general systems theory. General systems theory was developed by Ludvig von Bertalanffy, a biologist, and applies the concept of

biological system interactions to social organizations (Payne, 2005). Systems theory is useful in understanding how institutions work; rather than seen as a monolithic whole, society, groups and institutions are seen as units or parts in dynamic interaction (von Bertalanffy, 1969). At the time systems theory and ecological systems theory emerged the prevailing psychoanalytic worldview emphasized an individual's internal state. Systems theories expanded outward to look at a person's interactions across multiple system domains, such as other persons, institutions, or environments. In addition, von Bertalanffy (1968) argued that the existing research paradigms singularly focused on elements (variables) in closed systems that were set apart or isolated from their environment(s) and did not take into consideration the dynamic that occurs within open systems (p. 31).

Systems theory elements include boundaries, equifinality, inputs and outputs, entropy and feedback loops that help the system maintain equilibrium, or balance. A boundary is the demarcation that separates one entity from another. Boundaries may be porous (open) or impenetrable (closed). Equifinality is the concept that there are multiple starting points that lead to a final end point (von Bertalanffy, 1969). An input is the energy or information that comes into a system and an output is the energy or information that is passed out (Payne, 2005). Feedback loops are the processes of incorporating information about the system that is then used to make changes the system needs to self-regulate and maintain balance (von Bertalanffy, 1969). Entropy, or decay, of a system occurs when systems do not receive enough energy to maintain themselves (Payne, 2005). Luhmann (2013) argued that systems grow during times of imbalance because growth occurs when systems readjust to new inputs and continual readjustments ward off entropy.

Ecological systems theory was developed by Urie Bronfenbrenner as a framework for understanding individual development within an environmental context. Bronfenbrenner (1979) conceptualized environment as a series of nested systems in which individuals interact with each other, as well as with institutions, policies, morals and values, and culture. Ecological systems

theory situates an individual within larger systems and environments with whom the individual interacts. These interactions may be directly with another individual, for example as a child with a parent; or the interactions may be indirect such as a workplace policy that governs the amount of time a parent can take to care for a child. In addition, interactions in ecological systems theory are bi-directional; the individual not only interacts with, and thus changes, his or her environment, but the resulting changes in environment changes the individual.

Ecological environments include the microsystem, mesosystem, exosystem, macro system and chronosystem and can be thought of as a series of nesting circles. The center innermost circle represents the environment of the individual. The microsystem is the next outer circle, representing the environment or setting where an individual interacts with others in dyadic (one to one) interactions (p. 7). For example, a child's microsystem might include parents and siblings, other close relatives, friends, school, and place of worship. The next circle is the mesosystem, which Bronfenbrenner (1979) described as "a system of microsystems" (p. 25). In the mesosystem a child might be impacted as a result of the interactions between her parents and teacher during a school conference. The exosystem is composed of the larger systems that may, but do not always, directly impact the individual at the center of the microsystem. Exosystems impact the individual in the form of institutions and policies that influence an individual. For example, several of the participants in my study discuss how their workplace either hindered or facilitated their ability to respond to their child in times of crisis. Another example of the impact of the exosystem on adoptive families in the study is the type of insurance the family has and what treatment the insurance company authorizes for the child. The child may never interact with the insurance company but the types of services the company authorizes can set the child and family on a course that has major repercussions. The outermost system is the macro system. The macro system consists of the social and cultural values, morals, laws and ideologies of the individual's environment. The chronosystem is the continuum of environments, events,

transitions that occur over time (Bronfenbrenner, 1979). The movement of members in and out of a family system through marriage, divorce, birth or adoption or death is an example of chronosystem events and transitions. A broader, socio-political example of chronosystem events include the development of intercountry adoption as an option for family building over the past 60 years in the U.S.

Together these systems envelop a child and his family and it is through the bi-directional interactions between the individuals and the many other systems that exist that the child grows and develops. An important aspect of ecological systems theory is the conceptualization of ecological transitions. According to Bronfenbrenner (1979) an ecological transition is the change of one's environment that leads to a new role or expected set of behaviors; for example, when a child begins school, a new sibling is born, or when parents divorce (p. 27).

Gitterman and Germain (1976, 1996) further developed ecological systems theory by developing a life model for practice focusing on the person-in-environment, or PIE. In the PIE model, an individual is seen as having a reciprocal relationship with their environment and issues of conflict or stress are a result of a person's fit within their environment. The Life Model approach recognizes that both individuals and their environments change over time. More recent developments in ecological systems theory incorporate greater emphasis on the natural environment's impact on individuals and communities in addition to social environments (Besthorn, 2013). What ecological systems theories and perspectives share in common is an emphasis in situating a person's experiences within their environments in more holistic way than attempting to isolate symptoms and directing resources only to the identified problem. The goal of finding balance and equilibrium is another common aspect of ecological theories. For example, the Relational Worldview model developed by Cross (1998) is another ecologically-oriented framework that conceptualizes health and wellness from an indigenous perspective. The Relational Worldview model views a person as consisting of four aspects: the mind, the spirit, the

body and the context (including history, culture, and environment). From a Relational Worldview perspective problems occur when these quadrants are out of balance.

Systems theory and ecological systems theory as applied in social work practice still often centers on assisting an individual or communities with maintaining equilibrium, which some define as maintaining the status quo or social order to the benefit of institutional systems and less on effecting institutional or structural change (Besthorn, 2013; Payne, 2005). While I agree that systems theory may be interpreted by some in the field to advocate for maintaining the status quo there is great potential for social workers to use general and ecological systems theory to help families understand and critique the systems with whom they interact and assist in advocacy and empowerment actions that dismantle oppressive institutional and systemic practices and policies.

Social Constructionism

A common task for adoptive parents is to assert their position as the “real parent” of their child in a society that privileges married, heterosexual, biologically-formed families. To understand that adoptive parents in the U.S. feel the need to assert themselves as their child’s “real” parent speaks to the way societies construct historically and culturally specific meanings for social roles, and the consequences administered to those who violate these accepted meanings. Social constructionism is the theory of the ways in which shared meanings are developed and communicated within social contexts. Although each person has his or her own view of the world, it is through our social interactions with one another and within social groups that we co-construct agreed-upon realities (Berger & Luckman, 1966). These shared realities become social conventions that guide behaviors, and are legitimized through our institutions.

Social constructionism comes out of postmodern thought and critiques modernist assumptions about the nature of “truth” (Burr, 2003; Fawcett, 2013). Social constructionism asserts several assumptions including: 1) an understanding that knowledge is founded on biased

and subjective observations of the world around us; 2) our understanding of our world is located in specific historical and cultural contexts; 3) knowledge is created, communicated and maintained through our social relationships and interactions; and 4) knowledge is tied to social action (Burr, 2003).

Social constructionism argues against “truth” as an objective, universally accepted or valued concept (Burr, 2003). Although each of us may see the same object, how each of us interprets or finds meaning from that object may differ considerably since we all have experienced life in different ways that impact how we then “see” the world around us (Gergen, 2009). Language is an important tool for social construction; it provides a way for each of us to share and describe our experiences and through this sharing of language, both verbal and non-verbal, we communicate and work to agree upon meanings (Burr, 2003). Given the importance of how people make meaning of their experiences, social constructionism is linked to phenomenology (Fawcett, 2013).

Gergen (2009) asserts that outside of social and historical contexts, words, phrases and terms are meaningless (p. 8). An example of this can be seen in translation and interpretation between people speaking different languages. The interpreter may be challenged at times if one culture does not have a word or phrase for a construct in another culture. An example from my own culture is the Korean word *han* (한), which has no direct comparative word or concept in English but roughly connotes a personal embodiment of collective national sorrow or grief as a result of historic oppression (Park, 1993). Another example is the construction of “mother.” An infant begins to babble and says “mama.” The child’s mother, excited that her baby said her name, reinforces “mama” by smiling, praising, and repeating the word while pointing to herself. In other words, the child’s babbling is turned into the construct “mama” when adults reinforce and shape the babbling into a meaning. Eventually both the child and the mother understand that “mama” means the same thing. Other cultures reinforce different words for the construct of

“mother” but may be based on other early linguistic sounds most babies first utter (i.e. ma, ba, da).

Language, also defined as discourse, can be examined for its meanings and messages. Foucault (1971) asserts that discourse is used by those in power to create rules and structures, to define acceptable or unacceptable behavior and is “the site of struggle and conflict where power relations are acted out and contested” (Burr, 2003, p. 55). For Foucault, power is the ability to define the world in a way that allows a person to do whatever and however they want. An example of this related to disability is the power that the medical profession has over people with disabilities. Burr (2003) states that doctors, who have positions of power, “have the capacity to legitimate their own version of an event (the patient’s symptoms) by making a diagnosis, possibly denying that of their patient who may have a different story to tell about what is happening to their body” (p. 137). Institutions such as hospitals and medical clinics reinforce these power dynamics because those in these institutions have the power to define “disability” or “illness.”

Despite the social work profession’s value for social justice and equity, Foucault (1999) also challenged the profession’s practices as institution power that serves to “surveil individuals and redress them” (p. 92). Consider the terminology that has come to be known as Positive Adoption Language (PAL). Developed by Marietta Spencer (1979), an adoption worker at Children’s Home Society in Minnesota, PAL was an attempt to change the negative meanings associated with adoption. For example, the individual considering placing a child for adoption would no longer be seen as “abandoning” their child, but rather “creating an adoption plan” (Spencer, 1979). While PAL was embraced by adoption agencies and adoptive parents, many birth parents and adopted individuals have begun to critique these constructions as glossing over and minimizing the grief and loss often associated with adoption (Butterbaugh, 2013).

Critics of social constructionism argue that constructionism denies or minimizes the materiality of our lives (Burr, 2003), something Siebers (2008) also discusses in his theory of

disability.

Disability Theory

Disability theory developed as a response to the medical model of disability that positions disability as a defect or condition that needs to be fixed or eliminated through medicalized interventions in order to restore a person's functioning to that of a person without the defect or condition. With the medical model of disability, the individual is seen as having something "wrong" with them, and the medical approach to disability is, as Davis (1995) writes, about "enforcing normalcy." As a response to the medical model of disability, the social model of disability looked instead at the social, institutional and environmental barriers to a person's functioning and looked at ways in which mainstream society constructs disability (Siebers, 2008). Disability advocates would argue that functioning is not the result of a person's impairment(s), but about the structural and societal barriers and restrictions that oppress persons with disabilities. For example, instead of putting resources toward finding a "cure" for autism, which suggests that people with autism are defective or should not exist, disability advocates argue for neurodiversity acceptance and work to change policy and institutional practices that discriminate against people with autism (Bagatell, 2010).

In his book *Disability Theory*, Siebers (2008) expands on the social model of disability by identifying several aspects of current thinking on disability that need deeper consideration. First, Siebers argues for inclusion of disability in cultural and critical studies, as well as in identity studies which have mostly focused on racial, gender, and queer minority identities. Considering disability as an identity is complicated since it is one of the few identities in which a person might suddenly gain, sometimes without any warning. Most of us have relatively stable identities in terms of our race, ethnicity, gender, and sexual orientation; some of these clearly are more stable than others. But disability is an identity that one can be born with or one can obtain gradually or suddenly (p. 5). In addition, disability is an identity that most of us will, if we live

long enough, acquire - and not by our choice (p. 59). Given this likelihood, Siebers argues that critical and cultural studies need to incorporate disability to understand disability culture, and expand critical disability studies.

Likewise, disability must be included as a minority identity; the history of oppression of people with disabilities and history of advocacy and civil rights work must be examined through the same theoretical frameworks used by other minority studies disciplines (Siebers, 2008). One of the useful frameworks for thinking through the inclusion of disability in cultural, critical and minority studies is to consider intersectionality (Crenshaw, 1991), the overlapping and multiple identities people possess. Intersectionality as a framework does not support one identity as superseding others in importance, but rather acknowledges the ways multiple identities interact with each other (Collins, 2000). For example, an adopted Korean girl with a disability in the United States must negotiate with a society that inherently is oppressive to females, Asians, and people with disabilities; each of these identities on its own has its own ramifications in terms of oppression, as well as the consequences of the interactions between two or more of these identities (i.e. being an Asian female, being an Asian person with a disability, being a female with a disability, and being an Asian female with a disability).

Siebers (2008) also critiques the social constructionism framework for its minimization or denial of the materiality of disabled people's bodies (p. 55). While Siebers appreciates that through social constructionism people are seen as being more than isolated diseases or defects, he is concerned that social constructionism has a tendency toward "privileging performativity over corporeality, favoring pleasure to pain..." (p. 57). In other words, regardless of how successful disability advocates are for dismantling social and institutional discrimination against people with disabilities, there exists at the end of the day the disability itself and in particular the pain associated with many disabilities, which as Siebers argues, cannot "be overcome simply by changing cultural attitudes (p. 202)."

Guiding Research

The medical model of conceptualizing children with disabilities centers the individual child as the client or unit of analysis. A family systems model would include the other family members and their relationship to the child as the client or unit of analysis (Seligman & Darling, 1997). By choosing a social ecology or systems theoretical approach to this study, I include the other systems with whom the families in this study interact, such as medical and health systems, schools, neighborhoods, extended family and friends, communities and other supportive programs or services (Seligman & Darling, 1997). Bronfenbrenner (1979) emphasizes that ecological transitions are a developmentally crucial point in time because it usually corresponds with a change in status and expectation for an individual (p. 6-7). In considering ecological transitions in the context of adoption, I was sensitized to potential role confusion for children entering an adoptive family with a role that is likely different from the one they occupied while in transitional care or previous placement settings. Ecological transitions helped me understand how both parents and children internalize new roles and the accompanying behavioral expectations each exhibit after an adoption. For example, adoptive parents undertake a new role of “parent” to a child with a history tied to another set of parents; or a child takes on the role of a “child” after developing survival skills that forced them to take on adult roles. Bronfenbrenner (1979) states,

“...whether parents can perform effectively in their child-rearing roles within the family depends on role demands, stresses, and supports emanating from other settings...parent’s evaluations of their own capacity to function, as well as their view of their child, are related to such...factors as flexibility of job schedules, adequacy of child care arrangements, the presence of friends and neighbors who can help out in large and small emergencies, the quality of health and social services, and neighborhood safety. The availability of supportive settings is, in turn, a function of their existence and frequency in a given culture or subculture. This frequency can be enhanced by the adoption of public policies and practices that create additional settings and societal roles conducive to family life.”(p. 7)

Social constructionism helped me frame how constructs related to family, adoption, permanency and disability are constructed by parents and professionals. For example, “special needs” is a social construct created by social workers and child welfare professionals and agreed upon by the public at large. In child welfare and adoption discourse, the term “special needs” has become an umbrella term used to describe a plethora of characteristics ascribed to children who in some way differ from “single, healthy, white infant.” Thus, the placement of “special,” an adjective meaning as “superior” or “better” next to the noun “need,” meaning “duty, obligation, or a lack of something” (Merriam Webster, 2011) highlights or differentiates the needs of children with disabilities that separates them from other children.

The contemporary definition of “special needs” includes many other characteristics other than a child’s disability including “prenatal insult, adverse parental background, and ethnic minority status” (Barth, 1991b, p. 318; Barth & Needell, 1996). Nelson’s (1985) study of special needs adoptive families outlined a typical set of criteria for a child’s inclusion in the study: over age eight; diagnosed with a physical, intellectual or emotional impairment; and/or part of a sibling group of two or more. Erich & Leung’s (1998) definition of “special needs” included characteristics other than disability and used special education status as a proxy variable for learning disabilities; and furthermore did not disaggregate race, age or membership in a sibling group from disability or control for non-disability related factors.

The social construction of disability is largely based on the medical model of disability as a defect or deviation from the norm. As Jones (1996) writes, the agreed-upon social construction of disability was created outside of the disability community and focuses on what sets people with disabilities apart from others. While the term “special needs” appears to be less focused on defining a child based on their disability, it is often not used in people-first language. People-first language is the usage of describing a person without the prefix of a person’s disability, respecting

a person's humanity instead of focusing on their disability. In addition, not everyone agrees that "special needs" is a more preferable term (Siebers, 2008). In a 2003 British Broadcasting Corporation survey on words that people with disabilities found most offensive, the term "special" was ranked fourth most offensive (Cousins, 2009). In addition, rather than re-framing "special needs" in a less negative way, the term has essentially become synonymous for "disability" – reinforcing the idea that being older, part of a sibling group or from racial minority group can be itself a "disability" for a child in need of an adoptive home.

That disability is often defined as part of, but not distinguished separately from, other "special needs" is an important consideration when assessing whether the child welfare system is able to serve the specific needs of children with disabilities who have been adopted. Cousins (2009) states that children with disabilities are "invisible," and that describing children with disabilities in need of adoptive homes in generic "special needs" terms instead of articulating the child's specific disabilities unintentionally invalidates the child, "reinforcing their invisibility" (p. 60). "Special needs" offers a positive connotation on children historically considered "hard to place" while also de-emphasizing disability in a way that is more palatable to prospective adoptive parents. Some professionals argue it is time to eliminate the term "special needs" as it no longer fits the current situation of children needing adoption since the majority of the children now could be considered to have "special needs" under the broad definition (Maza, 2014).

In examining the experiences of adoptive parents who placed their internationally adopted child or children in out-of-home placement because of the child's disability, I considered the ways in which these families interacted with each other within their micro, meso, macro and exosystems, and the ways in which these larger environments impacted the family's functioning. I explored the ways in which these parents constructed their world, how they defined parenting, their family and roles of family members, the child and the child's disability, and whether these constructs changed over time. I also analyzed the language adoptive parents use to describe their

experiences, define concepts, and explain power dynamics with regard to their relationships with the professionals with whom they interact.

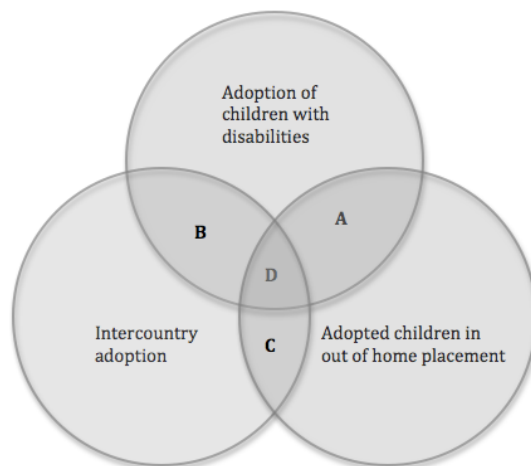
Chapter 3: Literature Review

Chapter Overview

In this chapter, I review the previous research relevant to the placement stability of internationally adopted children with disabilities. As you see below in Figure 3, there are three main areas of research applicable to this study. First, I review the literature on the adoption of children with disabilities including two major areas of focus: the adoption of children with intellectual and developmental disability (IDD) and the adoption of children from foster care with “special needs.” Next, I review the literature on adopted children in out-of-home placement including the literature on adoption disruption, dissolution and displacement. Last, I review the research on international adoption.

Further, in this chapter I review the literature on the areas of overlap that occur in Figure 3. I will review the literature on intercountry adopted children with disabilities and the research on the placement stability of children with disabilities. The gaps in the existing research are the areas marked C and D in Figure 3: the placement stability of internationally adopted children, and the placement stability of internationally adopted children with disabilities.

Figure 3: Literature review content areas



Overview of Research on Adopted Children with Disabilities

Large, nationally representative studies of the health and wellbeing of adopted children have been scarce until relatively recently. The 2000's brought an increase in these studies with the inclusion of adoption as a category in the 2000 U.S. Census (Kreider, 2003). A 2003 National Survey of Children's Health study found that adopted children are more likely to have special health care needs than their non-adopted peers (Bramlett & Radel, 2008). The authors of the study defined special health care needs consistent with the Maternal and Child Health Bureau and included children that currently had, or were at risk for, a physical, developmental, behavioral or emotional condition. In this randomly sampled study, 37 percent of adopted children were categorized as having special health care needs compared to 17 percent of non-adopted children (Bramlett, Radel & Blumberg, 2007). The 2000 Census was the first to include questions about adopted children and results found that internationally adopted children (11.7 percent) had similar rates of disability as domestically adopted (12.2 percent) children (Kreider & Cohen, 2009). The most recent Census data from 2010 however found 7.8 percent of internationally adopted children and 13 percent of domestically adopted children over five years old had one disability, and 1.8 percent of internationally adopted children had multiple disabilities compared to 3.4 percent of domestically adopted children (Kreider & Loftquist, 2014).

The National Survey on Adoptive Parents conducted in 2007 examined adopted children's physical, social-emotional and cognitive wellbeing of children adopted domestically (both private and foster care) and internationally. Results found that similar percentage of children adopted in private domestic arrangements and internationally had moderate to severe health issues (2.6 percent and 2.5 percent respectively) compared to 3.2 percent for children adopted from foster care. Children adopted from foster care had the highest percentage of attachment disorder diagnosis (2.7 percent) compared to private domestic (1.4 percent) and international (1.9 percent). Children adopted from foster care and internationally had similar rates of ADHD diagnoses (3.3

percent and 3.4 percent respectively) compared to 2.5 percent for domestically adopted children. Internationally adopted children had the highest percentage (3.6) of social behavior problems than foster (2.6 percent) and domestic (2.2 percent) adopted children (Vandivere & McKlindon, 2010).

Research on the Adoption of Children with Disabilities

The majority of the research on adopted children with mental health or intellectual/developmental disabilities (IDD) focuses on children with “special needs” adopted from foster care (Barth, 1991a; 1991b; Barth & Needell, 1996; Groze, 1986, 1996; Howard, Smith & Ryan, 2004; Nalavany, Gliddens & Ryan, 2009; Rosenthal & Groze, 1991, 1992). Outside of the foster care adoption literature much of the research on children with intellectual/developmental disabilities or special needs adopted domestically in the United States focuses on motivations to adopt, family functioning, and post-adoption parental satisfaction, with a particular emphasis on adoptive mothers (Forbes & Dziegielewski, 2003; Glidden, 1990; Glidden & Cahill, 1998; Glidden, Flaherty & McGlone, 2000; Goetting & Goetting, 1993). Adoption disruption as an indicator of family functioning is another segment of the literature on the adoption of children with IDD or other special needs (Barth & Berry, 1988; Coyne, 1990; Festinger, 1990; Glidden & Johnson, 1999; Groze, 1986; Hollingsworth, 2003; Lightburn & Pine, 1996; MacDonald, Lieberman, Partridge & Hornby, 1991; Nelson, 1985). While there is some cross-over in the literature where studies of children with special needs in foster care includes children with IDD, and conversely where some of the children included in the domestic IDD adoption literature may have had some foster care experience there exist fairly separate bodies of research.

In more recent years an emerging focus on domestic adoptions in general integrating all domestic adoptions of children with special needs including those with IDD helps provide a more comprehensive broad look at adopted children with disabilities; however in some ways our understanding is obscured since the definition of what constitutes “special needs” and the degrees to which IDD is included specifically in the larger definition is not typically well-defined. Perry

and Henry (2009) called for a definition of special needs limited to physical, developmental and mental health disabilities instead of one that includes factors such as race, age and siblings.

Domestic Adoption of Children with Intellectual and Developmental Disabilities

In 1956, *Pediatrics* published a letter to the editor written by Paul W. Beaven, then Chairman of the Committee on Adoption for the Upper New York State Chapter of the American Academy of Pediatrics. Writing what he believed would be a controversial call to action for adoption agencies to encourage the adoption of children with mild to moderate intellectual disabilities (written as mental retardation at the time) instead of choosing institutionalization. Beaven (1956) argued that institutions and foster home did not provide a sense of permanency for a child. “If we believe that *all* children, legally free for adoption, who can benefit from family life should be adopted,” Beaven wrote, “then these retarded children should have the benefit of a search for the legal home for them,” (p. 9710).

In general, most research on adopted children with IDD focus on parental satisfaction and post-adoption family outcomes. In particular the work of Glidden (1990, 1991, 2000, 1998, 2000) has delved into the experiences of parents that adopted children with IDD. One of the limitations is that most of these do not particularly focus on the adopted child, as much as they focus on the adoptive parents. Perspectives of the adopted child with IDD are absent. Another consideration in these studies is the singular focus on mothers, in particular on maternal depression, on family functioning and parental satisfaction without inclusion of fathers or adopted children perspectives. This is common in adoption literature, as women tend to be the majority responders as participants in research studies on adoption.

Most research has found that parental satisfaction of the adoption of a child with IDD is high. In a study of 42 families that had adopted children with intellectual disabilities, Glidden (1990) asserted that parental satisfaction was high because unlike birth parents, the adoptive parents had “chosen the child,” and therefore, “chosen the disability” (p.179). The sentiment of

“choosing a child with disabilities” was echoed in a study of adoptive parent motivation to adopt a child with severe developmental disabilities (Goetting & Goetting, 1993). Participants expressed that they were “called” to adopt a child with IDD and that adoption provided one with a “unique parental role.” (Goetting & Goetting, 1993, p. 502).

Several studies measured level of maternal depression as one outcome of parental satisfaction and most used the Beck Depression Inventory (Glidden, 1991; Glidden, 2000; Glidden & Cahill, 1998; Glidden, Flaherty & McGlone, 2000, Glidden, 2000). Research authors focused on mothers because mothers tend to be the primary caregivers for children with disabilities (Perry & Henry, 2009). In the majority of the studies looking at parental satisfaction the number of fathers involved in the study is small or non-existent.

Another area of the literature focused on post-adoption family functioning (Glidden, 1991, 2000; Glidden & Johnson, 1999; Lightbun & Pine, 1996; Marcenko & Smith, 1991; Nelson, 1985). In most studies, overall family functioning was found to be high (Glidden, 1991, 2000; Glidden & Johnson, 1999). Glidden (1991) sampled 87 families that had adopted children with IDD and sought to assess factors that both stressed and buffered placement stability. Lower maternal depression, experience with disabilities and religiosity were factors that contributed to better family functioning in these families. Marital satisfaction (Glidden & Cahill, 1998; Glidden, Flaherty & McGlone, 2000; Sar, 2000), family strengths (Glidden & Cahill, 1998; Glidden, Flaherty & McGlone, 2000; Glidden, 2000) and religiosity (Glidden, 1991; Groothues, Becket & O’Connor, 2002; Marx, 1990) were variables measured to determine family functioning. Lightburn and Pine (1996) sought to understand how families coped with the stress involved in parenting children with IDD. Their mixed methods study of 52 families found that the availability of resources, particularly financial resources such as adoption subsidies and Medical Assistance or SSI, was a factor in the parent’s ability to manage. In a study of the post-adoption

needs of families that had adopted children with developmental disabilities, respite care was the most cited (23%) service parents identified as needing (Marcenco & Smith, 1991).

The adoption of additional children with intellectual/developmental disabilities was evidence in some studies of parent satisfaction and high family functioning (Glidden, 2000, Glidden & Johnson, 1999; Lightburn & Pine, 1996). Glidden, Flaherty & McGlone (2000) took that hypothesis further and compared large and small adoptive families that had adopted children with intellectual/ developmental disabilities and found that parents with larger numbers of adopted children with disabilities rated parental satisfaction higher than parents of smaller families of adopted children with IDD.

Studies on family functioning also looked at placement stability, including adoption disruptions and dissolutions. Glidden & Johnson (1999) followed up with a longitudinal study of children with Down syndrome and found that none of these families' adoptions had been disrupted or dissolved. Coyne (1990) found that parents that adopted children with developmental disabilities had an 8.7% lower rate of disruption than those who had adopted children with other "special needs" (Coyne & Brown, 1985). Perry and Henry (2009) noted in their literature review that studies in which adoption disruptions and dissolutions of children with IDD occur are those in which the adoptive parents were not informed about the disability prior to the adoption.

Marx (1990) focused on the motivations to adopt a child with a developmental disability. This qualitative study found that adoptive parents were motivated to adopt based on religious beliefs, previous experiences with people with disabilities, and to ensure a child would not have to be raised in institutional care.

Adoption of Children with "Special Needs"

Studies that examine "special needs" adoptions typically define "special needs" as age at time of adoption, number of placements prior to adoption, history of abuse and neglect, and diagnosed disability (without specifying intellectual/ developmental disability) and look for

correlations with placement outcomes, often measured through parent satisfaction reports or placement stability. Previous knowledge of a disability (including, but not specifying intellectual/developmental disability) or potential for disability was found in many studies to strengthen parent satisfaction (Barth, 1991; Groze & Rosenthal, 1991; Perry & Henry, 2009). For example, Barth (1991) found that in his study of children prenatally exposed to drugs that adoptive parents who did not know about the prenatal exposure reported the highest levels of dissatisfaction with the adoptions. Barth (1991) also recommended that children with disabilities could be adopted if parents were adequately prepared and advocated for adoption as both a more humane and less costly means of caring for children. Schmidt-Tiezen and McDonald (1998) found that children had developmental or emotional disabilities were less likely to have a permanency plan for adoption than children with medical or physical disabilities.

Variables included adoptive family characteristics in the special needs adoption literature typically include marital/relationship status (single, married, divorced) (Barth & Needell, 1996; Groze, 1986; Howard, Smith & Ryan, 2004; Nalavany, Gliddens & Ryan, 2009, Rosenthal & Groze, 1990), parent's age(s) (Groze, 1986; Howard, Smith & Ryan, 2004; Rosenthal & Groze, 1990), race (Nalavany, Gliddens & Ryan, 2009), family income (Groze, 1986; Howard, Smith & Ryan, 2004; Nalavany, Gliddens & Ryan, 2009), and mother's education level (Barth & Needell, 1996; Howard, Smith & Ryan, 2004; Nalavany, Gliddens & Ryan, 2009). Fewer studies factor in religiosity (Erich & Leung, 1998; Rosenthal & Groze, 1990).

Child variables included gender (Barth & Needell, 1996; Howard, Smith & Ryan, 2004; Nalavany, Gliddens & Ryan, 2009, Rosenthal & Groze, 1990), age at adoption (Barth & Needell, 1996; Groze, 1986, 1996; Nalavany, Gliddens & Ryan, 2009, Rosenthal & Groze, 1990, Sar, 2000), race/ethnicity (Barth & Needell, 1996; Groze, 1996; Howard, Smith & Ryan, 2004; Rosenthal & Groze, 1990, Sar, 2000), placement history, including previous adoption disruptions (Groze, 1986, 1996; Howard, Smith & Ryan, 2004; Rosenthal & Groze, 1990, Sar, 2000), length

of time in the home (Barth & Needell, 1996; Rosenthal & Groze, 1990), placement with siblings (Groze, 1986; Rosenthal & Groze, 1990), and history of abuse and/or neglect (Groza & Ryan, 2002; Groze, 1996; Howard, Smith & Ryan, 2004; Nalavany, Gliddens & Ryan, 2009, Sar, 2000).

Studies that differentiate specific disabilities have included separate definitions for physical disability (Groze, 1996; Howard, Smith & Ryan, 2004; Rosenthal & Groze, 1990, Sar, 2000), mental health disability (Groze, 1996), IDD (Howard, Smith & Ryan, 2004; Rosenthal & Groze, 1990, Sar, 2000), medical or health (Barth & Needell, 1996; Howard, Smith & Ryan, 2004; Rosenthal & Groze, 1990, Sar, 2000), learning disability (Groze, 1996; Howard, Smith & Ryan, 2004; Nalavany, Gliddens & Ryan, 2009; Rosenthal & Groze, 1990) or emotional disability (Sar, 2000). Few studies articulate the entity that determines a child's disability, such as a medical, psychiatric professional or as determined for receipt of special education services or an Individualized Education Plan (IEP) for school. Smith, Howard, Garnier and Ryan (2006) for example include disability status (termed "handicapped") as determined by the caseworker and may include a mental health or emotional disability (p. 29).

Behaviors are not always included as a disability; often behavior is measured through the use of the Achenbach Child Behavior Check List (Groza & Ryan, 2002; Groze, 1996; Nalavany, Gliddens & Ryan, 2009; Rosenthal & Groze, 1990, 1991) or Behavior Problem Index (Howard, Smith & Ryan, 2004). Education performance is used both as an independent variable (Barth & Needell, 1996; Nalavany, Gliddens & Ryan, 2009) and as an outcome variable (Rosenthal, Groze & Aguilar, 1991).

Typical outcome variables in these studies include parent satisfaction (Barth & Needell, 1996; Nalavany, Gliddens & Ryan, 2009); family functioning, most commonly measured by FACES II or III (Groze, 1996; Rosenthal & Groze, 1990; Sar, 2000); parent-child relationship, typically defined through closeness or attachment to child (Barth & Needell, 1996; Groza &

Ryan, 2002; Groze, 1996; Howard, Smith & Ryan, 2004; Rosenthal & Groze, 1990); and adoption disruption, which will be discussed in much more detail below (Barth & Needell, 1996).

Overall, a general finding in most studies is that adoptive families respond that they are satisfied with the adoption of their child. More than 90% of the parents in Howard, Smith and Ryan's (2004) study rated their adoption as satisfied or very satisfied. (p. 21). Rosenthal & Groze (1990) and Goetting (1986) found correlations between lower satisfaction and higher parental education and suggest that this is correlated to higher expectations for academic achievement among highly educated parents.

Learning disabilities and receipt of special education services were a focus in several studies. In Groze's (1996) study, approximately half of the children were receiving some special education services at school. A study conducted by Howard, Smith and Ryan (2004) found that 40% of the children adopted from foster care, 32% of intercountry adopted children and 24% of domestic infant adopted children received special education services (p. 20). Fifty percent of the children in Erich and Leung's (1998) study received special education services. Nalavany, Gliddens and Ryan (2009) focused on behavioral problems of adopted children with disabilities. Examining a sample of children adopted from foster care, the study found that lower satisfaction among adoptive parents was due to the behaviors of the child, not the disability itself. In addition, the authors discussed behavior related factors associated with children with disabilities including their increased likelihood for maltreatment, child welfare involvement, and termination of parental rights. Rosenthal and Groze (1992) found that minor disabilities and learning disabilities, but not physical disabilities, were correlated with negative outcomes.

Intercountry Adoption Research

Although Americans have been adopting children from other countries since the end of WWII, most research on this population of children has tended to focus on their post-adoption

adjustment and their ability to attach to their adoptive parents. Very little is known specifically about intercountry adopted children with intellectual/developmental disabilities. Literature on intercountry adopted children tends to emphasize delays, not disability and focus primarily on two areas of development: 1) the degree to which their pre-adoptive experiences in their country of origin impact their physical, cognitive and social development and the degree to which their post-adoptive placements provide gains in these areas, and 2) the racial and cultural identity development of these children. While a discussion of the racial and cultural identity development of intercountry adopted children is beyond the scope of this research proposal, several authors have focused on this area of development (Lee, 2003; Lee, Grotevant, Hellerstedt, Gunnar, 2006; Lee & Quintana, 2005; Westhues & Cohen, 1998). This review will also not discuss the literature focusing on attachment issues among intercountry adopted children, although understanding attachment development among children from institutional settings is important, and Reactive Attachment Disorder is sometimes included as a disability (see Chisholm, Carter, Ames, & Morison, 1995; O'Connor, Marvin, Rutter, Orlick & Brittner, 2003).

Intercountry Adoption of Children with Disabilities

Historically, intercountry adoption research has emphasized intellectual/developmental *delays* to the exclusion of research on intellectual/developmental *disabilities* among this population (see McGuinness & Dyer, 2006 for a comprehensive review of the literature on the overall development of intercountry adopted children). Intercountry adoption studies typically focus on the intellectual/developmental delays that can be improved, mediated, or eliminated either through the support of the adoptive family and/or other medical or educational services (Albers, Barnett, Jenista, & Johnson, 2005; Gunnar & Pollack, 2007; Gunnar, Bruce & Grotevant, 2007; McGuinness & Dyer, 2006; Rutter, 1998; Weitzman & Albers, 2005), or on the factors that impact parent satisfaction and family stability including attachment problems and risk factors for

disruption/dissolution (Palacios, Sanchez-Sandoval & Leon, 2005; Pugliese, Cohen, Farnia, & Lojkasek, 2010; O'Connor, et al, 2003; Reinoso & Forns, 2010; Rijk, Hoksbergen, ter Laak, van Dijkum & Robbroeckx, 2006; Verhulst, 2000). Measures often include the Achenbach Child Behavior Check List (Mainemer, Gilman & Ames, 1998; Palacios et al, 2005; Rijk et al, 2006; Verhulst, 2000) or other behavioral assessments (Sar, 2000), parent satisfaction reports and parenting stress (Judge, 2004; Mainemer et al, 1998).

Judge (2004) studied the impact of early institutionalization on intercountry adopted children and found that six months after placement, children's developmental delays decreased significantly from pre-adoption measures. However, the Judge study did not differentiate between "delays" and "disabilities." Similarly, Kadlec & Cermak's (2002) study of 124 children adopted from Romania focused on developmental delays and found that length of institutionalization was the most significant factor in the amount of developmental gains after adoption. Bruder, Dunst and Mogro-Wilson (2000) surveyed adoptive parents who enrolled their Chinese-adopted child in early intervention services under Part C of the Individuals with Disabilities Education Act (IDEA) yet focused more on the parent's report of their child's behaviors than on the use of disability services or concerns about developmental disability.

What struck me about the literature on intercountry adoption and disabilities was their lack of discussion of intellectual/ developmental disability and a general separation of behavior and disability. In these studies, "behavioral" and "emotional" problems are not connected to mental health, neurodevelopmental or intellectual/ developmental disabilities (Gunnar & Pollack, 2007; Palacios et al, 2005). Neurodevelopmental disabilities are often framed as inattention behaviors (without a discussion of ADHD) (Dalen & Rygvold, 2006; Judge, 2004; Kadlec & Cermak, 2002; Mainemer et al, 1998; Palacioa et al, 2005) or prenatal exposure (emphasis on drugs over alcohol) without a discussion of fetal alcohol spectrum disorders (FASD) (Johnson, 2002). A study by Landgren, Svensson, Stromland & Gronlund (2010) is one of the few that researched the impact

of prenatal alcohol exposure on the neurodevelopment of adopted children. In their study of Swedish children adopted from Eastern Europe, they found that 52% of the children had characteristics of fetal alcohol spectrum disorders (FASD), with 30% identified as having fetal alcohol syndrome (FAS). Of those children with identified FAS, 90% were also diagnosed with one or more neurodevelopmental, behavioral, cognitive or neurological disability including ADHD (51%), intellectual or cognitive disability (23%) and autism (9%).

The lack of “naming” intellectual/developmental disabilities may be due to two factors; the time frames of these studies and/or age of the children involved. Studies on the development of intercountry adopted children thus far may be biased toward relatively “healthy” children. Most intercountry adopted children sampled for past studies often focus on infants and toddlers who are most likely to be adopted (Gunnar et al, 2007; Jenista, 1999; Mainemer et al, 1998). Post-test measures are typically conducted six months or a year after adoption against baseline measures taken when the child is first adopted or compared to the child’s functioning while still in institutional care using tools such as the Denver Developmental Screening (Groothues, Becket & O’Connor, 2002; Judge, 2004; Mainemer et al, 1998). Therefore, the research is limited to mostly young children, measured within short time frames post-adoption. There is little longitudinal research available that specifically measures long-term outcomes of intercountry adopted children with disabilities.

Howard, Smith and Ryan (2004) broke down disabilities of adopted children (foster care, infant domestic adoption and intercountry) including discrete categories for physical disability (3%), intellectual disability (2), chronic medical problems (11%), learning disability (27%), emotional disturbance (21%), behavioral problems (24%) and developmental delays (24%)(p. 16). Kreider and Cohen (2009) disaggregated “disability” (not specifically naming intellectual/developmental disabilities) from “special needs” and developmental delays. Using the 2000 U.S. Census, the authors sought to find whether intercountry adopted children had different rates of

disability compared to domestically adopted children and the general population of children and if so, what factors contribute to these differences. Unlike previous studies, Kreider and Cohen (2009) did not focus on language delays or behavioral or psychological adjustments; instead they categorized disabilities according to sensory, physical, mental and self-care impairments and found that 11.7 percent of intercountry adopted children had at least one identified disability, compared to 12.2 percent of domestically adopted children.

Research on the Placement Stability of Adopted Children with Disabilities

Special Needs Adoption Disruption, Displacement and Dissolution Research

The ultimate measure of a child's successful adoption outcome is whether the child remained living in the home until the age of majority. Berry (1997) called the potential for disruption "a fact of life in special needs adoption" (p. 78). While the majority of adoptive placements provide stability for children, there are times when adopted children leave the home before the age of majority. A disruption occurs when the adoptive parent(s) decide not to finalize the child's adoption (Festinger, 1986). Although discouraged by most adoption social workers, in the case of foster care adoption a child can be in a pre-adoptive placement for up to a year or more before an adoption is finalized. Children adopted internationally occasionally disrupt as well. Some countries require adoptive parents to finalize the adoption in the United States and issue those children specific visas and appoint guardianship to the adoptive parents until the adoption is finalized (U.S. Department of State, n.d). If the parent decides not to finalize that adoption, this is also considered an adoption disruption.

An adoption displacement is when a child leaves the adoptive home for an alternative residential setting that could include, but is not limited to, shelter, hospitalization, residential treatment facility, group home, or foster home (Festinger, 2009, Schwam-Harris & Rittner, 2004, Wells & Whittington, 1993). Adoption dissolution occurs when the child's adoption has been

finalized in court (either the U.S. for domestic adoptions or in the child's country of origin for international adoptions) and the adoptive parents' parental rights are later voluntarily or involuntarily terminated in the United States. Although both disruptions and dissolutions occur, frequently the literature employs the term "disruption" to mean both disruptions and dissolutions and very little research has been conducted on adoption displacements.

Among research studies of special needs adoptions, disruption rates of 6 to 23 percent have been found, with most studies reporting in the range of 10 to 25 percent (Berry, 1997, Coakley, 2008; Festinger 1986, 2001; Goerge, 1995; Roberts 1980; Tremetiere 1984; Unger et al. 1977). Child's age at the time of adoption and level of behaviors were most often correlated with disruption for "special needs" children adopted from foster care (Barth & Berry, 1988; Berry, 1997; Groze, 1986). Groze (1986), however, did not list disability in the definition of "special needs." In a study by Nelson (1985) the adopted child with special needs ended up in out of home placement at least once in approximately 20 percent of the families that participated in the study although 97 percent of the families did not experience a formal disruption or dissolution. Smith, Howard, Garnier and Ryan (2006) found that children with disabilities had a 41 percent higher rate of disruption than children without disabilities, likely because in this study the definition of disability includes behavioral and emotional disorders as well as physical and developmental disabilities. It is interesting that studies refer to mental health issues but do not add them specifically as a category of disability (Smith et. al, 2006).

Few studies examine displacement rates of adopted children. Displacement rates between 2 to 11 percent have been found for children adopted from foster care (Allphin, 2000; Goerge et al., 1995; Groze, 1996; Festinger, 2001; Howard & Smith, 2003; McDonald et al., 2001; Smith & Howard, 1999). Dissolution rates for children adopted from foster care are fairly low across those studies that disaggregate disruption and dissolution. Rates of one to two percent have been found (Groze, 1996; GAO, 2002; Festinger, 2002).

Studies of disruption and dissolution for children adopted from foster care identify three categories of reasons why adoptions disrupt or dissolve, including child related factors, parent related factors and systems or agency related factors. Child related factors include age, in particular the child's age at the time of the adoption (Barth et al, 1996; Festinger, 1986; Kadushin & Seidl, 1971; Rosenthal et al, 1988; Rosenthal, 1993; Schwam-Harris & Rittner, 2004; Smith et al., 2006). The child's history of placements, including multiple foster care placements and previous adoption disruptions or dissolutions, have been found to be a factor (Barth et al., 1988; Festinger, 1986; Partridge et. al, 1986). A child's emotional and behavioral disability also has been found to be a significant factor in placement stability (Barth et al, 1996; Barth & Berry, 1988; Rosenthal et al, 1988).

Very few studies of adoption disruption, displacement and dissolution related to intercountry adoptions have been conducted, and those mainly were conducted of intercountry adoptions in Europe or Scandinavian countries (Berástegui, 2003; Elmund, Lindblad & Hjern, 2006; Hoksbergen, 1991; Palacios, Sanchez-Sandoval & Leon, 2006) Hocksbergen (1991) found that 50 percent of the intercountry adoptees that were placed in residential or psychiatric treatment facilities in the Netherlands did not return to their adoptive families. Disruption rates in Spain have been found to be just less than one percent (Berástegui, 2003; Palacios et al., 2006). Elmund, Lindblad and Hjern (2006) examined the out of home placements of intercountry adopted children. Because the Swedish government has national data on all its citizens, including health data, this study provides strong representative data for Swedish intercountry adoptees. Results of the study found that intercountry adopted children 10 years of age and older were five times more likely to experience a residential treatment care and three times more likely to experience foster care in Sweden (p. 440).

However, fewer studies have looked at disruption, displacement and dissolution rates disaggregating intellectual/developmental disabilities from the other characteristics of "special

needs.” In a study of 1,588 adopted children with developmental disabilities, Coyne (1990) found an 8.7 overall percent disruption rate, with lower rates of disruption among families that had fostered the child prior to adoption (4.4 percent) compared to 10.4 percent in those placed in new adoptive families (Coyne & Brown, 1985). Perry & Henry (2009) highlighted that disruptions that occur when adoptive parents are unaware of the child’s intellectual/developmental disability prior to the adoption are similar to biological families placing out a child with a disability.

Adopted Children in Out of Home Care

The literature on adopted children in out of home care is concentrated on two areas, hospitalization and residential treatment. Even so, most of the research merely describes these two placements as settings that are chosen due to the child’s mental health or behavioral disabilities, and do not examine particular outcomes for adopted youth in these settings. For example, a typical description of adopted children in out of home placement looks at rates of out of home placement for adopted children, as in Howard, Smith and Ryan’s (2006) study of adoptive families. Compared to a control sample of non-adopted children, domestic infant (7%) and intercountry adopted (7%) children had slightly higher incidences of post-adoption residential treatment placement than children adopted from foster care (6%) however, these results were not statistically significant (p. 24). Studies of adopted youth perspectives about their in experience out of home placement are limited. Grotevant & McRoy (1990) examined adopted youth with non-adopted peers in residential treatment centers. While adoption status was found to be a factor in adopted youth’s behaviors (important factor for 66%, a minor factor for 18%, no factor for 16%), there were otherwise no significant differences in diagnoses or symptoms between the two populations. In another study, Young, Corcran-Rumpp and Groze (1992) implemented a treatment and permanency planning program for youth in residential treatment. The rate of adopted youth who terminated their treatment prior to the recommended treatment time was higher (37.5%) than typically found. Dickson, Heffron and Parker (1990) conducted a case

review of 375 adolescents admitted to in-patient, psychiatric treatment and found 11.7 percent of the cases were of adopted youth, not including stepparent adoptions. Much further research is needed on the placement and experiences of adopted youth in out of home placement, particularly in treatment foster, group home care.

Rationale for Further Research

What is missing from the current research speaks to the underlying gaps in the current literature. The biggest gap is the lack of quality adoption data. Basic information, such as the total number of children adopted in the U.S. each year, and through which channels, is unavailable. Due to availability of nationalized health and demographic data, researchers in many European countries have the capacity to provide comparative samples and follow children longitudinally. The 2010 U.S. Census data is a helpful start; the adoption status of children under 18 living in the home was included for the second time, allowing for some analysis that was not possible prior to 2000. However, information on type of adoption is still unavailable in the Census data.

As Jenista (2005) asserts, most of the children adopted from foreign countries could be considered to have “special needs” under the broad definition – which in the U.S. child welfare system includes children that are older, part of a sibling group, a member of a minority population, or who have a disability (Barth, 1991b). The ambiguity around what actually constitutes “special needs” is part of the reason there are such varied findings in studies on adopted children, particularly when it comes to disruption and dissolution (Mainemer et al, 1998). Further research must disaggregate intellectual and developmental disabilities from the other characteristics that define “special needs.”

While both domestic adoption and international adoption outcome studies measured child behaviors, most frequently through the Achenbach Child Behavior Check List, domestic adoption research was more likely to measure parenting resources and strengths, marital stability, stress and parental depression. Intercountry adoption studies focused more heavily on the child’s

behaviors and development using tools such as the Denver Developmental Screening Assessment. Intercountry adoption research also utilizes demographic indices such as family income or level of education along with parent self-reports, reinforcing the emphasis in international adoption literature on developmental *delays*, not intellectual/developmental *disabilities*. The distinction appears to conceptualize “needs” as an issue of *elimination* rather than management or maintenance, thus the focus on delays over disabilities.

The focus on “severe emotional and behavioral problems” begs the question of whether or not these are coded terminology for undiagnosed or unacknowledged mental health and/or neurodevelopmental disabilities. Because many of the neurodevelopmental and mental health disabilities manifest as behaviors, to the outside world these children’s disabilities are hidden and are socially constructed by the public as being the result of “problem children” or “problem parents.” Children with visible disabilities – those disabilities that have a physically evident component – appear to be more stable in their adoptive homes with adoptive parents rating higher levels of satisfaction than children with intellectual/developmental disabilities that are neurologically based and manifest in behaviors, such as Attention Defecit Hyperactivity Disorder, Fetal Alcohol Spectrum Disorder, Autism Spectrum Disorder and mental health disabilities (Groze & Ryan, 2002; Rosenthal & Groze, 1990; Rosenthal, Groze & Aguilar, 1991).

Adoptive parents are more likely to understand how to address medical and physical problems but struggle with disabilities that manifest behaviorally (Asbury et. al., 2007, Gaviday-Payne & Hudson, 2002; Mainemer et al, 1998; Nalavany, Glidden & Ryan, 2009). Adoptive parents of children with mental health or intellectual/developmental disabilities struggle to find support service systems, especially if accompanied by behavioral issues. An adoptive parent whose child has FASD shared with me that her son’s teacher did not understand his neurodevelopmental disability and “would never tell a child in a wheel chair that he could walk if he only tried harder” (C. Fletcher, personal communication, May 1, 2011). It is these behavioral

issues, according to the literature, that places adopted children with intellectual/developmental disabilities and their families at risk for out-of-home placement either through the county child welfare system or through private institutions such as residential treatment centers, group homes, and the Ranch for Kids – or for adoption disruption or dissolution.

In summary, I found that post-adoption functioning is a main focus of research on adoptive families. The research on the adoption of children with disabilities with IDD also focused on examining adoptive parent motivations for adopting a child with a disability, with special attention on adoptive mothers' satisfaction in adopting. The research on the adoption of children from foster care with "special needs" tends to examine child characteristics such as pre-adoption experiences, on family functioning. Intercountry adoption research is heavily focused on the impact of developmental delays, rather than developmental disabilities, on post-adoption family adjustment. The research on post-adoption placement stability (adoption disruption, dissolution and displacement) largely examines disruption rates of children adopted from foster care. The existing research is helpful in understanding the parent and child characteristics that impact post-adoption family functioning, including post-adoption placement stability. However the use of "special needs" as a broad term that may or may not include disability as well as the tendency to examine developmental delays instead of developmental disabilities pertaining to intercountry adoption suggests more research is needed to better understand how intercountry adoptive families can best be supported.

Chapter 4: Methods

Chapter Overview

In this research study I employ qualitative methodologies with a grounded theory approach in order to understand the experiences of adoptive parents who have placed an internationally adopted children into an out-of-home placement. This chapter will describe my research approach, my positionality, research question(s), the study sample, instrumentation, a detailed description of the methods I used in the collection of data, my rationale for and approach to data analysis, and issues of trustworthiness.

Research Approach

My aim for this research study was to gain a better understanding of the experiences of a subpopulation of families who are frequent users of highly intensive and costly services, many of which do not fit the family's needs, leading to the exhaustion of the family's emotional, social, and financial resources. For this study I was guided by ontological and epistemological assumptions rooted in qualitative inquiry with a pragmatic and grounded theory approach.

Applied research engaged with an eye toward outcomes is a tenet of pragmatism (Creswell, 2007). For this inquiry I bring a pragmatic worldview to my approach to inquiry, guided by a commitment to choose a methodology that best fits the research question. My research approach was to seek methodologies most appropriate to address the research question. Qualitative research consists of several characteristics including a naturalistic and interpretive inquiry approach with the researcher as key instrument, emergent design flexibility, purposeful sampling, and inductive data analysis (Creswell, 2007; Denzin & Lincoln, 2005; Patton, 2002). Naturalistic inquiry is the exploration of a topic in the subject's natural environment instead of a laboratory, without predetermined categories or controls used to test a subject's action (Patton, 2002) and includes the contexts that influence the participants (Creswell, 2007). Although interviews with questions will, to some degree, impose upon a participant's natural environment, naturalistic questions are

open-ended and leave room for the study participants to express what they desire to make known (Patton, 2002). For example, one question I asked the participants was “What does disability mean to you?” Some of the participants responded with a definition but others talked more broadly about how disability has impacted their lives. Asking clarifying questions about the participant’s statements and providing them with the opportunity to review their responses in written form was one of the ways I sought to represent as accurately as possible the ways the parents in this study made sense of and assigned meaning to their experiences (Denzin & Lincoln, 2005).

I chose to apply a grounded theory approach in order to expand beyond the phenomenon to develop a theory or theoretical constructs that could be explored further. I wanted to know “what is?” as a starting point in understanding these families’ experiences but also to begin to consider what actions these parents undertook as a result. Glaser and Strauss (1967) were the first to define a process of conducting a qualitative research methodology in which theory was developed from the data. At the time, grounded theory as a methodology challenged the positivist research environment largely considered at the time to be the only legitimate form of scientific inquiry. By outlining a detailed process and strategies for conducting grounded theory, Glaser and Strauss put forth a methodology that responded to critiques that qualitative research was unsystematic, less rigorous, anecdotal, and overly subjective (Charmaz, 2006).

Corbin and Strauss (2008) reconceptualized grounded theory to include theoretical constructs, in addition to theory, derived from data (p.1). Charmaz (2006) added a constructivist framework that makes explicit the ways researcher and participant together construct meanings from the participant’s experiences (p. 130). In addition, with a constructivist framework the researcher understands the research process is itself a construction and includes reflections of what the researcher brings (in terms of biases, positionality, and assumptions) to the inquiry (Charmaz, 2006, p. 131).

Grounded theory methodology encompasses several main components including the use of constant comparative analysis, constructing codes and categories from the data, simultaneously analyzing data while collecting data, theoretical sampling, and memo-writing (Charmaz 2006; Glaser & Strauss, 1967). Constant comparative analysis is the process of analyzing data through comparing with other data. For Glaser and Strauss (1967) the process of data analysis and generating theory was outlined as four major stages the authors call the “constant comparative method.” The first stage is to code data into categories, then compare the codes with previous codes in the same or similar categories. The second stage is to integrate categories. As category properties and dimensions begin to begin to interrelate, a theory begins to emerge. The next stage is to begin to delimit the theory; seeking ways to synthesize several categories into a higher level construct while maintaining the breadth of the data. The final stage of Glaser and Strauss’ process is to write the theory. Others conceptualize constant comparison as one component of the process, rather than the entire process. Corbin and Strauss (2008) define constant comparison as the process of comparing an “incident” or selected data with others as the researcher moves through the analytic process, noting the similarity or difference of these incidents through the construction of categories and constructs (Corbin & Strauss, 2008).

Like other forms of qualitative inquiry, codes and categories are inductively constructed from the data rather than being pre-determined in an attempt to make findings “fit” proscribed constructs. In grounded theory, the aim is not to look for representation across the general population, but seeking variability and diversity in order to shed light on constructs (Corbin & Strauss, 2008). Data analysis does not begin after all the data has been collected but is conducted throughout the process. The researcher may need to adjust the research process as information begins to emerge, for example, collecting more data or a different type of data based on what is needed. Theoretical sampling is used to seek sources of data that meet certain criteria to examine dimensions and properties of constructs (Glaser & Strauss, 1967). Corbin and Strauss (2008)

describe theoretical sampling as “follow[ing] the analytic trail” (p. 146) which might involve a process of collecting and analyzing data, developing concepts which lead to questions that lead to additional data collection, analysis and concept development in a “circular process [that] continues until the research reaches the point of saturation” (p. 144-145). Saturation is the point at which the researcher finds that subsequent analysis does not yield additional breadth or depth to the categories that emerged (Glaser and Strauss, 1967, p. 61). Memo-writing is another component of grounded theory. Memos can vary depending on the type of data and be used to analyze your data. Memos can consist of defining or comparing codes, categories and concepts; questioning or clarifying previous ideas or concepts; identifying gaps; or working out researcher’s assumptions or biases through bracketing (Charmaz, 2006; Corbin & Strauss, 2008).

Grounded theory’s emphasis on constructing theory or theoretical constructs directly from data fits well with the applied nature of social work research. Grounded theory that emerges from data rather than “from the armchair” (Glaser and Strauss, 1967, p. 14) speaks to theory that resonates with those who experience the phenomenon under study.

Positionality

I approach my positionality from an ontological and epistemological feminist perspective that argues researchers can not completely eliminate themselves from their past knowledge, assumptions, biases or experiences while engaged in the research project (Charmaz, 2006; Dominelli, 2002; Kanuha, 2000). I approach the research fully acknowledging the multiple ways my own experiences have informed the research process and benefit as well as challenge the research endeavor (Charmaz, 2006; Kanuha, 2000).

My own relationship to intercountry adoption is a personal one; at the age of almost three years old I was adopted from the Republic of Korea (South Korea) to Minnesota to white, European-American parents. Because of my age, health, delayed development and history of institutionalization I was deemed “special needs” and prioritized for adoption. When I arrived at

the Minneapolis/St. Paul airport, I was wearing a size 12-month dress that should have fit a child two years younger than me. Apparently I was so hungry for protein, my mom would make me four fried eggs for breakfast.

My relationship with the international adoption community was one of the major factors in my decision to become a social worker and eventually led to my interest in research on adoption. Exposure to the concerns of the community about adoption social work practice and research was the result of several years of participation in the intercountry and transracial adoption community prior to entering the academic realm. Additional knowledge was gained from my social work practice experience working in both public and private child welfare and adoption settings. Working at a small adoption agency writing adoption home studies and conducting pre-adoption trainings shaped my understanding of the agency perspective in providing adequate preparation for prospective adoptive parents. As an adoption worker for a large, public child welfare agency I gained insight to the children and youth who had experienced adoption disruptions, displacements and dissolutions. I also worked at an organization that provided pre- and post-adoption services, where I assisted adopted individuals and adoptive families struggling to find available or appropriate resources.

My interest in examining placement stability particular to intercountry adoption comes from my involvement with the adult intercountry adoptee community. Many years before Torry Hansen placed her Russian-born adopted son on an airplane and sent him back to Russia (Cave, 2010) or the Reuter's investigation on re-homing (Twohey, 2013), I had met adult intercountry adoptees who were placed in foster care, re-homed or abandoned by their adoptive parents before they reached adulthood. I also mentored an intercountry adopted youth while she was in a residential treatment facility and received calls from professionals and adoptive parents seeking resources to prevent adoption dissolution. All of these experiences inform this study. I recognize and acknowledge that my personal and professional experiences may both challenge and enrich

the research, and approach this reality by seeking ways to, as Corbin and Strauss suggest, “use our experiences to bring up other possibilities of meanings” (p. 80).

Apart from my own reflection about how my personal experiences inform this study and the ways in which my identity may or may not have impacted participant decisions to be part of the study, I recognize my identity status affected the way some of the adoptive parents related to me, particularly those parents who had adopted a child from Asia. My race, adoption status and gender may have influenced how the participants responded toward me (Charmaz, 2000). Parents attempted to join with me. One participant wanted me to meet her adopted child via the video conferencing; another parent wondered out loud about the possibility of having their college-aged adopted child contact me. Participants asked if I knew prominent adoption therapists or scholars including some with controversial attachment practices. During moments like these in the interviews, I acknowledged I knew of the therapist or organization but did not offer an opinion about the therapist or the therapeutic intervention. I also recognized my identity status as social work professional may have influenced participants. Sharing their story to a social work professional might have been unintentionally therapeutic for some participants. I also observed that participants often used language that assumed I understood what they meant because of either my background in social work and adoption or my status as an intercountry adopted person. At times I asked the participant to clarify or provide an explanation in order to decrease the possibility of my misinterpretation and to ensure that the data was from the participant, not the researcher’s experience (Kanuha, 2000).

One participant, “Mama” (a pseudonym), acknowledged that she had a tendency to defer to those she deemed as experts, telling me, “I have a tendency to put experts, including yourself, on a pedestal and I just take everybody for their word.” This statement reinforced for me that power dynamics exist between myself and these adoptive parents. Charmaz (2006) warns that power and status differentials often play out in interviews and can result in actions including withholding

information for fear of sounding inarticulate or unknowledgeable or due to mistrust of how the information may be used (p. 27).

In sum, my positionality shaped and guided the development of the questions I formulated to ask my study participants, the method of data collection I used, as well as the general concepts and conceptual frameworks I chose to guide this study. Throughout all phases of this study, I was reflective of the ways in which my positionality could be a useful starting point as long as I was ever mindful of the need to be open to possibilities that challenged or contradicted personal assumptions (Charmaz, 2006).

Research Question

My practice experience with adoptive parents, and in community organizing with internationally adopted persons, and the gap in the literature informed the research questions. The research questions created for this study were based on numerous conversations over the past 12 years with adoptive parents, internationally adopted individuals (adolescents and adults), adoption social workers, child welfare professionals, and mental health practitioners. A qualitative approach best fits the two main questions that this study is based upon: “Why, and how, do adoptive parents choose out-of-home placements for an internationally adopted child with mental health, intellectual or developmental disabilities?” Several subquestions included:

- What was the parent’s understanding of mental health, intellectual or developmental disabilities prior to adopting their child?
- How does the parent construct *disability*?
- What was the parent’s experience with accessing and utilizing services?
- How has this experience impacted their life?

Sample

In general, adoptive parents are a small subpopulation of parents in the United States, and

adoptive parents who have adopted children through intercountry adoption are an even smaller subset. Further, adoptive parents whose intercountry adopted children have one or more disability and who have experienced out-of-home placement due to their disability(ies) is a unique sample for which very little is known. Therefore, my criteria for recruiting and selecting participants for this study was to find 1) adoptive parents, 2) with intercountry adopted children that 3) with a diagnosis of a mental health, intellectual or developmental disability who were willing to share their story in order to better understand the range of experiences that might be possible.

The recommended sampling goal for qualitative inquiry varies. I set an initial target goal of 20 to 30 participants was set as a broad parameter. I did not request for both parents (if available) to participate in the study. A guideline of inclusion criteria was established for the selection of participants. Participants needed to be over 18 years of age, currently residing in the United States, and had adopted child through intercountry adoption. These adopted children had to be: 1) between the ages of six and 21 as of the date of the interview, 2) diagnosed with a mental health, intellectual or developmental disability by a mental health or medical professional at least six months prior to the date of the interview, and 3) had experienced at least one out of home placement after the adoption had been finalized. Post-finalization out of home placement could include a temporary or permanent stay in 1) a shelter, 2) family foster care, 3) residential treatment center, 4) hospital treatment center, 5) group home, 6) transfer of legal and physical guardianship or custody with another caregiver, or 7) an adoptive placement with another family.

I recruited participants through the dissemination of a flyer publicized by organizations and agencies that work with adoptive parents and their such as adoption agencies, adoptive parent peer-to-peer support groups and organizations, medical clinics that specialize in intercountry adoption medicine, county agency foster care and adoption units or county agency children's mental health units, adoptive parent list-serves and online groups and social media channels. I contacted agencies and organizations by phone or email with an outline of the purpose of the

study and requested assistance in posting the information and flyer to their organization members in both physical and online open spaces such as bulletin boards, as a general notice on their website or in community spaces (Appendix G and H).

In addition, I created a website (<http://jaerankimresearch.wordpress.com>) where the information about the study was posted as well as my contact information. For online forums such as discussion boards, Facebook groups, Google groups, or other electronic social networks, I contacted the administrator of the forum and ask the administrator to post the call for participants on my behalf. In some instances I disseminated or posted the call for participants personally (for example, the information to the website was posted on Twitter, my personal blogs, Facebook and Google+). At no time were individuals contacted personally by me with a request to participate.

When potential participants contacted me, I screened them for eligibility. A total of 39 persons representing 39 families contacted me inquiring about participation in the study. A total of 20 persons did not participate due to not meeting the criteria for participation (9), declining to participate after initial discussion (3), and not responding to a third follow-up email or phone call to schedule an interview time after initially agreeing to participate (8). The remaining 16 participants followed through and completed the interview. Three of the participants brought a spouse to the interview. Thus, the total number of participants included 19 parents representing 16 families. I continued the recruitment and selection process until I reached saturation.

Table 1 below describes the participants who completed my study. Couples that participated in the interview together are shaded in the table. The sample was largely female (84%), white (100%), married (68%), and college-educated (95%). Three men participated along with their wives and in two of the three cases where couples participated in the interviews together it was the husband who contacted me regarding the study. The parents were between 39 and 64 years of age at the time of the interview and had adopted their children between 1992 and 2012. They lived in three primary geographic regions in the U.S. The names indicated in the table

below represents the pseudonyms chosen by the parent.

Table 1. Parent demographics

Pseudonym	Age	Gender	Race	Marital	Degree	Region	# of Adopted*	# of Bio
Mary	52	F	W	Single	JD	Midwest	2	---
Lily	59	F	W	Married	M	Midwest	2	---
Melissa	40	F	W	Married	B	Midwest	2	1
Chris	58	M	W	Married	B	Midwest	2	3
Debra	62	F	W	Married	M			
Patrick	55	M	W	Married	B	Midwest	2	1
Marie	55	F	W	Married	B			
Janet	53	F	W	Married	HS	Midwest	2 (1*ICA) 5 (*1USA)	5
Eleanor	53	F	W	Single	M	Midwest	1	---
Grace	64	F	W	Married	M	West Coast	1	---
Jane	65	F	W	Divorced	PhD	Mid Atlantic	1	---
Becky	53	F	W	Married	M	Mid Atlantic	1	---
Anne	47	F	W	Divorced	M	West Coast	1	1
Laura	40	F	W	Married	M	Mid Atlantic	2	---
Vicky	63	F	W	Single	M	Midwest	2	---
Sarah	48	F	W	Partnered	M	Mid Atlantic	2	---
Mama	63	F	W	Married	M	Midwest	1	---
Amy	61	F	W	Married	MD	Midwest	2	---
Dan	57	M	W	Married	JD			

* The asterisk indicates the parent has taken legal guardianship of the child and has not legally adopted the child as of the interview date.

The families in this study had 43 children among them, including 10 biologically born children and 27 intercountry adopted children. The intercountry children were adopted from four regions: Asia, Africa, Easter Europe and Latin America. Regions, instead of naming specific country of birth, was chosen to protect the confidentiality of the family since some of the families adopted children from small or unique programs that may identify the family if named. Children were between three months and sixteen years of age when adopted. Eighteen of the intercountry adopted children had at least one out of home placement. Table 2 below describes the intercountry adopted children demographics. The children’s diagnoses (Dx) are described in table 3.

Table 2. Intercountry child demographics

Pseudonym	Gender	Parent	Year of adoption	Age at adoption	Region	OHP	Dx
Adam	M	Janet	1990	16 yrs.	Africa	Y	d, h
Liam	M	Grace	1992	4 mos.	Latin America	Y	b, i, k, s
Eddie	M	Lily	1993	6 mos.	Latin America	Y	b, c, h, s
Sasha	F	Jane	1994	4 mos.	Eastern Europe	Y	a, i, k, r
Hannah	F	Dan & Amy	1995	5 mos.	Asia	N	i
Michael	M	Patrick & Marie	1995	3 yrs.	Eastern Europe	N	a, o, l
Lucy	F	Lily	1996	3 mos.	Latin America	N	b, c
Carter	M	Becky	1996	6 yrs.	Eastern Europe	Y	a, b, g, h
Jerry	M	Patrick & Marie	1997	3 yrs.	Eastern Europe	Y	a, b, h, j, m, q
Tim	M	Dan & Amy	1997	5 mos.	Asia	Y	f
Isabel	F	Vicky	1998	5 yrs.	Latin America	N	a,
Nicole	F	Mama	2000	4 yrs.	Eastern Europe	Y	a
Mary	F	Eleanor	2000	11 mos.	Asia	Y	c, n
Ryan	M	Melissa	2002	9 mos.	Asia	Y	t
Sofia	F	Vicky	2004	7 yrs.	Latin America	Y	a, d, g, m
Kathy	F	Anne	2004	6 mos.	Asia	Y	c, i, l
Dennis	M	Laura	2004	15 mos.	Eastern Europe	Y	c, f, n
Sam	M	Melissa	2007	4 mos.	Asia	N	
Mark	M	Mary	2007	11 yrs.	Latin America	Y	h, j, k, m, o
Charles	M	Mary	2007	9 yrs.	Latin America	Y	h, j, l
Elena	F	Debra & Chris	2007	11 yrs.	Eastern Europe	N	h, j
Marina	F	Debra & Chris	2007	11 yrs.	Eastern Europe	Y	h, i, j, m
Carrie	F	Janet	2007	6 yrs.	Africa	N	d, c, h
John	M	Laura	2008	3 yrs.	Eastern Europe	N	a, c
Becky	F	Janet	2010	11 yrs.	Africa	Y	h, l
Elizabeth	F	Sarah	2012	12 yrs.	Africa	N	
Caleb	M	Sarah	2012	15 yrs.	Africa	Y	d, o

Table 3 lists the categories and overall number of developmental, mental health and

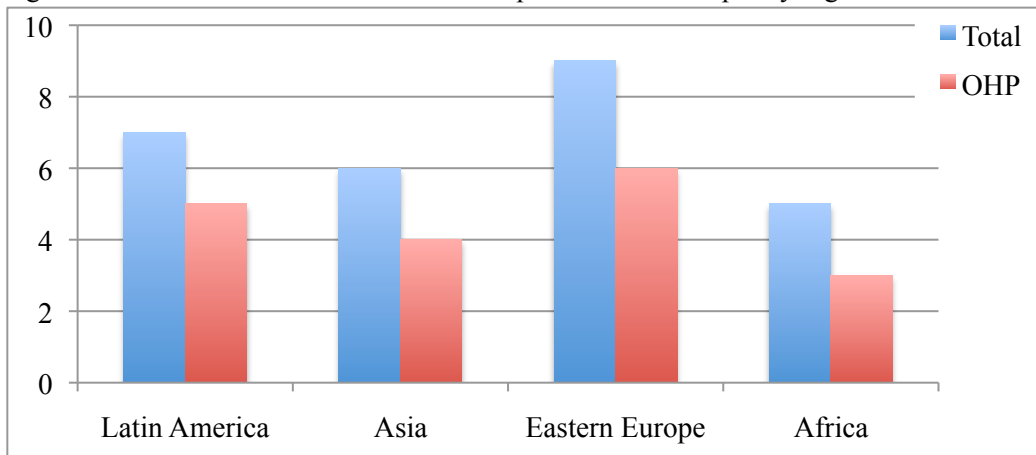
other disabilities these children were diagnosed. The children’s names are pseudonyms chosen by the parent or myself at the parent’s request.

Table 3. Number of intercountry adopted children in study by disability category

Developmental		Mental Health		Other	
a. Fetal Alcohol Spectrum Disorder /Alcohol Related Neurological Disorder	7	h. Post-Traumatic Stress Disorder	9	s. Substance abuse	2
b. Learning Disability	6	i. Anxiety	6	t. Chromosome Disorder	1
c. Attention Deficit Hyperactivity Disorder	5	j. Reactive Attachment Disorder	5		
d. Intellectual/Cognitive Disability	4	k. Bipolar Disorder	4		
e. Attention Deficit Hyperactivity Disorder	5	l. Depression	4		
f. Autism Spectrum Disorder	2	m. Oppositional Defiance Disorder	3		
g. Other developmental disability		n. Mood Disorder	2		
		o. Schizophrenia	2		
		p. Attachment Disorder – not RAD	1		
		q. Conduct Disorder	1		
		r. Obsessive Compulsive Disorder	1		

Figure 4 shows the breakdown between the intercountry adopted children with out of home placement by region.

Figure 4. Number of ICA with out of home placement in sample by region



Instrument

In qualitative research, the researcher is the instrument (Creswell, 2007; Patton, 2002). A semi-structured interview guide was created with selected questions to guide the conversation but, as is appropriate with grounded theory research, I left room for new questions to emerge (Charmaz, 2000). For example, after the second participant mentioned being “surprised” by her experience parenting her children, I thought the question might facilitate some interesting data and incorporated the question, “What has surprised you in parenting your child?” in future interviews. I purposely created open-ended questions in order to promote the likelihood the participant’s response would be from their point of view, rather than based on what they might believe they “should” answer. Additionally, since the data generated from this study will be used in further research, categories used in future studies need to emanate from the participants’ own experiences (Patton, 2002). The interview guide was peer-reviewed with selected committee members with expertise in qualitative research methods and content expertise in adoptive families. Figure 5 below shows the interview guide.

In addition, I created an eco-map of each family during the second coding cycle based on emerging data (see Appendix). After transcribing and coding a couple of the interviews I recognized these families experienced so many interactions within meso, macro and exo-systems that creating an eco-map of each family enabled me to visualize all of the many people and places with whom these families interacted. In addition to visually representing the multiple systems of the family, an eco-map allowed me to explore the nature of these interactions (positive, negative, broken) with individual family members. For example, a parent may have a tense or negative interaction with their child’s therapist, but the child herself may have a positive relationship with that therapist.

Figure 5. Interview guide

Interview Guide

[Inform the participant of the nature of the study, the known benefits and risks, and obtain consent. Explain confidentiality; have the participants choose a name they would like to be referred to in the study. Ask for permission to tape the interview]

This first question is to get a general sense of who you are and to get to know you and your family.

Question 1. Tell me a little bit about your family. [Could do a genogram; have parents give pseudonyms for children if they want to include “names” and year of birth and year of adoption]

Question 1b. Describe for me how you came to adopt your child.

[Prompts: Did something in particular prompt this decision? How did you come to the choice to adopt internationally?]

These next few questions are so I can get an understanding of your understanding of disabilities, both before and after you adopted your child.

Question 2a. What does the word “disability” mean to you?

Question 2b. What did you know about intellectual and/or developmental disabilities or mental health disabilities in general prior to adopting your child?

Question 2c. How did your adoption agency present or discuss the potential risks of adopting a child with a mental health or intellectual or developmental disability?

Question 2d. How did this information affect your decision to adopt?

[Prompt: Did you discuss what potential disabilities you were willing or able to accept? Did it make you change your mind about where to adopt? Were you open to adopting a child with disabilities? Did you turn down children because of their disability or risk of disability]

These next few questions are so I can get an understanding of your experience of parenting this child with diagnosed disability

Question 3a. Describe for me what disability or disabilities your child has been diagnosed with.

Question 3b. Describe for me what it is like parenting a child with an intellectual and/or developmental disability or mental health disability.

[Prompts: What have been some of the surprises? What have been some of the challenges?]

The next few questions are about your experiences with out-of-home placement services.

Question 4a. How did you come to make the decision about seeking out-of-home placement services?

Question 4b. Tell me about your experiences of having your child in out-of-home placement.

[Prompts: How has this experience affected your family? What helped? What did not help?]

Question 4c. What does the future look like in terms of your relationship with your child at this point?

The last few questions are to elicit parent expertise about the experience of placing an internationally adopted child with MH or I/DD in out-of-home placement.

Question 5a. What would you like people who do not have your experiences know or understand about adopting a child with MH or I/DD?

Question 5b. What advice do you have for adoption agencies about ways they could or should prepare and/or support families who have adopted children with MH and I/DD?

Thank you so much for taking the time to talk with me today. Is there anything else you would like for me to know about your experiences?

[Follow up with any references, information for the family, etc.]

Methods

Data Collection Procedures

Interviews. Upon confirmation that the participant met all the criteria for the study, I explained the options for conducting the interview; participants could choose to conduct the interview a) in person, b) by secured video conferencing, or c) by phone and a date was set. Participants who were able to attend the interview in person were given a range of options for the location of the interview including my office located at the university, the participant's home, or a neutral location such as a private room in a public space, such as a library or coffee shop. Participants that met in-person for the interview completed the consent form prior to the start of

the interview. If the interview was held by video conference or phone, I emailed the participant the consent form (Appendix A) and requested they mail, email or fax the signed consent form to me. Six participants whose interviews were conducted by video conference or phone did not send their signed consent form to me prior to the start of the interview. For these participants, I read the consent form aloud to them and had them orally record that they agreed to participate, and requested the participant sign and mail the consent form to my office. I received all of the necessary consent forms. All participants voluntarily participated in the study.

The 19 interviews were conducted between February 14, 2013 and March 6, 2014. Three were in my office, five in the participants' homes, three in private rooms in a public space, six by secure video conference, and two by phone. Interviews lasted approximately 60 to 90 minutes. I informed participants I would be recording the interview using a digital recorder and that immediately after the interview I would upload the audio file from my digital recorder to a secured and encrypted file on my computer. I also explained that the designated computer used for this study was a laptop that was brought to each interview but was not used to take notes during the interview. Participants were informed that as compensation they would receive a \$25 gift card to a major discount store. Three participants declined the gift card and the others accepted. I then reminded the participants that I wanted to ensure the confidentiality of their participation and asked if they had a pseudonym that they would like me to use in the dissertation or articles. I also explained I would be using pseudonyms for their children and would remove identifying information such as the state and town in which they live(d), names of schools, clinics, therapists and placement settings. A few of the participants asked me to choose names for them and the others provided me with pseudonyms. Next, I completed a demographic information sheet on the parents to obtain age, identified gender, identified race, relationship status, education level, current state of residence, and information on their children including year of birth, gender, year of adoption, country of adoption and current diagnoses (Appendix E).

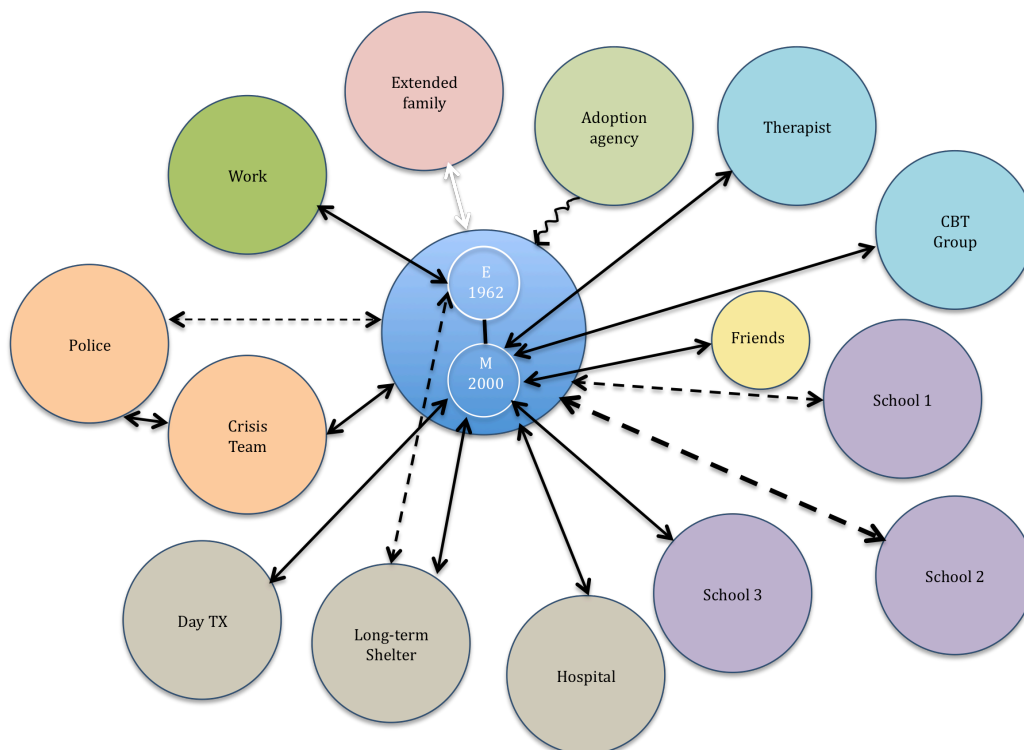
At the sixty-minute mark if the interview was not close to being completed, I informed the participant of the time and suggested that in order to be respectful of their time we would need to move on to the final questions, or we could continue. I allowed participants to also let me know if they wanted to continue at another time. All of the participants continued with full knowledge of the time. Actual interview times ranged between 39 to 159 minutes. Upon the completion of each interview, I explained to the participant that I would be sending them a copy of the transcribed interview. Participants were informed that upon receiving the transcript they would have the opportunity to clarify, add, change, or withdraw any (or all) of the interview. All of the participants agreed with their final transcript, with only two participants asking for minor corrections or the deletion of particularly sensitive material.

After thanking the participant and upon leaving their presence I immediately uploaded the audio file to the computer, checked that the file was successfully uploaded, and erased the audio file from the recorder. The folder in which all audio files were uploaded was additionally secured through encryption requiring an additional password in order to access the folder. The interviews were transcribed during the same period of time the interviews were taking place. Following the interviews, I completed a “contact summary form,” (Miles & Huberman, 1994) (Appendix F) and a memo to document my impressions of the interview or note areas of focus for the next interview.

Eco-maps. During the second coding phase I implemented some changes based on the data that was emerging. I began the research including general systems theory as one of the conceptual frameworks of this inquiry. However, from the data emerging from the second coding cycle, I determined that ecological systems theory was a more appropriate fit as it focuses more on the development of individuals within and across multiple environments than general systems theory. I wanted to add a further step of creating eco-maps for each of the families in order to better understand how the families interacted with other systems in their lives.

Using the framework developed by Hartman (1995) as a guide, I created an eco-map of each family. The family and identified internationally adopted child or children formed the center circle. Surrounding the family are the other systems with whom the family interacts and the family's relationship to these systems were represented by lines. Arrows designate the direction of interaction between the family and the system. The strength of the relationship is represented by the line's width, and the nature of the relationship (positive, tenuous, stressful, broken) is represented by the line's character/style (straight, jagged, dashed). Ecomaps allowed me to see the family's interactions with systems in their environment and see patterns of interactions within a family and across families. Figure 6 below shows the exomap for Eleanor and her daughter Mary. Sixteen family eco-maps were constructed and analyzed (Appendix D). Ecomaps were color coded by type of organization or entity.

Figure 6. Eleanor's Ecomap



Data Analysis

Data consisted of transcripts, contact summary form notes, memos, and ecomaps. I implemented a combination of coding and data analysis approaches including line-by-line coding (Charmaz, 2006) and process coding (Corbin & Strauss, 2008). I coded without the use of coding software because I was interested in exploring how to code by hand and I sought to understand the coding process and gain a deep familiarity with the data.

I conducted initial coding while interviews were being transcribed by memoing code ideas based on phrases and data I found interesting or insightful. A codebook was developed with some of these initial codes. To aid in the coding process, I created a table for each interview consisting of three columns. In the first column, I copied and pasted the entire transcript for one of the participants. In the second column, I went through the transcript and pulled out words, phrases or sentences I thought were particularly informative. In the final column I used a variation of line-by-line initial coding (Charmaz, 2006) through creating a process code based on processing actions (e.g. "Thinking about adopting"). Process codes were added to the codebook.

Each transcript was coded in this way. I added new codes and codes that had been previously entered in the codebook until each transcript had been coded. Throughout the coding process, certain phrases and words began to come forward as potential themes or central phenomena. Some of these phrases or words were codes, and others were *in vivo*, which means the code consisted of word(s) taken directly from the participants (Corbin & Strauss, 2008). I used second coding cycle (Saldaña, 2009) or axial coding (Corbin and Strauss, 2008) to further explore broader themes and to interconnect categories (Appendix C). Axial codes include codes that explain or inform influences, contexts, conditions, consequences or actions of a thematic code (Creswell, 2007). In addition to coding transcripts, I coded contact summary sheets, and memos. These secondary texts related to the interviews were coded first using open coding. Any new codes I found were added to the codebook and later analyzed with the interview data and

provided additional dimensions to the codes.

Throughout the coding phase the codebook began to organize itself by code categories through an iterative process of adding new codes or thinking about the appropriateness of a code. Often I would create a code that was similar to another code that had been applied; when this occurred, I considered whether these codes could be combined, if the new code expressed a new dimension of the other code, or if there were unique differences between the two codes that argued for the inclusion of both codes. If I was not sure, both codes were kept for further consideration. After all of the transcripts had been coded, I then went back to each of the transcripts in order by the date of their coding and re-coded them side by side with the full code book, using the constant comparative approach in which the second transcript was compared to the first transcript, the third transcript was compared to the first two transcripts, and refining, collapsing and expanding codes as I went through each transcript.

I analyzed the ecomaps by memoing patterns of relationships I found among the parent, child and the other entities in their environments. For example, I noticed that many of the families had stressful relationships with their child's school through analyzing the visual data. I then wrote memos about what parents described in their interviews about their relationships with their child's schools and compared that data to what was represented in the ecomaps.

Addressing Trustworthiness

The issue of validity in qualitative research is one that is open to interpretation (Lincoln & Guba, 1985). Since the purpose of qualitative inquiry is not to generalize findings, and recognizing that participants and researcher both construct meaning from the data, I conceptualize validity similar to Creswell (2007) and aim for findings that resonate with the participants and researcher(s). Lincoln and Guba (1985) describe undertaking the task of validity as establishing "trustworthiness" by addressing four issues including truth value, applicability, consistency and

neutrality through implementing methodological techniques that impart credibility (p. 300). Additionally, Creswell suggests implementing validation strategies (p. 207) that researchers can use to increase validity. Establishing trust with my participants was one of my validation strategies. While the interview itself was one moment in time, I often spent time ahead of the interview with the participant discussing the broader context of my work, my positionality as an international adopted person, the location of this study in terms of my broader research agenda and answering questions. Another validation strategy I employed was using multiple sources of data including interviews, contact summary forms, ecomaps, and memos (Lincoln & Guba, 1985, p. 307). I also employed member checking. Participants were sent copies of their transcripts and invited to discuss any ensuing thoughts they had about their responses. I also sent them a copy of an article I wrote in which I discussed preliminary themes and invited them to share their thoughts about the accuracy of my interpretation of what they shared with me. I also used peer review with established faculty with research and content expertise in qualitative methodology, child welfare, and intercountry adoption, in particular during times when I needed to check in about my interpretation of data or other concerns. For example, one participant commented on multiple online conversations (blogs, Facebook pages) where I was mentioned by name. The nature of the comments created an impression that the participant might be struggling with having participated in the study or concerned that I might be mishandling or misinterpreting the information she shared. In my peer debriefing with members of my committee we considered the appropriateness of keeping this participants data in the study. I also shared my conversations with the participant including my suggestion that the participant might want to withdraw from the study. After weighing multiple options, I decided to keep the participant's data with the full understanding that the participant may change her mind and withdraw. I kept a detailed account of the online conversations by taking a screen shot of the pages and documenting them in my field journal to establish an audit trail. Finally, as Finlay (1995) articulates, use of reflexive

analysis is an opportunity to enrich the inquiry by articulating the research process, making explicit the researcher's positionality, and documenting a methodologically sound study (p.532). Bracketing, a phenomenological term for recognizing and setting aside one's own subjective emotions, experiences or thoughts about a phenomenon, is used to focus more deeply on the participant's experiences while mitigating, as much as possible, the intrusion of the researcher's experiences.

As Corbin and Strauss (2008) emphasized, "researchers are translators of other person's words and actions" and similar to other forms of translational and interpretive endeavors, must navigate the multiple different meanings that can exist among people with diverse lived experiences (p. 49). Charmaz (2006) warned that it is important we do not attempt to take ownership of our participant's views but that we seek to understand and "interpret" the meanings of their actions or words (p. 19). Yet, as someone who has experienced using an interpreter I am fully aware of the numerous missteps that can occur in the interpretation process. How I might use language to describe an object, process or feeling is not always translatable; there may be different meanings associated and the participants may disagree with my interpretation or they may agree but not like it. In addition, in constructing concepts and theories from the data I was fully aware that I was constructing concepts and theories from the stories the participants themselves had constructed as they attempt to "make sense out of their experiences and/or lives, both to the researcher and themselves" (Corbin & Strauss, 2008, p. 10).

Chapter 5: Findings

Chapter Overview

In this chapter I present the categories and themes that emerged from my interviews with adoptive parents, ecomaps, contact summary forms, field notes, and reflexive memos. I include quotes from the participant's interviews to illustrate specific categories and themes. Quotations have been edited for clarity including the removal of some speech disfluencies such as "um," but in some instances pauses, laughter, sighs, or other signals of the participant's tone are included in order to provide additional understanding to the participant's statement.

Each of the four main categories along with the category's themes and subthemes are discussed. Themes emerged throughout the secondary (axial) coding process as open codes began to group together. As I analyzed themes, four categories emerged. The four categories that emerged include 1) constructions of disability and intercountry adoption, 2) choices, 3) costs, and 4) consequences. Next, I present a framework how these four categories interact. I conclude this chapter with a discussion of the limitations of this study.

Category 1: Constructions of disability and intercountry adoption

Parents in the study were asked to share what the word or concept of "disability" meant to them. From parent responses, several themes emerged including 1) constructing disability, 2) constructing normal, and 3) constructing intercountry adoption.

Theme 1: Constructing Disability

Parents constructed disability by describing what they think disability is, as well as what they think disability is not. Parents often used comparisons to explain what disability means to them and these comparisons were highlighted through examples of behaviors or characteristics measured against an internalized idea of "normal" or "typical." Several subthemes around constructing disability emerged including a) defining disability, b) differentiating between developmental delays and c) disabilities, and re-framing disability.

Defining disability. When parents responded to the question about what disability meant to them, they often referred to functioning and included qualifiers such as “difficulty” or “inability” as well as action words like “interfere.” Parents made comparisons to what they consider “normal.” Table 4 below shows the words that parents used to define disability.

Table 4. Words parents used to describe disability

Words parents used to describe disability	Parents
“Activities of daily living”	Lily
“Autism”	Debra
“Condition”	Amy, Dan, Lily, Mary
“Conditional living”	Grace
“Emotional”	Anne, Debra, Eleanor, Grace
“Fetal Alcohol”	Becky
“Gets in the way”	Anne, Mary
“Intellectual differences”	Debra, Vicky
“Interferes with independence”	Anne, Amy, Debra, Janet, Melissa
“Interferes with normal functioning”	Anne, Patrick, Sarah, Amy, Dan
“Invisible”	Becky, Eleanor, Jane, Marie
“Makes it harder”	Lily, Mary
“Mental”	Anne, Becky, Dan, Patrick, Sarah
“Need additional services”	Janet, Sarah
“Need lifelong caregivers”	Melissa
“Neurological”	Laura
“Physical”	Anne, Becky, Dan, Debra, Grace, Mary, Patrick, Sarah, Vicky
“To do the things required to function”	Grace, Jane, Janet, Lily, Vicky
“To live one’s life”	Debra, Lily
“Visible”	Dan, Jane, Marie
“Unlevel playing field”	Mary

For example, Sarah, parent of two children from Africa, defined disability as “an inability to function in sort of the normal everyday life, like the rest of us.” Patrick, parent of three including two children adopted from Eastern Europe, defined disability as “anything that keeps someone being able to function in the normal way.” By using the phrase “keeps someone” here Patrick constructs disability as something that is not a personal characteristic but something external to oneself. Laura, parent to two children adopted from Eastern Europe, defined disability as “an innate difficulty behaving in a neurotypical or average physical manner as opposed to the general population.” With this definition, Laura revealed an academic understanding of disability as well as differentiating between the realm of visible (physical and medical) and invisible (intellectual, developmental, neurotypical and mental health) disabilities. Laura focused on behaviors, not functioning, in her definition.

Janet, Sarah and Melissa framed disabilities in terms of level of care or assistance that is required to function. Janet defined disability as a condition that interferes with a person’s ability to function in society without additional services. Some parents, including Marie and Vicky, talked about disabilities as a “difference.” Vicky described disability in terms of functioning and included physical and intellectual issues that are “a difference from what would be considered the norm.”

Prior to adopting most of the parents said they thought disability was a physical or medical condition. Through parenting their children these parents have come to expand their definition of disability. Patrick described disability as “how [people] can process things in their mind too,” and Becky, parent of one child adopted from Eastern Europe, said that she now thinks that the “worst disability you can have is having a mental health issue. Or having fetal alcohol spectrum disorder or an auditory processing problem.” Debra, parent of five including two children adopted from Eastern Europe, shared with me that over time she has become more aware of how trauma affects the brain and impacts a person’s ability to function, although she stated she has found there isn’t a

professional word or terminology that adequately described that type of disability. Chris, Debra's husband, shared that trauma-related disability is not understood, defined, or thought of as a disability, and that in our current DSM culture there are categories that are used to "hang stuff on" but that for their daughters, "we didn't have any [categories]."

Differentiating between developmental delays and disabilities. One of the challenges for parents is differentiating between disabilities, developmental delays, or typical behaviors, particularly in adolescence. Eleanor summed up this challenge when she said, "when you're in the intersection of can't and won't, it's hard to know what street you're on."

Melissa, parent to three including two children adopted from Asia, thought her son's disabilities were developmental delays and that he would eventually "catch up" to his peers. Over time she realized his disabilities were more profound than she thought. Jane, parent of one child adopted from Eastern Europe, said it was hard to figure out if FASD, other developmental issues, or adolescence was influencing her daughter's behaviors. Dan, parent of two children adopted from Asia, laughed that he and his wife Amy were pretty clueless about child development, making it more difficult for them to know if their son's behaviors were in the realm of typical development.

Vicky, parent of two children adopted from Latin America, expressed surprise that her daughter "really" had disabilities, not "adoption, attachment stuff." Other parents also discussed "adoption issues" related to attachment or adjustment as separate from disability. Anne, parent of two including one child adopted from Asia, seemed hesitant to talk about or define her daughter's disability. She told me she doesn't consider her daughter to have a disability. She described her daughter's behaviors as being a reaction to family tensions. Although her daughter had been diagnosed with ADHD, depression and anxiety, Anne only considered the ADHD diagnosis to be a disability.

Reframing definition of disability. Parents also pushed back on the negative societal connotation of disability and had redefined disability for themselves. Laura's personal experience with her own mental health disabilities led her to view of disability as not all negative. She said that because she's seen "everyone address it" (referring to finding ways to keep the mental health disability from impacting functioning) that she hasn't seen it as something that "needs to be destructive of your entire life." Grace also talked about this idea of "overcoming." Although she called disability "conditional living," she also stated she learned you can "survive" with a disability and that medication, therapy or a combination of both can help. Grace said she did not accept the "medical model" of disability because it "has such a negative connotation and [is] sort of pejorative" and "tends to put a negative tone on disability." Mary also redefined disability as "working to the best of your abilities to have the quality of life you deserve to have." By stating, "that they deserve to have" Mary indicated her feelings of responsibility to help her children achieve whatever she meant by "quality of life." Mary said she no longer saw disability as a "hindrance" and that she has "seen what can happen when success and disability, those words, are all reframed."

Mama suggested parents "shift" their thinking about their child's disability from negative toward thinking about how "strengths can be strengthened, and weaknesses can be minimized." Mama also suggested that everyone has a disability or some emotional or physical challenge and should "put it in the back of the curtain, let it go. Because we're all human beings, we're all struggling." Melissa credited her Christian faith as instrumental in reframing disability from a negative to a positive, and said, "I think God really used him to get to us."

One of the factors that influenced Melissa's conceptualization of her son's disability was the physical nature of his disability. People recognized and empathized with her in a way that parents of children with hidden disabilities don't experience. Melissa remarked that she wouldn't

want her son to be “normal” because in her view he *is* normal. She said, “would I want him to be a regular eleven year old today? I’m not sure that I would.”

Chris reframed disability on what he, as a parent, needed to do to assist his children’s functioning. He described that even though his daughter is almost an adult, her anxiety and mental health disability make it difficult to “come online.” He critiqued a strictly cognitive approach to behavior management, and said,

If we didn’t understand that she was disabled when she got up this morning...then she would get worse. Whereas we understand that she has something that is disabling her capacity to...get her clothes on, and walk out the door.

Becky learned that mental health and neurological disabilities are as disabling to a person as physical impairments and expressed frustration that the public often believes people with invisible disabilities do not deserve accommodations. “There’s a lot of them out there and we have to learn to deal with it better,” she said. Becky was critical that society limited enforcement for providing accommodations to those assisting people with physical disabilities (like side walk cut-outs, ramps, Braille signage) but not for children and people with invisible disabilities.

Eleanor’s framing of disability was that it was undeserved but unchangeable. Eleanor said,

It’s just how it is, man... [it’s] permanent, that everybody gets dealt a hand, if you’ve got all two’s you just gotta play better than the person who has a couple of aces.

Describing disability as a random set of cards a person is dealt and suggesting if you have a “lousy hand” you have to play better frames disability as an individual’s burden rather than a responsibility for society to provide accommodations or remove barriers to access.

Theme 2: Constructing “normal”

How does a parent construct their child as being “normal?” Parents generally described disability in comparative terms, using words such as “normal,” “typical,” and “peers” as a point of reference against which a disability was thought of as differing. Parents rarely defined what

“normal” or “typical” meant, indicating a potential assumption that these terms are universally shared by society.

Some of the parents commented on how “normal” their child seemed at first look, whether in person or through a referral photograph or video. Parents discussed using these visual mediums as a way to observe and thus provide evidence that the child was healthy and did not have any disabilities. What is striking about the use of videos and photographs is the way they may be used as evidence on a “face-value” level. That is, parents made assessments about the child’s health and wellbeing through limited visual observations and in some cases even made a commitment to adopt a child without having met them in person. Photographic and video referrals are powerful emotional tool and parents described how difficult it was to be objective, believing the child had been chosen for them by the adoption agency. Marie said, “And then we got the video of our first son...You know how they send a picture and a paragraph? I call it the day my water broke.” Melissa stated that once she received the referral photo, “we were not going back once we saw those pictures. It was like, I don’t know what they could have told me that I would have said that’s not the baby for us.” And Eleanor emphasized, “I got this picture with this little name on it, it was love at first sight. And it doesn’t really matter after that.”

Mama said that adoption agencies send videotapes of children to prospective adoptive parents to reassure parents that the child does not have any disabilities. In the video Mama and her husband Leon received, she observed the child in physical activities, showing a child who appeared to be free of physical and visible health problems or disabilities. The videos are limited because the assessment is visual and the videos may not reveal any internal or invisible health or disability concerns. In addition, parents cannot know if the videos are staged in order to show only the most positive behaviors from the child. Photos of children were shown to others to look for the facial features of Fetal Alcohol Spectrum Disorder (FASD) without knowing that FASD

may be still be present in a child without the characteristic facial features commonly associated with the disorder.

Chris and Debra had the opportunity to interact in person with their twin daughters as they lived in the town where the girls' orphanage was located. Chris and Debra relied on visual observation to assess if the girls had significant disabilities. Chris said his daughters "looked pretty emotionally healthy" and that he and Debra thought the girls were "fairly high functioning." Debra described the girls as "looking really delightful" and described their social and emotional behaviors as "pretty with it." Although Debra and Chris did not define what emotionally healthy or high functioning meant to them it is evident that from what they could see and observe the girls did not appear to show signs of physical, developmental or mental health disability.

Theme 3: Constructing intercountry adoption

The construction of intercountry adoption by adoptive parents was told mostly through the parent's descriptions of why they choose not to adopt domestically. The two major reasons parents chose intercountry adoption was due to fear of the birth parents, and wanting to avoid a "special needs" child associated with foster care.

Fearing the birth parent. Some parents shared with me that they chose against domestic adoption because they feared the birth family would come back for a child or they would be required to have an open adoption. Patrick, Becky, Jane, Anne, Mama, Dan and Grace worried about a birth parent "changing their mind." Several of the parents brought up the case of Baby Richard (Nolan, 2004), though not by the case name. In the Baby Richard case, the child had been placed for adoption by his birth mother without the birth father's knowledge. Two weeks after the child was placed with the prospective adoptive family the father petitioned to stay the adoption. During the four years the case was ongoing, including to the Illinois Supreme Court, the adoptive parents had custody of the child. Media covered the court's decision to award custody to

the biological father and the scene of the child crying as he is transferred to his biological father. The parents described this case as “the birth father came out of the woodwork,” and “taking the child away from the only family he knew,” revealing they did not know the details of the case other than to empathize with the adoptive parents for what they thought was a wrong court decision.

Dan and Melissa worried about being required to have an open adoption if they adopted domestically, highlighting the construction of adoption as having only one set of parents, and that raising a child through adoption is not shared parenting.

Fearing a special needs child. The other reason parents decided against adopting domestically was to avoid the risk of adopting a child with “special needs” through the foster care system. Lily and Sarah talk about not being “equipped” to deal with a “special needs” child.

Vicky said,

I did toy with domestic adoption and I felt a little guilty that I didn't do domestic but frankly I was hoping, I was thinking that internationally the kids would be healthier and they wouldn't have the socio- problems, the problems that are here with drug use, alcohol.

Vicky adopted one child and decided to adopt again. The second time when she received the referral for her second daughter she was upset to learn about this child's social history. Vicky said,

The referral says this poor kid has been in orphanages since she was two months old, her mother doesn't parent any of the other children, there's three total. She dedicates herself to drugs and alcohol. Her dad died in a street fight. So, I'm like, this is what I was hoping to avoid. This was the U.S. scenario that I was going to, that I would get.

Negative case. With the exception of one family all of the families expressed a desire to adopt through intercountry adoption in order to avoid birth parents or the likelihood of adopting a special needs child if adopting through the foster care system. Janet, however, represented a

negative case. Janet adopted her three African-born children in unusual circumstances. Her oldest son Adam was first her foster child through an international medical foster care program. After Adam's medical condition had been medically treated Janet and her husband expressed interest in adopting him, but due to immigration issues, Adam was forced to return to his home country. He then disappeared and several years later showed up at a humanitarian service organization. At that time, now 16 years old, Adam was declared legally free for adoption. Parents cannot typically adopt an identified child but as his former foster parent and with a current approved home study, Janet was granted permission to adopt Adam without going through the typical process.

Janet's two daughters came to her as re-homing situations. Janet and her husband had been providing respite for Becky one weekend when Becky's adoptive parents called Janet and told her that they would not be coming to pick up their daughter from respite. Janet's daughter Carrie had had two previous adoptive parents; Janet and her husband decided to obtain legal guardianship instead of adopting Carrie because Carrie did not want to be adopted again. With both daughters, Janet felt fully informed in choosing to adopt children with known disabilities.

Category 2: Making choices

Parent's constructions of adoption, disability, and parenting led them to make choices about adopting their child and parenting their child. I found four themes about choices emerged including, 1) choosing to adopt, 2) choosing services, 3) choosing out of home placement, and 4) choosing whether or not to dissolve the adoption.

Theme 1: Choosing to adopt

Wanting a healthy child. When parents expect the arrival of a child in a family, whether the child is entering the family through birth or through adoption, good health is a common desire. Expectant parents often declare, "It doesn't matter if it's a boy or girl, as long as it's

healthy.” Adoptive parents also typically desire a healthy child to adopt and the parents in this study, with a couple of exceptions, represented that viewpoint.

The parents in this study talked in terms of “wanting a healthy baby” as Lily and her husband said to their adoption worker, or that they did not want a “special needs” child. The choice to adopt through intercountry adoption was, for Chris and Debra, Lily, Becky, Eleanor, Vicky and Mama, an explicit attempt to avoid what they thought was a higher risk of adopting a child with a disability through the U.S. foster care system. Lily, Vicky and Sarah all mentioned specifically feeling they were not “equipped” to do a “special needs” adoption, indicating their sense that parenting a child with a disability would require resources or skills that they did not feel they could provide. “I did toy with domestic adoption and I felt a little guilty that I didn’t do domestic,” Vicky said, referring to adopting from foster care, “but frankly I was hoping, I was thinking that internationally the kids would be healthier and they wouldn’t have the socio-problems, the problems that are here with drug use, alcohol.”

Discussing risk of disability with adoption agency. Throughout the adoption process there are several opportunities for adoption agencies to discuss disabilities or risk of disabilities with prospective adoptive parents. Prospective adoptive parents typically attend an information meeting, pre-adoption trainings and work closely with a home study worker. One of my questions was about the conversations the parent had with the adoption agency around the risk that a child they adopt might have a disability.

Adoption agencies varied widely in their pre-adoption process according to the parents’ recollections. A few parents in the study used large, nationally recognized and voluntarily accredited agencies but others chose small, “mom and pop” agencies. “Mom and Pop” agencies typically have a couple of employees and are often founded by an adoptive parent who decides to facilitate adoptions after their own adoption experience. Chris and Debra used a “mom and pop” agency and their pre-adoption training consisted of being asked to read articles. Discussions

around disability consisted of the adoption agency founder raising some concerns about adopting an older child, and that the older the child might be, the more likely they would have some “issues” although they never defined what those issues were or might be. Chris describes this conversation as being “warned” and was then left to make their decision without any further discussion. Chris and Debra had raised three grown children and thought they were skilled parents. Mary was also told that any child over two years old was going to have “special needs” just by definition as a result of having lived in an orphanage but felt the agency never clarified if the special needs were about the age (as is often the case when talking about children in foster care), the child’s institutionalized history or potential multiple placements, or trauma. Mary said that the adoption agency never defined “special needs” and told me, “special needs” and disabilities are “just not put into the prospective adoptive parent’s vocabulary” and “they don’t get used with international adoption.”

When Melissa and her husband began the process of adopting their second child, the agency was well aware of the significant levels of disability that her first child had. Therefore the conversation about the risk of disability was quite different the second time around. Melissa said that this time the worker was “very intentional with us” and told the couple that it wouldn’t be “fair” to them to have another child with a disability. Melissa wished this discussion about disability had occurred with their first adoption. Additionally, during the second adoption process the social worker implied the family did not “deserve” to have two children with disabilities. The use of the word “deserve” by the adoption worker suggests a framework that a child’s disability is seen as a punishment for the parent, and reinforces a narrative of a child being a burden.

Patrick and Marie said the conversation around disabilities and risk of disability was generalized broadly enough to have little impact. He described the conversation as

...the boilerplate kind of warning that is meant for everyone. That “these could have blah blah blah blah.” Could have problems...You know, “may have adoption issues.” You

know, and sometimes you think “oh, adoption issues” and when they’re older they’ll wonder, “Who’s my mom, really?” and stuff like that, not anything life threatening. At least, in our ideas.

Many parents including Jane, Vicky, Anne, Mama and Grace were emphatic that their adoption agency did not bring up disabilities at all. Eleanor stated the discussion was “next to none” except for a mention of cerebral palsy and incest, the latter she considered out of place as she thought the other risks were more likely to occur. Mama said,

They did not educate us at all. No shape or form whatsoever. No education whatsoever. Absolutely nothing. They were more interested in our surroundings, our lifestyle, where we lived, who we were as parents – were we financially stable, were we emotionally stable – but as far as educating us on the possibility of disabilities once we adopted a child there was no conversation.

Sarah, parent of two older children adopted from Africa, said her adoption agency did not discuss the risks of adopting older children with her and her partner. Sarah said she was incredibly naïve to not consider the risks of adopting older children but that it was also the responsibility of the adoption agency to have these conversations with prospective parents.

Dan thought the adoption agencies could have done a better job with educating parents on the consequences of what he called “adopting an open question,” which highlights the limitation that medical and social reports cannot reveal much about a child. Dan also said that given he is of “at least average intelligence” and was naïve about these risks it is likely other families would not understand the risks involved on their own. All he recalls hearing about from the adoption agency was reactive attachment disorder.

Negative case. Laura was the only parent to praise the discussion of disability by the adoption agency. She recalled the trainers at their first orientation and general meetings discussed the risk of a child having disabilities and that the other parents attending these sessions were upset and accused the trainers of being negative. Laura remembered thinking that the social workers

were being honest. She also said that her social worker gave them extra readings and suggested books and articles to read, although attachment disorder was the main focus.

Completing the “willing to consider” forms. One of the many assessment tools that adoption agencies use is a form that prospective adoptive parents complete. The form, typically called a “matching” tool, lists child characteristics including physical, health and behavioral characteristics (i.e. cerebral palsy, cleft lip/palate, Down’s Syndrome, premature birth, HIV-positive, depression, anxiety, lying, stealing, sexualized behaviors) with two or three columns where parents can indicate a) they have the skills or are able to parent a child with these characteristics, b) they are not willing to consider these, or 3) maybe/willing to consider (see Figures 7 and 8).

The purpose of these tools is twofold; first, to help the adoption workers process with prospective adoptive parents the parent’s capacity to parent children with the listed characteristics, and second, to assist in matching a child to parents that have the capacity to parent them (Hannah & McRoy, 2011). As a tool grounded in the concept of helping to find families for children, adoption workers may not be aware of the mismatch between how the parents see these forms and the agency’s intended purpose. While the examples below in Figures 7 and 8 from Illinois and Ohio may not be the actual forms that the parents in this study completed, they offer a visual representation of the types caregiver matching forms adoption agencies might use.

Discussion about the forms came from the parents and as often happens in the emerging process of qualitative inquiry, the data regarding these forms were so compelling that I began to ask all of the parents about whether they completed a checklist if they did not mention it on their own. The data showed a disconnect between the purpose of the checklist from the adoption agency’s perspective and that of the adoptive parents. Adoption agencies use these forms or checklists to match children’s needs to prospective parents that have the capacity to meet those needs. Agency workers working with the parents in this study did not use these tools as a way to

prepare and discuss the characteristics of children in need of adoption. Rather, adoptive parents view the checklist almost as an “order form” or a way to request the type of child they desire.

Figure 7. Section of child/caregiving matching tool from Illinois

Requires injections	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Requires 24-hour/day monitoring	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Diagnosed with Fetal Alcohol Syndrome/Effects (FAS/FAE/FAD)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Needs speech therapy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Needs sensory integration therapy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Limited lifespan	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
MEDICAL ISSUES - Cont.	Yes, have the skills	Would consider	No, do not want to	Comments
Requires personal care attendant/nurse	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Needs occupational therapy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Needs physical therapy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Has hearing aid	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Deaf (needs signing)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Needs corrective lenses	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Blind (needs Braille)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Severe facial scars/body deformities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Has braces to walk	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Has prosthesis	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Uses wheelchair	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Uses oxygen tank	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Feeding tubes/technologically depend.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Has cerebral palsy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Has sickle cell anemia	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Other (specify)				
CAN YOU PARENT A CHILD WITH THESE BEHAVIORAL ISSUES?				
	Yes, have the skills	Would consider	No, do not want to	Comments
Antisocial Behaviors:				
Steals	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Lies	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Swears	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Selfish	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Runs away	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Tantrums/rages	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Jealous	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Argumentative	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Disrespectful	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Disobedient	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Sets fires	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Harms animals	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Passive/resistant	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Abusive	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Attention seeking	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Oppositional/defiant	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Loud, noisy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	

Figure 8. Section of child characteristic checklist from Ohio

	Will consider	Will not consider
Behaviors and Characteristics		
Head banging	<input type="checkbox"/>	<input type="checkbox"/>
Rocking	<input type="checkbox"/>	<input type="checkbox"/>
Tendency to reject father figures	<input type="checkbox"/>	<input type="checkbox"/>
Tendency to reject mother figures	<input type="checkbox"/>	<input type="checkbox"/>
Follows adult directions	<input type="checkbox"/>	<input type="checkbox"/>
Tends to form superficial relationships	<input type="checkbox"/>	<input type="checkbox"/>
Difficulty in attaching	<input type="checkbox"/>	<input type="checkbox"/>
Not affectionate	<input type="checkbox"/>	<input type="checkbox"/>
Fearful	<input type="checkbox"/>	<input type="checkbox"/>
Overly dependent	<input type="checkbox"/>	<input type="checkbox"/>
Manipulative	<input type="checkbox"/>	<input type="checkbox"/>
Stubborn	<input type="checkbox"/>	<input type="checkbox"/>
Defiant	<input type="checkbox"/>	<input type="checkbox"/>
Difficulty making friends and relating with other children	<input type="checkbox"/>	<input type="checkbox"/>
Wets during the day	<input type="checkbox"/>	<input type="checkbox"/>
Soils him/herself during the day	<input type="checkbox"/>	<input type="checkbox"/>
Temper Tantrums: Mild	<input type="checkbox"/>	<input type="checkbox"/>
Temper Tantrums: Moderate	<input type="checkbox"/>	<input type="checkbox"/>
Temper Tantrums: Severe	<input type="checkbox"/>	<input type="checkbox"/>
Poor social skills	<input type="checkbox"/>	<input type="checkbox"/>
Child can be disruptive in social settings	<input type="checkbox"/>	<input type="checkbox"/>
Difficulty accepting and obeying rules	<input type="checkbox"/>	<input type="checkbox"/>
Masturbation: Occasionally	<input type="checkbox"/>	<input type="checkbox"/>
Masturbation: Frequently	<input type="checkbox"/>	<input type="checkbox"/>
Masturbation: Past	<input type="checkbox"/>	<input type="checkbox"/>
Masturbation: Private	<input type="checkbox"/>	<input type="checkbox"/>
Masturbation: Public	<input type="checkbox"/>	<input type="checkbox"/>
Biting	<input type="checkbox"/>	<input type="checkbox"/>
Lying	<input type="checkbox"/>	<input type="checkbox"/>
Stealing	<input type="checkbox"/>	<input type="checkbox"/>
Frequently starts physical fights with other children	<input type="checkbox"/>	<input type="checkbox"/>
Physically aggressive toward other children	<input type="checkbox"/>	<input type="checkbox"/>
Physically aggressive toward adults	<input type="checkbox"/>	<input type="checkbox"/>
Gang Involvement (past)	<input type="checkbox"/>	<input type="checkbox"/>
Gang Involvement (present)	<input type="checkbox"/>	<input type="checkbox"/>
Self-abusive, self-harming	<input type="checkbox"/>	<input type="checkbox"/>
Suicidal thoughts or attempts	<input type="checkbox"/>	<input type="checkbox"/>
Poor anger management	<input type="checkbox"/>	<input type="checkbox"/>
Substance Use and Abuse		
Smokes cigarettes	<input type="checkbox"/>	<input type="checkbox"/>
Chews tobacco	<input type="checkbox"/>	<input type="checkbox"/>
Alcohol use	<input type="checkbox"/>	<input type="checkbox"/>
Alcohol abuse	<input type="checkbox"/>	<input type="checkbox"/>
Marijuana	<input type="checkbox"/>	<input type="checkbox"/>
Other substance abuse	<input type="checkbox"/>	<input type="checkbox"/>
Requires or has completed treatment program for substance abuse	<input type="checkbox"/>	<input type="checkbox"/>

	Will consider	Will not consider
Other Behaviors (continued)		
Uses foul language	<input type="checkbox"/>	<input type="checkbox"/>
Child involved in group or activity that physically sets itself apart from the mainstream and focuses on negative or deviant themes	<input type="checkbox"/>	<input type="checkbox"/>
Child obsessed with guns, knives, explosives, or other destructive devices or themes	<input type="checkbox"/>	<input type="checkbox"/>
Currently plays with matches/lighters	<input type="checkbox"/>	<input type="checkbox"/>
Fire setting	<input type="checkbox"/>	<input type="checkbox"/>
Sexual Behavior		
Sexually active	<input type="checkbox"/>	<input type="checkbox"/>
Seductive	<input type="checkbox"/>	<input type="checkbox"/>
History of inappropriate sexual behavior	<input type="checkbox"/>	<input type="checkbox"/>
Child involved in prostitution	<input type="checkbox"/>	<input type="checkbox"/>
Known sexual perpetrator	<input type="checkbox"/>	<input type="checkbox"/>
Sexual offender (juvenile adjudication)	<input type="checkbox"/>	<input type="checkbox"/>
Sexual perpetrator who has successfully completed treatment	<input type="checkbox"/>	<input type="checkbox"/>
Child at risk for offending sexual behaviors	<input type="checkbox"/>	<input type="checkbox"/>
Child has initiated sexual behavior toward other children or adults	<input type="checkbox"/>	<input type="checkbox"/>
Sexually acting out behavior (may include frequent masturbation, exposing or frequent touching of genitals, etc.)	<input type="checkbox"/>	<input type="checkbox"/>
Child has an alternative sexual orientation (may include homosexual, bisexual or transgender lifestyles)	<input type="checkbox"/>	<input type="checkbox"/>
Juvenile Court Involvement		
Unruly adjudication	<input type="checkbox"/>	<input type="checkbox"/>
Theft: Past conviction or current charges	<input type="checkbox"/>	<input type="checkbox"/>
Breaking curfew: Past conviction or current charges	<input type="checkbox"/>	<input type="checkbox"/>
Domestic violence: Past conviction or current charges	<input type="checkbox"/>	<input type="checkbox"/>
Cruelty to animals: Past conviction or current charges	<input type="checkbox"/>	<input type="checkbox"/>
Crime using a weapon: Past conviction or current charges	<input type="checkbox"/>	<input type="checkbox"/>
Other delinquency adjudication(s)	<input type="checkbox"/>	<input type="checkbox"/>
Previously incarcerated	<input type="checkbox"/>	<input type="checkbox"/>
Currently incarcerated	<input type="checkbox"/>	<input type="checkbox"/>
Registered sex offender	<input type="checkbox"/>	<input type="checkbox"/>
Court order for restitution	<input type="checkbox"/>	<input type="checkbox"/>
Court order for child support	<input type="checkbox"/>	<input type="checkbox"/>
Child is on probation	<input type="checkbox"/>	<input type="checkbox"/>
Child is on parole	<input type="checkbox"/>	<input type="checkbox"/>
Child has participated in Court diversion program(s)	<input type="checkbox"/>	<input type="checkbox"/>
Child has had serious on-going involvement with Juvenile Court for delinquent or	<input type="checkbox"/>	<input type="checkbox"/>

A popular saying among adoption professionals is that adoption is a means of finding families for children, not children for families. Thus while the caregiver matching tool, or checklist, is intended to be an assessment used to find families for children, the adoptive parents see it as a tool to find children for families.

Eleanor said adoptive parents thought if they checked that they did not want to adopt a

child with a disability that that they wouldn't get a child with a disability. I found it interesting that several parents laughed or said (like Melissa) that it was a joke on them, or joked about how they took the time to complete this form and still ended up with a child that was nothing like what they had indicated on the form. Melissa's statement was similar to what other parents referenced when she said, "the joke was on us, what did we know? We never would have chosen somebody like [our son]." Other parents laughed after talking about completing their form. Lily recalled completing a form where she and her husband could choose which types of children's issues they were able to accept and she told me, laughing, that they chose only "a healthy baby."

Anne said that she and her husband completed the form and when asked to describe the conversations she had with the adoption agency worker about those forms, her response was that the conversations were around substance abuse issues. Anne said she was asked if she was comfortable with a birth mother or a birth father having substance abuse issues, but the risk of a child having FASD was not mentioned. Grace recalls completing the form but doesn't remember what she checked as acceptable, other than that she thinks she must have stated she was okay with prematurity since her son was premature and low birth weight. She said she recalled that there were some "extreme things" they did not check but couldn't remember what those were. Sarah said she checked that she would accept anxiety and depression but none of the more significant mental health or behavioral characteristics.

Two parents, Vicky and Melissa, described completing these forms in more detail. Vicky was asked by the adoption agency to re-do the form, since the agency felt she had been too restrictive in her choices and caused the delay in being matched. Vicky agreed to expand her consideration to children with medical disabilities but remained clear that she was not open to a child with mental health or psychological problems since as a single parent of one child she did not think she would have the financial or supportive resources needed to parent a second child with mental health disabilities. Melissa described how the social worker helped parse out what

she should fill out on the form that would not make them seem too restrictive but that would have the highest chance of leading to a child that would not have a disability. Dan was the only parent who talked about feeling conflicted about completing the form.

They [the forms] forced me to come up against the disconnect between who I wanted myself to be and the kind of attitude I wanted to be which was loving, embracing, we'll take any kind of child and the reality that when it came time to commit to it I wasn't nearly as open and generous and loving and open-hearted as I would like to have thought of myself as.

Having stars in my eyes. A challenge for parents is to take in the information about the risk that a child might have a disability and actually be prepared for that reality to manifest. Parents shared that they were so intent on adopting that as Grace said, they had "stars in my eyes" and did not believe it would happen to them. Grace said,

I think even if there would have been [information about risk of disability] at that stage I don't think we would have retained it very well just because I think we were pretty intent on adopting.

Melissa made a similar comment. "Even if they had told us exactly what we were in for – I don't know," she said. "But it's good that you don't know what you're getting in for probably [laughs]." "I wanted to be a mother so badly, and also innocent I suppose, and ignorant – combination of those things," said Laura. Grace said,

"I think that there's a denial in the agencies, that or an ignorance. And I don't mean that in a judgmental sense but they don't approach, I mean their whole focus is getting what they call "forever families" and that can kind of, I don't know, I keep using this metaphor "stars in your eyes" – it's like a rose colored glasses. I think people at that point in time don't want to address any of the potential difficulties that might come up...I guess I'm trying to say I was in such a mind set that I wanted a child so bad I'm not sure I would have heard them."

Eleanor addressed the difficulty of making parents understand the risks.

I don't know how you get really hopeful people to really hear what's being said, other than to say it a lot. Everyone [at the adoption agency training] is thinking, "It's not going to be my kid." But the odds that it is, is much greater than that it's not.

Theme 2: Choosing services

Considering the developing symptoms and/or behaviors. Another theme that emerged from the parent's stories was the development of symptoms of behaviors that led parents to consider that the child may have a disability. For parents who adopted infants, developmental delays were the first sign that their child might be developing a disability. Many of the parents talk about early developmental delays or hiccups or as Laura described it, "leapfrogging" developmentally. This focus on developmental delays is significant because most of the literature on intercountry adoption frames developmental issues as delays, not disabilities and that the adoptive home provides the foundation for developmental catch-up. This focus on developmental catch-up may mask what could be developmental disabilities.

Melissa, Eleanor and Jane all adopted children who were both premature and low birth weight. Melissa son Ryan experienced delays in walking, talking, and behaviors, and she described him as slower to mature. She also described many health and medical issues that have becomes more of the focus as he ages. There were behavioral issues as well, but for Melissa and her husband their attention focused the physical and health disabilities and they seem to have accepted the behavioral issues as a byproduct of the physical disabilities. Eleanor considered the prematurity, as well as the adjustment to a new culture, when taking into account her daughter's development and expected it to take longer to reach developmental milestones. Jane enrolled her daughter in early intervention programs but also noted that all of her daughter's developmental milestones were late. Laura's son was adopted at 16 months and was considered failure to thrive; he seemed to be progressing well developmentally although there were definitely some delays. At

about four years old she noticed changes in development and it was then that he was assessed for disabilities.

Lily described her son as dysregulated as an infant in his eating and sleeping. Grace recalls that her son always seemed to have some “difficulties” that she describes as looking like anxiety. Mama said, “all along we knew something wasn’t quite right.” She described her daughter as having poor coordination and difficulty with reading. Amy and Dan identified their son’s constant need to be held as an early sign of developmental problems but attributed this as shock at being adopted into a new language and culture. They also noted delays in language as well as extreme temper tantrums.

Social functioning and behavioral issues were common symptoms described by parents. Becky and Laura discussed their child’s hyperactivity. Tantrums and “rages” were another symptom parents described as signaling something deeper. Patrick and Marie’s son Jerry had “rages” that Marie described as “every single day, I’m talking hour upon hour upon hour, and he would lose his voice.” Dan and Amy’s son had temper tantrums lasting 20-40 minutes, up to eight times a day. Vicky, Patrick and Marie described their child’s behaviors as “oppositional.” They, along with Lily, stated that their children never seemed to “grow out of” their behaviors. Tantrums turned into violence and aggression as the children aged. Lily’s son Eddie became aggressive when he was young and became worse as he got older. Eleanor said her daughter “has been violent since she was eleven months old.” Laura said her son Dennis had been having behavior issues before they adopted their second son but afterward, the behaviors became violent. Vicky’s daughter seemed to do okay at school but at home she was “oppositional and raging.” Sarah’s 12-year old daughter had violent tantrums. Sarah said she was “having major, major, severe temper tantrums at home, and wrecking places and biting us...” Debra and Chris’s daughter was also violent. Debra said the first year after finalizing the adoption was one of being “beaten up and having lemonade poured over your heads and our furniture and dishes trashed and

police at our house over fourteen times” including one incident when “she really assaulted me and it took two police men to pull her off of me.” Patrick and Marie’s second son exhibited aggressive behaviors toward his brother and parents soon after his adoption was finalized.

By the time school began many of the parents realized the significance of the child’s behaviors and began the process of seeking assessments and services. Dan said that for his son, fourth grade was a “disaster...His behaviors were so disruptive... As the year went on he kept getting pulled out of school.” Vicky’s daughter really struggled in fourth grade as well. “She was out of control,” Vicky said. “Running out of school...you know, hitting teachers.” Laura’s son had a teacher that seemed to dislike him because of his disruptive behaviors and as a result she thought Dennis gave up on trying to manage his behaviors at school. Laura shared that the teacher told her “he’s the worst kid I’ve ever seen” in front of her son and after that, Dennis started to act out even more. By kindergarten he was telling other kids that he was going to shoot and kill them, was running away from school and physically aggressive to peers and teachers. Lily said that when her son Eddie was in elementary school he suffered from severe anxiety that caused him to miss a lot of school. He wasn’t acting out at school but was having school phobia.

Managing safety. A major concern for the families was safety: safety for their child, for themselves, and for the other members of the family. Janet said hospitalizations or calls to the police were related to safety, when the child “becomes so explosive or either self-harming or harming others, we don’t really have a choice.” Violence was a major theme that cut across many of the families. When children were younger the violence was more controllable. Lily said, “He was aggressive at home starting at a pretty young age. As he got bigger...it got harder to handle.” Dan also talked about the difficulty of managing his son’s violence as he aged.

He was always a little peanut. We just began to think he’d always be a little guy...so he would lose control multiple times a day and I was always able to contain him and I would contain him until he calmed. And he was, as violent as he could be, but he was just a little guy. So he’d bite me, he would hit me and stuff, but I had a lot of practice of how I could

protect myself. And then he started getting bigger. He started growing, he hit puberty and it became more and more difficult for me to control him.

Marie's son threw things and broke walls. In addition to their concerns about their son's safety, Patrick and Marie worried that their son's behavior would harm others. In their contentious relationship with their local county child welfare agency seeking services for their son Jerry, Patrick said one incident made them realize that they and the county had very different beliefs about Jerry's capacity for violence. "At that point it's like, this county has absolutely no concern for our safety," said Patrick. "And that for me was my tipping point." Marie added that the social workers at the county didn't seem to think their son's violent behavior was a concern to other children, and that he was more of a safety risk to himself.

Some parents were concerned about their child's safety from others because their cognitive disabilities made them incredibly vulnerable to potential victimization. Mama's daughter Nicole was vulnerable to predatory men who contacted her through the Internet. Even with phone and Internet monitoring, Mama was unable to prevent her daughter from bringing unknown men into their home for sex. Jane was also so concerned about her daughter's vulnerability that she had her daughter get an IUD so she wouldn't become pregnant. Jane told me, "She's a victim waiting to happen." Vicky also was very concerned about her daughter's vulnerability with men. She shared that her daughter brought unknown males to the house for sex while Vicky worked evenings. "I could sometimes just go to the grocery store for 45 minutes and I'd be back and there'd be a guy here," said Vicky. Sometimes her daughter would leave the house alone late at night in order to meet up with men she had connected with over the Internet.

Dan and Amy's son was so violent and self-injurious that they worried he would hurt himself during his tantrums and aggressive outbursts. "When he would have these tantrums there was no concern about his physical wellbeing," said Dan. "He would throw himself back and whether he hit a wall, whether he was by a stairs...he would be on a sidewalk, maybe holding

some chalk, he would get frustrated, he would start hitting his head on the sidewalk and have little stones in his head.”

The level of violence was a major challenge for parents. Lily said, “I’d never seen a child like this. I never knew children punched holes in walls, bit holes, or hit their parents.” Chris said, “We had all the stuff, the knives, the threatening to kill, running away.” Added Debra, “beating us up, trashing the house...” For most of these children, the violence came when they were angry and feeling out of control. Laura said about her son John, “he’s very destructive when angry, and I think ultimately that destructiveness might be what may make me bring him to the hospital.” Sarah’s daughter was destructive and would bite her parents. Jane listed her daughter’s violent behaviors: kicking holes in the walls, hitting the dog, spitting, swearing and biting. “She bit my shoulder,” Jane said. “My hand is all scabbed up and I’m black and blue on my face.” Jane said she is far from alone in being assaulted from their child, and that parents of children with FASD often live with such violence.

I don’t know many people that have a child with FASD that don’t experience what I’m experiencing. Most people, the violence started much earlier. I know people who have broken arms and legs from their kids, starting when they’re five or six, they’re kicking holes in the wall.

Janet knew that the risk of her child being violent was likely; in their earlier fostering of this child, he had been violent, but he had also been younger and smaller. After they adopted him several years later, Janet said, “The risk of violence likely went up. I was bringing back a kid who had been through hell, and it didn’t take long, for the violence to start up again.” Chris also described understanding the trauma underlying the violence. He and Debra viewed their daughter’s behaviors as a result of developmental trauma. Vicky said she understood why she became the main target of her daughter’s violence. “You know, when she hits me, people will

say, well that's because you're the person she feels safest with. And it's kind of a back-handed compliment," she said laughing, "but that's true, you know."

When parents became afraid for their safety they often needed to call the police. In some cases, involving the police backfired from what they intended, particularly if the police recommend placing the child in juvenile detention against the parent's wishes. Sometimes the police do not understand the family's unique needs. For Debra and Chris, calling the police was intended to provide some safety and additional help in de-escalating the violence. However, Debra said that after 14 calls to the police, the police department told them the department would stop responding because Chris and Debra would not press charges. When Eleanor called the police she was questioned how her daughter, who is very small for her age, could have been the aggressor. "The cops come, and it's like, okay, she's half my size," said Eleanor. "But if she'd been my husband and twice my size...I mean really, you'd be taking it seriously. But she looks like this little kid half my size; doesn't mean the violence isn't real."

Given the level of violence of the children, was it possible that some parents feared they might respond by harming their child? Only a couple of parents talked about parental violence. Since the consent form I provided parents stated that I had to report any knowledge of child abuse as a mandated reporter parents may have chosen to stay silent about this topic, even if in a hypothetical context. Sarah was one of the two who voiced that there was a concern over the potential for abuse. Sarah told me,

Some of the stuff going on in the home I thought, should I be just reporting this to child welfare? Cause I was scared, really, those kids; one of them was going to hurt us seriously or we were going to hurt one of them. It got to that level of aggression and violence in the house.

Becky shared a couple of thoughts regarding parental aggression. First, she shared that the international adoption expert her family consulted told her that he knew of more than two dozen adoptive parents who had harmed their child in response to the child's behaviors and

aggression. Becky mentioned that she could understand how parents could get to that point. She said,

The thing that I'm surprised by is I thought I'd come in and be calm and be able to handle it, use time-outs, be able to remove myself from the situation – but these kids push buttons you never knew you had. And you do – you scream, punch a pillow, you punch a wall, you really want to punch your child. I hate to say that but to be real, it brings you to the point where you feel you've totally lost control. I think that's the most surprising.

This kind of candor was pretty exceptional, and Becky almost seemed relieved to be able to share this with me in the hope it would help other parents feel understood. Becky's comments reveal a fear that parents might have of not being able to control their child or the situation.

Choosing assessments. Eventually the parents in this study asked for or received assessments for their child. The assessment process involves a lot of appointments and testing. Some of the parents found the assessments helpful and others did not. Also, parents described a range of feelings about the assessors. The process of getting an assessment for a child is a task that can be confusing and difficult for many parents. Choosing the type of assessment and where the assessment will be conducted can be overwhelming. Options include having the child assessed through the schools for an IEP, a medical doctor (including a pediatrician) specialist, or a mental health professional. Some of the parents learned about or were aware of specialty international adoption clinics and were often said by them to be incredibly helpful to the family. Other parents did not choose how and where the child was assessed because the assessment followed a crisis hospitalization. Anne's daughter was assessed at an institution in a neighboring state where she ended up being admitted for treatment.

Some parents were able to get assessments completed or referred from private therapists. For Lily and her husband, calling the adoption agency led to a referral for a therapist in turn was able to help guide the family toward neuropsychological testing and that was helpful. Lily said the family would not have known about neuropsychological testing which she found helpful.

Vicky also took her daughter in for an initial psychoeducational assessment through a private practitioner for some selected tests including an IQ test, although Vicky said it was not a “battery” of testing. Patrick and Marie took their child to a private practitioner for an assessment but felt the practitioner was uninformed about adoption and attachment diagnoses.

Eleanor, Dan and Amy had their child assessed through the school system. Eleanor worked in a school system and had her daughter assessed through her district. The assessment results confirmed her daughter had disabilities, but the school refused to provide accommodations. Eleanor said “she met the technical criteria and they’re like, oh no. Cause she sits so nicely in class. Yeah, she’s sitting there nicely and she has no idea what’s going on.” Eleanor’s response to the school was, “ok, you just said she doesn’t have a learning disability so now you’ve got to teach her.”

Some parents sought out assessments at specialized clinics. Chris and Debra took their daughters to a well-known attachment agency in their area and went through a series of assessments and treatment. Laura, Vicky and Sarah consulted specialized, intercountry adoption clinics. Becky had her son assessed by a specialized well-known, but controversial, adoption specialist. Jane went to her pediatrician the day after they arrived back in the U.S. after finalizing the adoption for an assessment. The pediatrician was confident her daughter would catch up. However, Jane thought the developmental issues were more significant than what the pediatrician thought and had her daughter assessed by four different neurologists and several other medical specialists. Mama’s daughter underwent several assessments as well, by physicians and medical specialists.

Considering diagnosis. Once assessments are completed, the next hurdle for parents is to figure out what the diagnoses mean. A commonality among the parents in the study was that diagnosing children with complex needs and issues was difficult and over time their children were given many diagnoses that changed or were incorrect or inappropriate. Jane, a professional

psychologist, said there are “diagnosis du jour,” or trends, in diagnosing adopted children. “I think [attachment disorder is] such a – it’s like ADHD used to be, and Bipolar I used to be,” she said, laughing.

Another frustration mentioned by parents was that the diagnosis did not seem to fit their child. Eleanor said her daughter Mary “doesn’t really fit the criteria for pretty much anything. Like if it takes five check marks, she has four – in a whole lot of columns.” In addition Mary’s age at her last assessment “really restricts what you call stuff.” Laura had comments about this as well; she noticed that on one referral for assessment the psychiatrist had written that her son had bipolar disorder. Laura laughed, saying

But that’s not anything she’s ever said to us, it still says Mood Disorder NOS, like, everywhere. And I think it’s maybe just a hesitancy to give that diagnosis since he’s so young, but the way she talks about his mental illness, and I would say having seen bipolar, and – it probably fits better than maybe what’s going on and that’s probably the direction they’re headed at this point...I think they kind of want adolescence to happen to see if it’s really true, And I agree. I kind of think you don’t want to – and the labels, you’ll label him in the end anyway, but as long as you’re trying to do something to help it.

Mary said her son has been diagnosed with so many things she can’t remember them all and “everyone who examines him shakes their head and says, “he’s just a puzzle” trying to figure out the complicated child he is.” Laura said,

His special needs don’t fit a lot of the [diagnoses] – he can’t be pigeonholed to just the autism or – he’s not fitting into any of the categories which even at the school, his counselor says, “he’s just like this little mystery we don’t even know.

Mama said, of one program her daughter was enrolled in,

All they could ever really [tell] us was there’s something there but we just can’t define it, and we heard this over and over and over again...Out of desperation with psychologists not being able to figure out what is going on, and not being able to give an accurate diagnosis, my daughter’s being referred to a psychiatrist...the psychologist can’t quite put

their finger on it.

For many of the parents part of the issue with goodness of fit regarding diagnoses was that with complex developmental issues on top of trauma it was hard to figure out what was trauma, what was development and what was disability; and that sometimes there may not be a clear, clean diagnosis to, as Chris would say, “hang your coat on.” According to Janet, her daughter’s disabilities are still being figured out. “Cognitively, yes, she has some issues,” she said, “but no one has quite nailed them down yet. I can see them, and I know they’re there...” Debra said her one daughter was diagnosed with ADD because “there weren’t any other things...” Chris added, “I don’t know what the “new” thing is but it seems to make more sense, just in general. But the chronic trauma, like, Chronic Trauma Disorder or something like that?” Chris’ statement shows that new diagnoses, models or explanations are being developed all the time. Chris was likely referring to Developmental Trauma Disorder. Mary said of her son “I did suspect that Mark has [a dissociative disorder] too, it just, he has so many other things on his plate that...but I suspect he has it as well.”

Dan talked about the frustration of going to a therapist who kept changing the diagnosis. He said, “the first [therapist] was almost a joke, like every week I’d take Tim in and she’d have a new diagnosis. She’d go “okay, now I get it.” And, cause there’d be some new behaviors she hadn’t factored in to her original [diagnosis].” Sarah expressed a lot of frustration with the many different diagnoses her son was receiving from the professionals that were assessing him. She said,

We went to six hospitals over a one-year period, with each psychiatrist giving somewhat of a different diagnosis. And different anti-psychotic medication and that I think was the most frustrating for me, in that I had no control over where he went [due to the crisis hospitalization] what the psychiatrist would sort of diagnose and give him. [I] really had to trust that they knew what they were doing but I’m sure that anyone really...working with adolescent psychiatric mental illness, there’s still experimenting quite a bit.

For Sarah's son, a barrier to accurate assessment and diagnosis was the cultural incompetence and language barrier in a city where few clinics provide interpreters for her son. Sarah was told she would have to pay for interpreter services. In the end they diagnosed her son with schizophrenia but according to Sarah, "they just really don't know yet." She also said,

It's been a very, very long journey. A lot of complications because of the language barrier, because of his age, because of cultural differences, and also having so many people with different opinions, both on the medical and education side. It's been extremely frustrating.

Laura said parents receive a lot of conflicting advice making it a challenge for parents to know how to proceed with, or even agree about, a diagnosis. She said,

In one way it would be nice to have a good diagnosis so I'd have a better idea about what I should be doing because what you should be doing for attachment is different from what you should be doing for autism which is different from what you should be doing for bipolar or ODD, so...I think in that way that's frustrating and I feel it's more inconsistent parenting because of that.

Parents also expressed skepticism with the diagnoses that their children received. Grace, a licensed marriage and family therapist, was not impressed with the therapist at the residential treatment center where her son was placed.

The counselor was 27 years old, did not, was not a professional licensed person and kept wanting to label him borderline...I'm like, you complete idiot; he's not borderline!

When Becky had her son assessed by a local clinician, she was told her son had paranoid schizophrenia – though the clinician did not officially give her son that diagnosis, but said that "he's showing signs of that." Becky said, "I'm like, well I'm not going to accept that." Vicky's daughter received a diagnosis of intellectual disability (formerly called mental retardation). Vicky expressed skepticism, saying she didn't think her daughter "looked" like she had an intellectual

disability, perhaps based on the stereotype that intellectual disability as Down syndrome very specific physical features.

Dan and Amy were most impressed with a therapist who “never felt the need to have [a diagnosis]. She always said, I don’t know, he’s a complicated guy; let’s look at the behaviors.”” Chris and Debra also did not put much value in a diagnosis. Chris said, “So is it helpful to have all these diagnoses? Somewhat helpful. It gives us some place to hang some things on.” Referring to some of the therapists they worked with, Amy said, “What they wanted to do is they wanted to give Tim a diagnosis and treat a diagnosis, rather than looking at what his behaviors are and dealing with the behaviors. I mean, I think a lot of parents want diagnoses.” Although Dan and Amy did not place much importance on a diagnosis, some therapists need to submit a diagnosis to the insurance company in order to receive payment. Mama was one of those parents that wanted a diagnosis. Mama said,

I think with FASD it’s so easy to put co-occurring diagnoses. If they don’t know they’ll label it ADHD. And I feel that that is what has occurred and this is before the FASD diagnosis.

When I asked if she thought the diagnosis was accurate, she reflected,

You know, when I really think about it yes. But then, I think, okay – is this just a band-aid over what I want to believe? I guess I was so searching for an answer...I said to her psychologist, “is she borderline personality? Could it be narcissistic behavior? Could it be RAD, adoption issues, what?” She said, “you’re asking me for an answer and I can’t give it to you. It could be all of those things.

Theme 3: Choosing out of home placement

Out of home placements often followed a crisis hospitalization, pressure from police or as a result of advice parents received from professionals. After over 14 calls to the police, Chris and Debra were told the department would no longer respond to calls if they were not going to press charges, have their daughter arrested or placed in juvenile corrections. In addition, the woman

who operated the adoption agency they used in the U.S. for the home study warned them they might eventually need to consider an out of home placement, even going as far as to suggest they consider “sending them back” to their orphanage. Eleanor had similar interactions with the police. After several incidents involving the police and a crisis center, Eleanor was asked by one of the crisis workers if she had or would consider an in-patient program.

For Mary, two influencers ultimately helped shape her choice to place her older son in out of home care. A psychiatrist she trusted warned her she wasn’t going to be able to manage much longer. In addition, staff at the post-adoption support organization and leading the support group she attended encouraged her to consider out of home placement. “They were saying to me, your child needs more help than a couple of weeks at day treatment therapy,” she recalled.

Sometimes the recommendation for out of home care came from hospital clinical staff. Vicky recalls that after her daughter’s second admission to the university hospital for crisis treatment, they told her, “She’s been here twice. She needs to go to residential treatment.” Considering out of home placement for their son was not even on Dan and Amy’s radar until the school intervened. Dan and Amy describe it as a full-on intervention. Dan recalls being told, “You guys are trying to do so much for him, it’s not working. He should go into residential treatment for his sake, for your sake, and for your daughter’s stake.” Dan thought that they needed to handle their son themselves. After the intervention, Dan said, “This broke me, basically. But I mean, it convinced me.”

Theme 4: Choosing to dissolve or commit

Considering dissolution. Some of the parents talked about considering whether they wanted to continue to be their child’s parent. Mary and Sarah both talked about how important resources are to prevent dissolution. Mary said that without the help of the adoptive parent support network she found “we would have disrupted within six months. I could not and they [the children] could not have made this work.” Sarah also said she considered re-homing because “this

just isn't a good set-up, we don't have resources." Debra said that Chris' father had offered to pay to have them sent back to the country from where they had been adopted. Chris and Debra's mentor had also said that they might need to "send them back." Chris said,

We seriously debated about whether we should buy them a ticket back to their birth mother...At that time we didn't understand it. I mean, cognitively did, but – what do you do with these children [laughs]? What do you do with them? I mean they're like, they're like animals.

Patrick said he and Marie began talking about the possibility of dissolving the adoption with a therapist they consulted with after their county agency finally arranged to place their son in residential treatment following a crisis hospitalization. Patrick and Marie also consulted with the director of the specialized ranch where their son was placed after leaving the previous residential treatment center. Marie said the director asked if the family wanted to dissolve the adoption. Marie said,

And we didn't really know at the time, did we? Did we want to disrupt, or did we just need respite? We were still worried about where he's going to end up. We don't want him to not be part of us, yet we can't live with him.

Laura and Sarah questioned if they were the right parent for their child, whether the children would be better off with other parents. In the debates about re-homing this is one of the arguments; adoption workers sometimes defend re-homing by saying it doesn't serve the child to be in a home where he or she is not going to be parented well if the parents are at the point of, or are at risk for, abuse. Laura said,

You ask yourself, geez, maybe another parent would have been better for them...I'm like, probably there's someone else who could be more...or I don't know. And now I think adds to the layers of difficulty parenting and that's one of the harder parts I think.

Sarah said, "In the back of my mind I think, maybe they'd be better off. Maybe there's someone else out there who could handle this a lot better than we can." Sarah was also quite

aware of the 2013 Reuters re-homing investigative report and knew that there had been adoptive parents who had abused, and even killed, their intercountry adopted children. So in considering the idea of re-homing, what kept her back was the worry and fear that a re-homing might put her children at risk for abuse. Sarah said, “You have to deal with the reality of what if they went into a place that was worse? A family that was even less likely to handle their situation? I don’t know.” This highlights that in spite of her exhaustion and stress in parenting these children that she felt a lot of concern for their welfare. She did not say whether she loved these children or if she felt attached to them but her actions and words show that she did not want harm to come to them.

Other parents also talked about knowing that dissolving the adoption would ultimately harm the child. Lily said, “if it weren’t [for our mutual attachment] probably it would have been a disrupted adoption, but we could never do anything that would harm him.” Patrick, who with his wife Marie did dissolve the adoption of their middle son, acknowledged that “it was harmful for our son. And we know that it was harmful and so that’s...well so that is what’s hard about it.”

Sarah said,

They need a more traditional family and he needs someone who can be home with him and we looked into re-homing, we looked into putting them into foster care. We went through all these awful thoughts and at the end of the day neither of us could come to that – there’s no way here in reality, we can’t do this. To them.

Considering commitment. What does it take to commit to a child that has such challenging behaviors? Parents that talked about commitment seemed to express this in different ways. Mama said that one of the biggest surprises that she found regarding parenting her daughter was “that you can love somebody regardless, and never ever give up.” Lily said it was her bonding and attachment to her son, and her feelings that her son was bonded and attached to them, that made it easier for them to commit despite the difficulties. She said, “If we weren’t

[attached to each other] probably it would have been a disrupted adoption.” Lily also mentioned that like her marriage, being Eddie’s parent was something she pledged to do. “Even though we didn’t expect this, it’s kind of like our marriage, we – we’re married forever,” Lily said. “They’re our child forever. No matter what. And so, I think that’s a piece of it.” Jane said she never considered dissolving the adoption. “Despite all I’ve been through with her, that’s never crossed my mind. She’s a keeper!” Like Lily, she referenced marriage but in the opposite way. “It’s kind of like better or worse,” she said, “except you can get divorced. I’m not divorcing her [laughs].”

Parents also expressed the sentiment that they were saving their child from a worse fate and that committing to them meant keeping their child from future harm. Lily said, “he’s ours and I think he knows that and I think that’s helped him. Otherwise I imagine where he’d be, out on the streets probably.” Chris said that he and Debra just decided that they were going to do their best to give their children a chance and try to not dissolve the adoption. Once they made this commitment with each other and to their children, Chris said that it “changed everything.”

Janet talked about how she felt very committed to her children when they are in out-of-home care and that this sometimes is challenged or not believed by professionals. Janet shared that one of her daughters was waiting for a space at a special residential treatment center. “But I mean, it’s not like a forever one,” she said. “We’re very committed to her. It’s a six-month program, and we’ll be there for her when she comes out.” One of Janet’s other adopted children was in residential care and the staff treated her as if she had given up on her child.

It’s interesting how I think there’s an idea that you put your child in out of home placement that you don’t want contact with them any more and we had a real hard time getting past that hurdle; saying, we still want to be the parents, we still care about our child. We may not be able to live at home together but that doesn’t mean I’m out of the picture. Or that we want to be out of the picture.

Category 3: Costs

The third category are the costs that are incurred by families as a result of the choices they

made regarding adopting a child with a disability, choosing services, and the decisions they made related to placing their child in out of home placement. Themes that emerged related to costs include a) financial costs, b) social costs, c) relational costs and d) personal costs.

Theme 1: Financial costs

In addition to the high adoption fees of up to \$30,000 or more per child, other financial costs emerged as a theme. Parents found themselves in financial crises, were forced to cash out retirement savings for out of home placements not covered by insurance, and applied for SSI or county disability services on behalf of their child. Costs also included work related costs such as having to take time off of work or not being able to work in order to deal with service or parenting issues and money and time spent on legal advocacy on behalf of obtaining services for their child.

Monetary costs. Marie, Becky and Vicky mentioned feeling pressured to adopt a child that had been chosen for them because there was no guarantee that they would get another chance to adopt another child and they had spent tens of thousands of dollars. Marie said, “it just makes you feel really uncomfortable because you're in – you've paid this money – you're here. I mean, you're not just going to leave him.” And Vicky recalled asking her adoption worker, “What if I don't accept this referral?” After being told by the adoption agency that there wasn't another child available to adopt, Vicky said, “This is it then. And you know at this point you've put in several thousand dollars...”

The high cost of intercountry adoption had an impact on having resources for post-adoption services as well. Janet said that the former adoptive parents for her daughter had an attitude that they'd already spent so much money upfront that they weren't willing to spend any more money on therapy or other services. Janet said she has heard other intercountry adoptive parents have made similar comments.

I've heard, "I've already spent all this money on her and I'm not spending any more. I think there's gotta be a connection between when you financially spend that much money to adopt a child, don't you think there is...I don't know. If I did that, I just think somehow it would affect you differently, you would think differently.

Becky and Sarah shared that they were unable to afford post-adoption services. Becky said,

I had just spent thirty thousand dollars to adopt a child that no one else wanted and then had disabilities and I was paying so much money just to have medical, mental health expenses. So it did come down to money. Parents have to realize also that it costs a lot of money to adopt kids.

For Sarah and her partner Em, many of the post-adoption services that they were referred to by their adoption agency were too expensive for them to afford.

Interfering with work. Parenting a child with a disability had an impact on parents' work lives. Some of the parents talked about having to take time off of work in order to manage with parenting, change employment to accommodate the needed flexibility, or in some cases being unable to work. Laura said,

I always get a phone call from a school every day and I haven't really been able to go back to work in a full time office, 9-5, especially since my husband is even now, he's not regular hours...And so I think in that way I don't think I expected I'd be home this much of my life...

Chris quit his high income and high status job in order to work at home so he could have more flexibility with the children. Chris recognized most parents can't afford or are unable to work from home. Dan and Amy also talked about the privilege of having Dan as a full time, at-home parent since managing their son's services was so time consuming. Lily said she was "blessed" because "We've both had flexible professional jobs where we could take time off to attend to our children's needs. Not everyone has that."

Mama and Laura both assumed the main care giving for their children and had husbands who traveled frequently or worked long hours. Jane and Vicky expressed the difficulty of supporting the family as single parents.

Theme 2: Social costs

Social costs that emerged from the data included being subject to judgment by the general public, as well as by professionals with whom the families interacted. Another social cost to the parent was the inability to do the types of activities that other families' experience.

Feeling judged. One common desire expressed by the adoptive parents in the study was for greater understanding and less judgment, especially regarding their parenting. Parents described many situations when they were blamed by the general community or even within professional service staff as being the cause or exacerbating their child's behavioral issues. Comments parents received highlighted an assumption that parents were not setting limits or "controlling" their child. "People don't get it," said Becky. "I've had so many people judge me, neighbors down the street saying what a horrible parent I was because my son was so unruly." One neighbor told Becky that child protection should be notified and her son arrested. Vicky said people told her, "you know you just need...to have better limits, or you need to punish her more or just do this or that more." When Becky asked for support from her family and friends she said, "My mother, remember she was against it from the beginning, she was sort of like, "I told you so."” Becky said that her friends were no better. "A few people were like, "well I told you not to adopt.””

Laura had similar comments. "I think there's a lot of, people are quick to say, "oh your child [is] terrible," or "oh my God, I can't believe them." "For me, it's not to judge until you've walked in somebody else's shoes," Amy said. "People see children who are acting out in grocery stores and are, whatever, very judgmental. And they have no idea what that child is really like." Laura also said people have become more sensitized to multiculturalism but that in terms of disabilities, particularly hidden disabilities, parents don't correct their child's prejudice against

people with disabilities. “Kids need to be open to differences in behaviors and backgrounds,” Laura said. “I think probably the thing that hurt me the most, more honestly than adults, would be when a little kid would say, “Oh there’s that weird kid again.” Like, my kids say inappropriate things, but you know, [parents] need to say something. You need to address that.”

Becky said these types of comments show that the public thinks of disability only in terms of physical disabilities.

I think that when you have, when you’re seen pushing – as a parent – a child in a wheelchair, they’re like, “oh that poor parent, they must go through so much with that child.” When someone sees me walking Carter out of school and he’s having a meltdown, parents are saying just the opposite: “Oh my God, look at what that mother brought up. That child is bad.”

Being unable to do family activities. Another impact on the family that parents shared was the inability to do “normal” family activities. Before adopting, Debra and Chris were a social couple that hosted gatherings for family and friends but are now unable to have other people in their home. Parenting children with disabilities also impacted their ability to spend time with their older, grown children and their families. Lily shared that her parenting experience is vastly different than her sibling’s families. “We haven’t gone to dance recitals...it’s a very different ride. It’s a lonely ride,” she said. Sarah and Laura spoke about the difficulty of raising children that cannot participate in sports or clubs and who prefer to be alone. Sarah said, “we found it increasingly difficult to do things as a family cause he never wanted to go out, and when he did he was always very angry and very agitated if we did go out.” Laura said,

Dennis doesn’t really want to be with a lot of people. He doesn’t want to do team sports and you can’t really take him places without him acting up, so – and we don’t get invited to birthday parties...we go to amusement parks but we know there’s going to be a meltdown at some point and we’ll have to split up. It’s partly realizing that.

Janet said holidays, such as Christmas, are sobering because she will not be able to have all her kids together to celebrate. Janet said it was difficult to think about the loss of being able to do things as a family the way she would like.

Theme 3: Relational costs

Parents experienced relational costs including being isolated or lonely, as well as experiencing diminished interpersonal relationships with a spouse or partner or other children in the home.

Being isolated and lonely. Families often struggle when they don't have a support system in place either prior to the adoption or afterward. Chris described the isolation as, "you find out you're sitting in a little pool all by yourself." Lacking supportive family due to geography or attitude is very difficult. Sarah, Patrick and Marie talked said the geographic distance of their family support system negatively impacted their family. Sarah said,

[It's] been a huge issue that I wish we'd kind of thought through before adopting kids. Not realizing we were going to get kids with such high needs, I think it's definitely impacted our ability to cope not having that family support structure nearby.

Other parents experienced a lack of emotional family support. Grace, Becky, Jane and Amy shared their family's negative attitude toward their child. Amy said,

In fact [my parents] seemed to cut Tim a lot less slack so it was sort of...lecturing my parents on if he were in a wheelchair...they would cut him a lot of slack. For a while we weren't even allowed to go to my brother's house, so no, no support there.

Parents talked a lot about experiencing isolation and loneliness. Both of the words "isolated" and "lonely" were used frequently. Isolation is a verb and whatever individual feelings parents may have had about their isolation they experienced isolation as an action of separation by other people. Loneliness is a feeling and even parents who had emotional and physical support expressed feeling lonely. Sarah describes her life as a "very scary, very lonely experience" and

that she is so emotionally depleted trying to survive every day that it is too difficult for her to ask for help even when it is offered. Sarah said,

They'll say, why didn't you call me?" or, "where have you been, tell me how I can help." And I'm just like, I don't know. I don't even know what to ask for anymore.

One reason for this sense of isolation was the difficulty parents had finding skilled supervision for their children. Lily said, "we are pretty isolated, and our attempts over the past year to get less isolated have been really hard because our son requires supervision." Laura said part of the isolation was due to her son's lack of desire for social interactions and also because other parents and children are not very tolerant of his behaviors. Jane said that it was harder to make friends when her daughter got older and since her daughter was unable to participate in the extracurricular activities, Jane lost the opportunity to make friends with other parents in the community.

Managing impact on siblings. Families that had more than one child in the family talked about the impact of the child with a disability on the siblings. In general there were two themes related to siblings: first, that the siblings that did not have disabilities felt they were neglected, and second that as a result of their experiences, siblings gained a greater empathy and understanding for people with disabilities.

Anne became teary when she talked about how having their daughter in out of home placement impacted her non-adopted son. Lily said that it has been hard for her daughter, who also has mild disabilities. "She will tell you that she's gotten the short end of the stick," Lily said. Amy said she was taken aback when her daughter said that she never got any attention from her. When Amy pointed out how many hours she had spent with her daughter versus her son over a recent time period her daughter said, "well, its not the truth that matters, it's how I feel." Amy said, "And this is true, so whatever was true, she has feelings of abandonment by our family."

Chris and Debra's said about their older sons,

They've admired our perseverance but have also felt I think a little cheated at times, that we just aren't available to go see them. We aren't available that much...They are empathetic and understanding, but I think they've felt hurt at times.

When Melissa's oldest son Ryan had his first long-term hospitalization their middle child Sam regressed in his toileting and sleeping. They consulted a psychologist and Melissa said, "She laid out this timeline and it was [snaps], "tad a!" Of course! He was feeling the stress of [the hospitalization] that I just wasn't seeing it." Janet said that while her older children adjusted to the constant flow of full-time PCA's or staff in the home working with the adopted children, the youngest biological child struggled.

For Marie and Patrick the impact on their oldest son Michael was two-fold. First, they realized they were unable to give him the attention he needed. They also realized he had some developmental disabilities that did not get assessed or treated as early as needed. Marie and Patrick also felt that their youngest, biological son suffered from in-utero stress due to the stress Marie experienced parenting their middle son. Dan said,

The needy child's needs are so self-evident, so immediate, that you're so focused on them that it's easy to, you know, you're just trying to put out fires. And it's easy to miss the needs [of the other children]. And that's an area where I felt like with Hannah...we over-prioritized [our son's] needs.

One byproduct of placing a child in out of home care was that it allowed parents to focus on the other children in the home. Debra said that having her one daughter in out of home care "allowed us to actually help Elena help realize she was a person. I mean, she had such a small sense of self that we don't think she, I don't think she had a sense of self." The out of home placement allowed Debra and Chris to focus attention on their other daughter. A few other parents talked about this as well. Sarah said that one of the things that most helped her relationship with her younger child was when they placed her brother in out of home care. During a four-month placement, Sarah said, "we could really cater to her needs...we were able to

really mend.” Dan and Amy had the same experience. Dan describes the behavior change he observed with his daughter after his son’s placement in residential treatment:

Within four or five weeks, she’s hanging out down here [in the living room] instead of her room. We went to New York as soon as her school finished...she was holding my hand the whole time. Our relationship just completely transformed. She dumped the guy she was hanging out with. She wanted to hang out with us.”

Siblings tended to have two reactions to their brother or sister’s disability and behaviors. Vicky, Dan and Amy all shared how their older children felt a great deal of embarrassment over their younger sibling’s behaviors. Vicky said, “Her sister didn’t really want to have anything to do with her because of all this negative stuff, she’s just so embarrassed by it and so upset by it.” Vicky cried when she shared that after the last time the two of them visited Sofia, in an out of home placement, the older daughter Isabel said, “I guess I just have to accept her for who she is, and give her support.” Amy and Dan learned that their daughter Hannah didn’t tell her roommate or any of her friends in college about her brother.

Debra and Janet talked about how their other children have become more sensitized and interested in caring for people with disabilities as a result of having grown up with siblings with disabilities. Chris and Debra’s son worked part time as a PCA for a child who has similar needs as their daughter. Debra said she was proud to see how good he is at this job. “He has a whole new world of categories for behaviors and kinds of people that make him pretty empathetic to that kind of disability.”

Costs to marriage or partnership. Parents talked about the impact of parenting children with disabilities on their relationships and the importance of being united or “on the same page” with their co-parent regarding parenting and discipline. Janet, Grace, Becky, Mama, Anne and Sarah talked about the stress of having different parenting styles than their spouse or partner. Anne said the parenting differences were a contributing factor to their divorce. “He was

extremely strict and that made me really uncomfortable, so again, I don't think that helped matters," she said. "We had two very different styles." Grace also talked about the differences in parenting. "In a family there's usually one person involved that's really advocating for getting help, and the other parent is fighting and resistant to that idea, what they call co-dependent and just rescues the kid." Sarah advised that when preparing to adopt couples need to "really think carefully about your, you and your partner's parenting styles, your expectations." Becky and her husband Spencer struggled for several years in part due to different parenting styles, particularly around spanking, which her husband used as a discipline method. At one point Becky considered divorce. Laura recognized that she and her husband have what she called, "normal difficulties of having different styles of parenting" but that despite the differences, "we try not to undermine each other." Mama called the dynamic of parenting differences as "a real tug of war between the three of us."

Some of the families were able to grow closer as a result of these experiences and others experienced a breakdown in the relationship. Both Jane and Anne divorced and their ex-husbands have minimally been involved in any active co-parenting. Sarah's relationship was tenuous at the time of the interview. Sarah said that stress was the main cause of the relationship breakdown and that her partner had just given up on taking any parenting responsibilities at this point.

What we both found so hard was trying to find people who could really understand what we were going through. And so at a time when you need each other we were not there for each other because we were both pretty traumatized and just struggling to cope each day ourselves.

Debra said working from home and the ability to communicate frequently has helped her and Chris continue to have a strong marriage. Dan shared that he and Amy have mostly been united in their parenting. "When times have been tough, we've been sort of sharing the toughness" and that some couples "have very different ideas of how to deal with this child, and

we never had that.” Chris and Debra talked about how important it was that they find time to connect as a couple. One activity they used was to take a walk every day so they could get a break, even if it was for a half hour. This allowed them to connect, because respite care itself wasn’t helpful. Laura said after the boys are in bed that they use that time to focus on themselves and credits that time with helping them stay strong as a couple.

Parenting these children requires constant care giving and many parents spoke about how difficult it was to get time away. Mama described she felt she was a single parent and lacked respite due to her husband’s frequent work travel. Chris said the first two years after adopting their daughters the two of them could not both be out of the house at the same time, “not even for a couple of hours.” As a result, even making it to parent support groups sometimes proved to be too difficult, not to mention time for the two of them to get away and spend time together as a couple. Chris said,

We would deal with escalating behaviors if they knew we were going to leave for a day or two and then we’d deal with more when we got home so it really was a net, wasn’t a net plus. It was a net loss usually when we tried it a couple of times.

Many parents referenced that one of the benefits of having a child in out of home placement was being able to have some respite.

Theme 4: Personal costs

Personal costs parents experienced included the effect on the parent’s wellbeing, feelings of guilt and grief, and the loss of their vision of the “dream family” or “dream child.” In addition to the personal costs to the parents, the child experienced personal costs as well.

Acknowledging toll on personal wellbeing. Many of the parents talked about how their experiences affected their health or mental health. Janet talked about how in the past few years she has realized parenting her adopted children has “taken more out of me than I planned.”

The theme of being exhausted and depleted was a common one. Lily said, “It takes a tremendous amount of stamina” to parent a child with significant disabilities. The exhaustion is what may prevent some parents from seeking support and help. It might not be that parents aren’t willing to seek help; it may be as Chris said, they’re too depleted.

Okay, I’ve got someone to call but I don’t even want to call, I don’t have the emotional capacity to make that phone call. And if they suggest something, what am I going to do with that? [Laughs] because you’re so, you’re just so depleted.”

Debra added, “There’s no margin.” The exhaustion can interfere with a parent’s ability to make the best decisions or act in the child’s best interests, according to Marie.

If you’re worn to the point of exhaustion where you’re hospitalized or you’re never believed or you’re continually put back into the situation that’s dangerous, well how can you, without any relief, how can you go back and love and be the kind of person that you need to be? It’s like telling a soldier go out there and fight this fight but not giving them a gun, in fact you’re [smacks hands] pile driving them. That’s what this is like. A wounded warrior.

Parents described having secondary trauma, PTSD or depression as a result of parenting these high needs kids. While many parents talked in terms of stress, some parents had clinical responses to their situation. Marie said, “you can’t run into a burning building without getting burned yourself.” The secondary trauma and stress was a contributing factor to the breakdown in Sarah and her partner Em’s relationship. Sarah said, “at a time when you need each other we were not there for each other because we were both pretty traumatized, and just struggling to cope each day ourselves.” Jane was another parent who said she had PTSD and depression. Becky experienced major depression for a couple of years. That depression was one of the reasons she said that she missed advocating for her son’s special education needs in those years. She said,

I knew something was wrong and I went into a depression for four years. It was awful. In fifth grade he was expelled...Even at that point, the school wouldn’t entertain – never said

he needs an IEP or 504. So I guess I was the dumb one but I was so depressed I couldn't even function.

Patrick joked that mental illness is hereditary and that "you get it from your children."

Both Patrick and Marie laughed. Patrick said,

In some respects there's some truth to that because parents of some of these kids truly develop post traumatic stress disorder from their parenting. Their personalities change as their lives have changed...you're on edge and stressed and stuff like that. It just changes how you are.

Feelings of guilt and grief. One of the predominant feelings parents expressed having was guilt, in particular parents feeling guilt for placing the child in out of home placement. Vicky cried as she shared what she thought her daughter felt. "I know how I'd be if I were her age and not at home, and I feel bad about that." Mama said she felt she had abandoned their daughter. "I feel bad that we had to, we were pushed into a situation where we had to put her in a strange place," she said. "I feel extremely guilty about that." Sarah and Mary said they never imagined that their adopted child would have spent more time out of their home than with them. "For me, what's been really, really hard is coming to terms with – this is my son, and yet we haven't had the chance to spend more than really six or seven months with him at home," said Sarah, whose son was adopted two years ago. Mary's oldest son has spent less than seven months total in the home during the seven years since his adoption was finalized.

As Marie and Patrick shared their attempts to find a new adoptive home for their son, Marie was concerned that they would be judged as trying to "get rid of" their son. Marie shared that they always were in contact with their son and with the prospective adoptive families. "I just want you to know it's not like we just dropped him off and we never had any [contact]," she said. "We had contact, we made sure that he knew us and we knew him..."

Some parents expressed guilt about their own parenting. Dan said,

I feel some guilt about all of this ‘cause I was never a nurturing type of person, it just doesn’t come naturally for me. I look back, this was a kid that needed more nurturing. He would have benefitted from if I’d sort of stepped up a little more.

Laura also questioned her parenting. “I always feel guilty and there’s that, always feeling like I’m not quite a good enough parent” Laura said. Laura also wondered if she was the right parent for her child. “There’s layers of guilt with them also being adopted ‘cause you ask yourself, geez, maybe another parent would have been better for them.”

Coming to terms with the loss of the dream child or dream family. Many of the parents had dreams or ideas about their adopted child that were not realized. Marie called it “ambiguous grief” and Grace called it a “work in process” to come to terms with the loss of the dreams she had for her child.

It’s hard. It’s – I wouldn’t say it extinguishes hope but you kind of have to learn to survive as a parent with a child with a disability. Because I can’t pin my hopes and my dreams – and what I want for him may or may not happen. It’s a huge letting go process.

Becky said,

I just went into it blindfolded. Thinking I was going to become instant soccer mom, to a wonderful boy that my family would love; he’d travel with me and as a single mom we’d be perfect. It didn’t happen that way.

Jane and Laura shared the sadness they felt when thinking about the possibility their children might not attend college. In addition, Laura’s husband, a doctor, had more difficulty coming to terms with the loss of the dream child they envisioned when they adopted.

He’s having a harder time I think letting go of the dream child that he had in his mind. And I think he still is sometimes bitter about that. He says, you really don’t understand, I’ve got these [colleagues] whose kids are going to go to medical school and their kids are doing this and that and I can’t really say anything.

Costs to the intercountry adopted child. The intercountry adopted child experiences a

tremendous amount of personal costs. While this study did not focus on the intercountry adopted child's experience, several parents mentioned their child's thoughts and feelings about having a disability. In particular two themes emerged, first that children believe themselves to be "bad" and second, that they often tried to manage their behaviors in public in order to hide their disability.

According to the parents, some of the children saw themselves as a bad person because they can't or don't always understand why they behave the way they do, they only know that other people don't like the way they behave. Describing a therapy treatment that he and Marie were involved in with their son Jerry, Patrick said,

We would actually hold him and he would go, like, "I'm bad! I'm bad!" He would just say, "I'm bad! I'm bad! I'm bad!" said Patrick. "So he really got...messages about that he's a bad person. You know, and I think he's never gotten rid of those, really. I don't think so.

Jane's daughter Sasha told her mom, "I am so happy I have FASD!" and when Jane asked why, she said, "It's such a relief it's not me, it's my brain." Jane said, "She had been seeing herself as a bad kid." Chris said his daughter is very self aware about her behaviors.

She doesn't feel safe with herself. And because she knows she's going to behave in a certain way she can't help it, she does it anyway, and then she has such a deep core of shame, since she can't live with herself, and so it just goes from bad to worse.

Vicky said that her daughter was diagnosed with depression and said, "That is true, she was depressed about, you know, being where her life is leading her now, and how she has so many deficits." Laura's son Dennis also keenly felt his disabilities. Describing one incident, Laura shared, "he wouldn't calm down and was running down the street saying, "why can't anyone make me better, or feel good?"" Laura went on to share, "Dennis doesn't like to be different. And he doesn't like to be in the "dumb" group. He's at the age where he knows what all these levels really mean, and what groups are and he's very sensitive to that. So I worry, that

becomes so much more clear in middle school.” Amy said about her son Tim, “he hates the way he is. He doesn’t want to be the way he is.”

Several parents also shared that their children often tried to reduce the stigma of having a disability by trying to hold it together while in public and in school. As a result, once the child was home where it was safe, and where he didn’t have to try to look “normal” to his or her peers, it was almost like they just burst and exploded on to the parents. The pressure to try and keep up and appear “normal” was too much for some of these kids. “With our son, when he was younger there was such a discrepancy between home and school behavior,” said Lily. “It seemed like he would hold it together at school and then come home and unleash on us.” Laura expressed similar sentiments. “I think he holds it together at school pretty well, and then at home he just can’t any more” said Laura. One of the results of this behavior was that others outside the home often didn’t believe what was happening at home. “She would hold it together, the teachers would say they couldn’t see it, she held it together in school until the last quarter,” said Vicky. “To the outside world, Jane’s daughter seems fine. “When I tell people what goes on in this house, they don’t believe me. But most people don’t see that. She doesn’t do it when somebody’s here in the home. And she pretty much only does it with me.”

Vicky said her daughter Sofia would try to try to act as if she was just like the rest of her peers. “She would take her sister’s algebra with her to school to pretend she’s in algebra.” Siebers (2006) describes such behaviors as “performing normalcy, of inserting oneself in society and escaping the alienating experience of being disabled” (p. 118). Goffman (1963) asserted people attempt to pass in order to avoid the stigma associated with having an undesirable identity.

Category 4: Consequences

Consequences are the actions that result from the interactions between the choices parents make and the costs associated with those choices. Although costs might in other ways be

considered a type of consequence, as conceptualized in this study costs are part of a reciprocal exchange with choices. Consequences are conceptualized as the actions and behaviors that result from the reciprocal exchange between choices and costs.

The category of consequences organized into two main themes including 1) behavior changes and 2) emotional changes. Behavior changes were the actions that the adoptive parents implemented as a result of their experiences including a) becoming an advocate, b) developing coping skills and c) planning for the future. Emotional changes were the changes in beliefs or attitudes and included a) being disillusioned about intercountry adoption, b) realizing strengths, c) finding hope, and d) recognizing privilege.

Theme 1: Behavior changes

Becoming an advocate. Parents advocated in a number of ways both large and small. Parents particularly learned that having a child with a disability mean they were going to have to advocate for services, and that having a diagnosis may mean their child is entitled to services, but that no one was going to go out of their way to help locate those services or help them with the often very bureaucratic red tape involved in getting them signed up for and accessing those services. Melissa said, “if I could tell somebody something about disability, there are resources, and nobody’s just gonna lay them out for you. That you really have to advocate for yourself.” Some of the parents used legal channels, particularly around school, to advocate for services their children needed. Many parents took their advocacy far beyond their personal family situation and out into the larger community. Laura and Melissa participate in advisory committees related to disabilities, which has been a way to connect them with other parents and impact broader macro and exo-systems around issues of disability like policies and institutional structures. Jane, Janet, Vicky, Chris and Debra also advocated through becoming trainers, educators and organizing conferences around disabilities.

Developing coping skills. Parents described a number of coping mechanisms they used.

Some of the parents chose to attend therapy for themselves including individual therapy, couples counseling and family therapy. Dan shared that initially they sought a therapist for their son, but that “most of the time we didn’t see him with Tim. We’d just go and talk with him...what we really needed was understanding of what was going on and strategies for how to deal with it, so it was really a therapist for us as much as for Tim.”

Some parents used their faith to cope. Anne and Melissa both shared that faith has been a big part of supporting them, not just a church community, which others referenced, but that their personal faith had supported them. Melissa said by focusing just in the short term helped her to stay calm, other wise she would get overwhelmed and “panicky...so I really try not to think too far ahead.” Becky said it helped to have the mind-frame that “every day was a new day...some days were good, some days were bad. Some days if we made progress, I’d just focus on those happy moments.” Anne and Mama also talked about trying to just take it “a day at a time.” Thinking of what they needed to do in small chunks of time felt more manageable and doable for parents. Parents also reflected that things might be worse. Jane acknowledged that she knows other adoptive parents who experience a higher level of violence and destructive behaviors from her children and so while she doesn’t make light of it, she said, “there’s some solace in knowing it could be worse.” Comparing her situation to those of their adoptive parents whose children have been in jail, who have alcohol or substance abuse problems, or involved in prostitution, Jane said, “I have to remember those things.”

Planning for the future. How are the parents imagining what the future will bring, in terms of their relationship and role? Many parents talked about coming to terms that the child would need support from them in adulthood because of their disability. Lily’s son attempted to live independently but ended up moving back into the family home. Lily imagined that he would live close to them if he does attempt to live on his own again because she and her husband are his “safety net.”

Chris said he had to come to terms that their daughters would be with them for a while. “It’s taken a long time to accept the fact that probably, if the children stay in our home, we need to think in terms of age 25.” Chris also described parenting children with disabilities as “a longer term model than we had hoped and thought.” While he hoped that in the next five or so years his daughters would be able to function enough to live independently, he acknowledged that he doesn’t know if that’s realistic. Laura remained hopeful that her son would be able to live independently, although her husband was less sure. “I think he’s sort of convinced himself that [Dennis is] going to be living at home the rest of his life,” she said. “I don’t think that’s necessarily true.” Melissa said she and her husband will be Ryan’s “lifelong caregivers” and said she does not anticipate he will be able to live independently. She said,

We kind of joke about when the other two are gone that it’ll be the three of us doing our thing [laughs]. So I guess that would be, really lifelong...Although I try not to go too far [thinking about the future], otherwise I get overwhelmed.

Transitioning to adulthood and future assistance for children was a concern that parents discussed in terms of making sure those services would be available in the future. Vicky said that it was helpful to have an intercountry adoption medical specialist talk advise what to have in place now to ease the transition to adult disability services. Sarah was pessimistic her son’s situation would improve enough for him to live independently so she was thinking ahead.

If he doesn’t improve much more than he is now then he can’t live independently. I mean he cannot initiate anything on his own and he needs to be supervised for everything. So unless there’s some major change in him, just, medication or something, I suspect he will be living in a supervised home.

Dan mentioned two concerns about his son’s future: his son’s cognitive and developmental disabilities and his behavioral and mental health disabilities.

He really has two categories of special needs. One is his sort of cognitive limitations. So under the best-case scenario, he’ll always have those. So he could perhaps, as Amy said,

live independently with support. When he's getting overwhelmed getting violent, and if that doesn't change, he won't be able to live independently. He won't be able to live in an unsupervised setting. And we don't know the answer to that question. There's a range of possibilities...but that range of possibilities almost certainly does not include evolving to a place where he could function independently like the rest of us.

When asked if she could envision a time when her daughter would be living on her own, independently, Eleanor said, "Oh yeah, I don't." She continued, "I mean, she has no vision of not ever living in our house with me." Jane felt that it was important her daughter learn how to be independent because as an older parent, she already was anticipating she was going to die sooner than some of her daughter's friend's parents.

Anne's focus for the future for her daughter was relational. Her therapist suggested working on the relationship she would like to have with her daughter as an adult. Anne said,

I feel really hopeful about that. I think we're in a good place and I'll probably always regret I wish I would have handled things differently when she was younger but I'm happy that we'll be in a really good place as she moves on to adulthood.

Parents expressed concern about whether their children would manage their disabilities as adults. "Obviously when somebody diagnosed with a mood disorder is going to have life-long issues," said Eleanor. "It's just not, you're not going to outgrow it." Janet said, "It's going to be life-long; it's not something they're going to get over easily." Mary worried whether her sons will continue to work on their health and mental health on their own once they are adults. Mary said, "I have no control over what he's going to do, any day...we've had some brutally honest conversations that as he gets to be an adult he may not be so lucky [if he doesn't comply with treatment]." Mary's legal knowledge helped her son avoid the corrections system and she said "keeping him out of the system has given him another chance for the future.

Parents also talked about their child's hope and dreams for their future and whether or not it was realistic that, for instance, the child would be able to attend college. Eleanor stated that her

daughter Mary was “very interested in going to the [state university]” but did not think it was realistic. Vicky was empathetic with how the reality of her daughter’s disability might meet up with her daughter’s expectations.

She’s also got her dreams...so you know, she’s going to have to meet the reality. I mean, a lot of people do, you know, but that’s not going to be easy. You know, it’s really hard seeing her have to deal with all these problems.

Jane’s daughter also had aspirations for college and targeted a post-secondary program that catered to students with intellectual and developmental disabilities. “Part of me really doesn’t know if she can do it cause she’ll never be able to live independently,” said Jane. “I don’t know that they can give her the support she needs.”

Given the magnitude of their trauma, Janet said her hopes for her children include emotional, rather than only behavioral or functional, goals.

I really hope they can find the stability and enough healing to be able to experience some of the joys in life. In all honesty their lives have been very difficult and they haven’t had that may joys. And I hope they can experience that.

Theme 2: Emotional changes

Being disillusioned about intercountry adoption. The adoptive parents in this study began growing their families with much enthusiasm and high regard for intercountry adoption. One of the emotional consequences resulting from their experience was disillusionment about intercountry adoption. In particular, parents came to think of intercountry adoption as a business, instead of as a child welfare service. Mary said, “The agencies don’t say we have children with special needs because they don’t have proof of it and because they don’t want to dissuade [prospective parents], it is a business.” Marie, Lily, Grace and Jane also made comments suggesting that the reason adoption agencies do not discuss disability honestly with prospective parents was that it would hurt business. Eleanor said,

There's no nice way to say this – but it is not about children, it's not about creating families, it's all about commerce. And no, you're not buying a baby and you're not paying off a birth mother, but a whole lot of money changes hands that employ a whole lot of people. And that's kind of more like what it seemed like to me.

Several families worked with agencies that had been closed due to poor practices, and some agencies had been indicted for fraud. Sarah, Chris and Debra, Becky, Marie and Patrick all worked with agencies that had since been shut down. Many other parents including Chris, Eleanor, Jane, Mary, Janet, Sarah, Laura, Patrick, Marie and Vicky said they were misled by the adoption agencies or adoption organizations in the U.S. or in the child's birth country or said the agency had ethically questionable or incompetent practices. Sarah adopted her children through an agency that was indicted in 2013.

They almost made the process seem too good to be true. So easy. They were like, yeah you can do that, you can do that, just say this, don't say this, and our process moved on very quickly. They did not share a lot of information, they just said they did not have a lot of background on these kids.

Mary said, "I think the agency on our side had a very "let's turn our heads, we don't see this." So there was a lot of willful blindness. I think that happens all over the world."

Realizing strengths. One of the emotional consequences for parents was that they recognized their child's strengths, gifts, or talents. They also articulated that as a result of their experiences, they – as parents – gained or realized strengths in themselves that had previously been taken for granted or had not yet developed.

Janet admired her son's resiliency. As a young adult, he now speaks about his experiences to others, in particular about how difficult it was to be adopted, an immigrant, and his struggle to find a sense of identity in the United States. Janet was proud of her son's ability to accept his disability, traumatic past, and adoption. Mary also had a lot to say about the resiliency she sees in both of her boys. Her face lit up as she talked about their strengths.

Any one of those would be enough to make the average person not want to get out of bed in the morning. And it amazes me that these kids get out there, give it all they have.” She shared that even in the darkest times “they find joy in things, they have their interests and they have their passions...my younger son said just the other day, “I’m happy.” And I just shake my head and think, “would I be if I were in their shoes?” I don’t know.

Mary also acknowledged that her sons work very hard in their therapeutic work. “They could have refused to go to therapy, to take meds – yet something in them, they want to do different. So they’re doing the work, the painful work.” Melissa called her son “a gift to our whole family” and admired his strength. “He is a tough kid,” she said. “We always tell him, “You have to do such hard things.”

Parents wanted to share that underneath the external behaviors, that their children were not the “bad kids” they were often judged. Lily said that even with her son’s behavioral issues “he also is such a sweet kid. To this day, he’s not a bully, he’s not – and I think that might have made it a little bit easier.” Becky said, “Carter’s not [bad], he’s got the sweetest heart and is the most resilient child I’ve ever met.” Mama said her daughter Nicole “loves helping people, she’s very compassionate, very kind.” Dan described Tim as “a very sweet, sweet guy. He just has these challenges that make life so difficult for him.” Dan also said his son is misunderstood because of his violent outbursts.

Something I always want to make sure is understood about Tim – he is not a sociopathic, psychopathic type. He has such a conscience. Whenever he loses control he is so remorseful. Some of the times he’s most suicidal are because he feels so bad.

Parents shared that they’ve learned some important lessons about themselves through this experience of parenting as a result of their experience. Debra shared that her relationship with her older children has improved in some ways.

I think it’s allowed us to have conversations with our children that we probably wouldn’t have had outside this experience and to be more aware of their needs, and how we

parented and the environment that was in our home when they were growing up and what was lacking; and I think it has opened the doors to more deeper communication with them as well, and that's really a net plus.

Anne and Melissa felt their experiences improved their religious or spiritual growth.

Melissa said that as a Christian, her son "kind of got us there quicker, I think God really used him to get to us." Janet talked about expanding her worldview and openness to her children's culture.

[I see] the richness that my [internationally adopted] children bring in...Because I was able to go there and spend a lot of time in the country, we made a lot of friends and the people there, I just love them dearly...I would have really missed out had I not gone there to see the riches...and just the things that are important to [my son].

Parents also shared that they've become more resilient and stronger than they were before their children came into their lives. Laura described herself as an "over-achiever" and that she is "parenting people opposite than me, but that has also been good in a way." Marie said that her experiences made her a "better person." Despite the hardships, she said, "I feel like through getting burned myself through some of the pain that I've gone through has actually made me better. In a lot of ways; I mean, it's tested me in ways that I probably have never been tested before." For Mary it was patience.

I've always been, "let's get there now," and a hundred miles an hour and on to the next place. And you can't do that, I can't do that, with these children who have so much to overcome.

Melissa shared that both she and her husband have been surprised at how much stronger they are than they thought.

Finding hope. Another emotional consequence for parents was finding hope. A few things parents talked about it in terms of thinking that things could be worse, accepting that there are things they could and could not do, and feeling that their role is to be the person who, through their parenting, gives their child a chance to succeed. Many of the parents understand that their

children will have a lifetime of struggles but that they hope they will be able to have some joy in their life. Janet said her son is doing well currently and she hopes he continues to stay on the path he's on. She said of her daughters, "I have hope for them, and that's really important. There are days when I don't feel very hopeful but I think they're going to have long-term healing, it's going to be life-long; it's not something they're going to get over easily. My daughter won't be 100% recovered after six months of treatment you know. I hope for them that their behaviors won't put them in a place that will hurt them." Janet also said that she accepts that she's done what she can and that hope is something she can do to help them, given all the things she can't change for them.

Chris told me, "the miracle, or the "a-ha" thing is that every child has this spirit inside them that wants to be loved and cherished, and deeply wants to trust somebody. And, if they can get there, if the parents can hang on, if we can do this with [our daughters], there's a lot of hope for a lot of families."

Recognizing privilege. An emotional consequence for the parents was that they recognized their privileges. Demographically, the adoptive parents in the study were highly educated, white, and majority middle- or upper class in terms of socioeconomic status. Despite these parents' privilege they still had a lot of difficulty accessing services highlighting that families who lack these privileges might struggle even more in terms of being able to access services.

Some of the privileges parents brought up included financial stability and flexibility in work situations. Several of the couples had one or more parents who worked from home or were able to take some time off to care for the children. "We have also been blessed; we're not wealthy but we've both had flexible professional jobs where we could take time off to attend to our child's needs. Not everyone has that," said Lily. Chris said,

I was an international leader for an organization with 5,000 people in it. And [I] realized, you know if we're gonna keep these kids, it's gonna take both Debra and I. And we got permission to [change to a job working from home] to do that, which is not something most people can do.

Added Debra, "We have the privilege of both being at home and being in this together and being able to talk to each other. I don't know if we would have survived if we hadn't had those opportunities."

Although Lily questioned how difficult it would be to have been an at-home parent, maybe because of the assumption of the less financial resources a one-income family would have, or maybe because of the escape that work can provide for a parent, others saw the ability to be a stay at home parent as a privilege. Melissa and Dan both considered the ability to be an at-home parent as a privilege, allowing them the ability to be able to respond quickly to their children's needs.

Some parents thought their educational and professional backgrounds gave them a privilege in being able to understand and advocate for resources. "You know, we can say that it's, hasn't been that bad, but Dan's an attorney" said Amy. Dan added, "like in our [insurance] appeal. You know, I was able to draft the appeal, I was spelling out the liability they were exposing themselves to." Dan's legal knowledge and the time he had as an at-home parent gave him the ability to exert pressure on the insurance company. Dan said, "We have financial resources, we're educated enough to be able to access other resources, so it has been – it couldn't have happened to a nicer family [laughing]." Lily's job as a social worker meant she had colleagues to help in terms of resources as well as providing emotional support. "I have people I can talk to about, who understand more than just about anybody most of the things I've been through" she said. Amy's professional connections helped her access resources for her son. While she and Dan were trying to work with their insurance company over residential placement

coverage, they learned that one of Amy's good friends and colleagues was the person who approved extended care for that insurance company.

Mary and Melissa said as English speakers they were able to communicate with the systems and institutions that they needed to work with to get services. The paperwork can be overwhelming; Melissa said, "We talked about, I'm a college-educated person...who speaks English. And for people who really need it, it's such a huge barrier."

Jane's professional education and work experience also allowed her to find resources for her daughters.

She had all the supports because the reality is, we're privileged, we're white, I had a great job, we have education and she had early intervention and I demanded from the school what she needed no matter what the diagnosis. And it's because we're privileged, we're white and we're privileged, and educated. And that's not fair, but that's...not fair in any area of life in the United States. But that's the way it is and I wish it weren't.

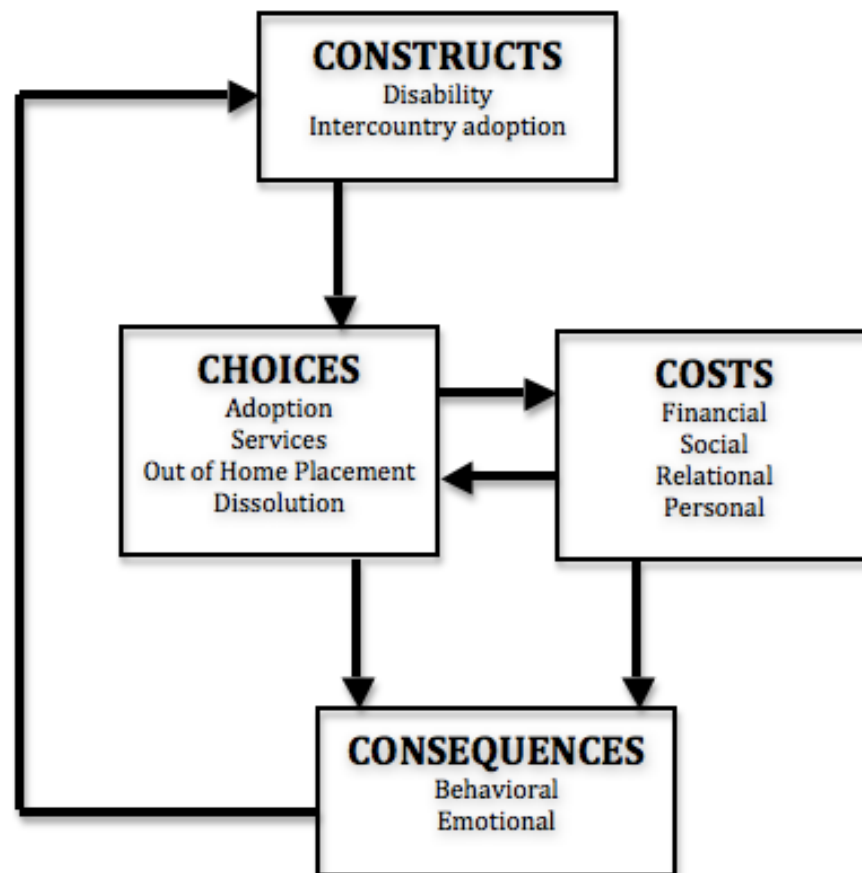
The Adoption Displacement Decision-Making Framework

For the parents in this study the decision to place a child in an out of home setting was the result of several factors. In order to understand the interaction of these factors, I developed a framework in which to understand the ways in which adoptive parents come to make decisions about displacement, that is, why they chose to place a child in out of home care. Figure 9 depicts the framework's four categories that emerged from the data: constructs, choices, costs and consequences. These categories interact; constructs inform choices, choices and costs have a reciprocal interaction and lead to consequences. Consequences in turn inform constructs, which again influences choices and thus in this way the continuous loop of parent's thoughts and actions produce a dynamic and interactive representation of how adoptive parents come to choose out of home placement for their child.

For example, the adoptive parent may have a construction of disability as only a physical or

medical impairment. This then leads the parent to choose to adopt a child that appears to be free from visible physical or medical disability, not realizing that the child may have, or be at risk for, an intellectual, developmental or mental health disability. Or the parent may have a construct that domestic adoption means birth parent risks, or that foster care adoption means disabilities, and therefore chooses to adopt through intercountry adoption.

Figure 9. Adoption Displacement Decision-Making framework



Parents made many choices throughout the adoption process; some of the major choices involved adoption (what agency, domestic, foster or intercountry adoption, what country), services (agency-based, school-based, medical-based), out of home placement (type of placement,

location of placement) and dissolution (whether or not to dissolve the adoption). Each of these choices had associated costs, and these costs influenced the choices parents made. For example, if the financial cost associated with a particular out of home placement was prohibitive because the parent's insurance company would not cover it, the parent might have made the choice to have the child in a different placement. If that placement was unequipped to address the child's needs, the family may experience personal or relational costs due to the stress of needing to seek yet another placement.

As a result of these interactions between constructs, choices and costs, parents experienced behavioral or emotional consequences. Consequences were the actions parents made due to their experiences and were behavioral, such as becoming an advocate, or emotional, such as realizing their strengths. The distinction between costs and consequences in this model are that costs are the literal and figurative expenditures or losses associated with the choices parents made, and consequences are actions related to the dynamic interaction between the choices and costs. Consequences in turn provided a feedback loop to constructs; for example, one of the emotional consequences for parents was to see their child in terms of strengths, not deficiencies. This emotional consequence changed the way the adoptive parent constructed disability, which in turn impacted the choices the parent made leading to different costs and consequences, which again impacted the parent's constructions.

6: Discussion

Chapter Overview

Through this study I aimed to answer the question of why and how parents come to choose out of home placement for their intercountry adopted child with a mental health, intellectual or developmental disability. In addition, four sub questions guided this study and including: 1) what were the parent's understanding of disability prior to adopting their child, 2) how do parents construct disability, 3) what was the parent's experience with accessing and utilizing services, and 4) what has been the impact on the family's lives. I begin this chapter with a discussion of how the adoptive parent displacement decision-making model presented in the previous chapter answers the question of why and how adoptive parents choose out of home placements for an intercountry adopted child with a disability. Next, I discuss how the model relates to social constructionism, ecological systems theory and disability theory, followed by a discussion of the answers to the sub questions. I end this chapter with a discussion of the implications of this study's findings on social work practice and policy, directions for future research that will build upon the data that emerged from this exploratory study, and concluding thoughts.

How Parents Choose Out of Home Placement for an Intercountry Adopted Child with a Disability

In the previous chapter, I presented a framework for understanding the ways the adoptive parents in this study made decisions regarding placing their child in out of home placement. This framework was based on the categories that emerged from the data and explains how parent constructions, particularly about disability and intercountry adoption, inform the choices that were made regarding adoption, use of services, out of home placements and whether or not to dissolve the adoption. The choices these adoptive parents made or considered had associated

costs, which in turn influence their subsequent choices. Upon making choices regarding their child and sustaining the associated costs, these parents engage in behavioral or emotional changes, which are the consequences of their choices and costs. These behavioral or emotional changes may change or reinforce these parent's constructs, which then in turn influences the choices and costs these parents experienced.

The Adoption Displacement Decision-Making framework helps explain the process by which the adoptive parents in this study placed their child in out of home placement. To provide additional understanding of the ways in which adoptive parents are choosing out of home placement I situate the framework in the contexts of social constructionism, ecological systems theory and disability theory.

A social constructionist understanding of placing a child in out of home placement. The cultural context that influenced how the parents in this study constructed their beliefs and ideas about disability and adoption is one that is formed by English and American legal, political and moral values. My own professional experience working in both private and public agencies as well as previous historical research on adoption law and policies provided me with an understanding of the basis upon which adoption agencies set their policies for administration and practice that the adoptive parents in the study likely would not have known or understood. According to the parents' narratives, some of the adoption agencies and social service agencies shared the adoptive parent's constructs about disability and intercountry adoption, and other times they differed. One example of the difference in how adoption agencies construct intercountry adoption from the adoptive parents was in the use of the "willing to consider" form or check list. Adoptive parents constructed the form as a means of eliminating undesired qualities in a child they hoped to adopt. Parents sometimes felt pressured to "consider" some characteristics they were not comfortable with due to internal pressure, such as guilt for wanting a child without any disabilities or health care needs, or external pressure such as an adoption worker advising that

they the other country's adoption workers would pass over their application if it appeared they were seeking a "perfect" child. Adoption agencies, on the other hand, view the form as a way to match a child to parents that can meet the child's needs. As an adoption worker for youth in foster care waiting for adoption, I often assessed the responses in the parent's checklist against the youth on my caseload to see which parents had the capacity and willingness to parent children for whom I was seeking adoptive homes. In other words, adoption social workers construct the form as a means of finding families for children, while adoptive parents may construct the form as a means of finding children for families.

The disconnect in the way each of the two groups construct discussion around children with disabilities meant an opportunity for *preparing* families for parenting a child with a disability was missed because the focus was on *preventing* the adoption of a child with a disability. Adoptive parents in this study constructed intercountry adoption as "not special needs" that may or may not be consistent with how it is constructed by intercountry adoption agencies. Certainly adoptive parents described feeling their adoption agency did not challenge this construction and may have actually validated their construction by minimizing or concealing the risk that the intercountry adopted child might have disabilities. As institutions, adoption agencies and adoption social workers have tremendous power (Burr, 2003; Foucault, 1971) to set the discourse around adoption and adoptive parents, already vulnerable and scrutinized through the home study process, may feel they cannot challenge the agency's discourse.

The discourse and construction of disability and adoption were critical aspects of the decision making process for adoptive parents, and informed all of the decisions that the parents in this study made. This framework explains how adoptive parents reinforced or redefined their previous constructs as a result of their experiences. For some parents this involved taking on the challenge of trying to re-shape the public and private discourse around disability and adoption by

sharing their lived experiences. Participating in this study was one of the ways in which the parents in this study actively challenged the dominant discourse.

An ecological systems understanding of placing a child in out of home placement. An important aspect of ecological systems theory is the interactions between individuals within multiple environments including the macrosystem, exosystem, mesosystem and microsystem. The parents in this study were impacted by the social and cultural values and ideologies in their macrosystem including the larger constructs and ideologies of disability and intercountry adoption. This might explain why even those who had previous personal and professional knowledge about disabilities still viewed disability as a physical or medical limitation and as an individual, not societal, burden. The larger ideologies of intercountry adoption as a means of rescuing and saving orphans unencumbered by birth parents who want to interfere in the adoption or who caused the child's "special needs" through abuse and neglect was a prevailing belief that informed the decisions the parents in this study made.

In addition, the parents in the study were impacted by the policies, laws and regulations of institutions that made up their exosystems including federal, state and local government agencies, adoption laws in the U.S. as well as in their child's country of origin, and private insurance and government disability and medical policies (such as Supplemental Security Income (SSI) and Medicaid). Parents also had to make choices and incur costs related to their micro and mesosystems, for example having to manage relationships with extended family or non-disabled siblings in the home, their child's teachers and administration at school, or within their faith communities.

Another important contextual consideration is the relevance of Bronfenbrenner's (1979) concept of ecological transitions in these families' lives. The parents and children in this study experienced numerous environmental transitions that led to new roles and expectations such as when their child was diagnosed with a disability, needing to change schools, or having to figure

out how to parent from a distance while their child was in out of home placement. Overall, from an ecological systems perspective, the families in this study were impacted by their interactions with people and institutions within their many social and physical environments. Through these interactions, the parents in this study also made an impact on others in these systems.

A disability theory understanding of placing a child in out of home placement. Siebers (2008) calls for a nuanced understanding of disability that is not positioned solely on the end points of the medical model – social model dichotomy. Siebers calls for an understanding of “complex embodiment” which acknowledges both the reality of the physical manifestations of disability (including pain and constricted functioning) as well as the limitations imposed on people with disability through inaccessible environments (p. 25). Siebers also advocates for an understanding of disability that supports an intersectional identity perspective in which disability identity is included with other identities (such as race, gender and sexual orientation).

The parents in this study began making choices based on the medical model of disability, that is seeking services and interventions that might eliminate or moderate the disability and its associated behaviors. Over time, some of the parents came to understand their child’s difficulties as less about the child and more about constraints of systems and a society that did not accommodate differences. These parents saw their child as much more than their disability. Yet they acknowledged the complex embodiment that was their child’s experience and often felt powerless to help.

While the intercountry adopted persons were not interviewed in this study, their adoptive parents hint at some of the ways their children struggled with identifying as a person with disabilities. As children and young adults, parents shared their children know that they are different from their peers and want to be “normal.” Some of the parents shared their children have stated they wished there was something that could make them feel better or make them think differently. The children with intellectual and learning disabilities understand their cognitive

differences and dislike being academically behind their peers. A number of the parents in this study talked about redefining disability as a construct and have seen their child's strengths over their limitations; however the children themselves may have a different perspective about their strengths and limitations and how that figures into their own self-definition and identity.

Parent Understandings of Disability Prior to Adopting Their Child

The parents in this study had varied understandings of disability prior to adopting their child. Some of the parents had personal or professional experiences with disability that informed their knowledge and understanding while other parents had relatively little experience. Yet a common thread amongst these parents was that prior knowledge or understanding of disability did not better prepare them for parenting a child with a disability.

The process of adoption can be time consuming, bureaucratic and filled with uncertainty and parents choose adoption for many diverse reasons. However, except for Janet, the choice for many parents to adopt a child born in another country was in part based on parents' understanding of disability and the desire to adopt a "healthy" child, an option that seemed unattainable through domestic, foster care adoption. It is the adoption agency's task to help prospective adoptive parents understand disability and the risk of adopting what Dan called, "an open question." The parents in this study, however, felt their adoption agencies did not fulfill this task. Thus, with the exception of Janet, prior knowledge about disabilities did not better prepare adoptive parents in parenting their child.

Parent Constructions of Disability

Constructions of disability tend to fall on two ends of a spectrum in which the medical model of disability views disability as something to be cured, treated, and eliminated while the social model of disability views disability as socially constructed and functioning is impaired due to environments that do not constrain and limit accessibility for everyone (Siebers, 2008, p. 25).

The families in this study are living in a society where the predominant construction of disability is based on the medical model.

Parent constructions of disability changed over time and broadened from an initial conceptualization of disability in visible, physical and medical terms to one that included invisible disabilities. Parents talked about initial constructions of disabilities as wheelchairs, visual impairments and Down syndrome. Juxtaposed with examples of physical disabilities, parents often voluntarily shared with me that they did not consider mental health or neurodevelopmental disabilities as “disability” until after they adopted a child with these disabilities. How adoptive parents construct disability cannot be entirely isolated from how parents construct intercountry adoption. This study revealed that adoptive parents constructed intercountry adoption as “not disabled.” With the exception of Janet, all of the other parents in this study stated they did not want to adopt a child with chronic or severe disabilities. If the parents considered adopting a child with a disability, they expressed they would accept a child with mild or correctable disabilities. Parents attempted to find services that had a medical model perspective aimed at treating and eliminating the both the disability and the behaviors associated with the disability. However, over time many of the parents shifted over to a social model of disability and began to construct disability in terms of institutional and societal responsibility for access and less about individual functioning. Many of the parents also redefined disability from a negative connotation to one in which their child had strengths and gifts. The parents also spoke in terms of differences in functioning instead of thinking of their child as unable to function.

Parent Experiences with Accessing and Utilizing Services

The eco-maps created for each family in this study reinforced the findings from the parent interviews that these families had multiple disability-specific interactions in their micro, meso and macro and exosystems. In particular the eco-maps highlight the families’ complex

interactions with adoption agencies, schools, churches, medical and psychological clinics, hospitals, insurance companies, police, parent's employers, state and county human service agencies, private social service agencies and mental health service organizations. Some institutions were more difficult for parents to navigate than others. In particular parents named schools and governmental agencies as least responsive and most difficult to access. Parents also described feeling judged and criticized by the professionals in the organizations, and that the professionals communicated poorly and did not involve the parent as much as parents wished. Parents described the services as expensive, difficult to access, and not always effective. Parents also described ways in which macro and exosystem dynamics impacted their relationship with their child or other family members, for example when a school system deemed a child ineligible for an Individualized Education Plan (IEP), it impacted the dyadic relationships between the child, his or her parents, and the child's teachers because the disabilities are not addressed in the classroom with needed accommodations.

How Parenting a Child with a Disability Impacted Their Lives

Parenting a child with a disability impacted the families in this study in many ways both positive and negative. Parents and siblings were subject to violence, strained relationships with extended family and experienced diminished personal health and mental health status. Parenting children with disabilities also led to an increase in personal growth for many of the parents. Many took on advocacy roles in small and large ways, from intervening on the local level in their communities to educate others in their neighborhoods, churches and schools about disabilities to becoming experts in disabilities and training professionals and policy makers. Several parents created or took on leadership roles in support groups for parents of children with disabilities.

Coming to terms with the reality that their child had a disability was a task that many of the parents struggled with initially but had, by the time of their interview, redefined the situation from a negative connotation and acknowledge as part of their child's being in a variation of

Kirk's "shared fate" theory. In the 1960s, H. David Kirk, a psychologist and adoptive parent, challenged the adoption industry with a theory that adoptive parents chose to either accept that their adopted child was biologically different from them or reject that difference. What made Kirk's theory provocative was the prevailing belief at the time that adoption should mimic the biological family as much as possible. Children were placed in families with parents based on eye and hair color in order to look as if they could have been the adoptive parent's biological child. Kirk found that families in which the adoptive parents accepted the biological difference between them and the adopted child and did not try to pretend that they were "just as" biological families had stronger parent-child relationships than homes in which adoptive parents that rejected biological difference. According to Kirk (1964) parents that accepted difference saw their lives with their adopted children as having a "shared fate" moving forward together as a family despite having different past histories. The movement toward openness and acceptance that adoptive families are not worse than, just different, from biologically formed families was a major paradigm shift.

The concept of "shared fate" applies in other ways for adoptive families. For example all of the adoptive parents in this study self-identified as white, while two thirds of their intercountry adopted children were racially different and all of the children were culturally different. The parents that adopted across race and culture acknowledged those differences. The parents that adopted transculturally but not transracially did not acknowledge the cultural differences. However all of the parents acknowledged the biological difference. In terms of disability, all but one of the adoptive parents acknowledged the differences regarding their child's disabilities. Perhaps these parents overwhelming commitment to continue to parent their children through the many out of home placements was the result of a feeling of shared fate.

Implications for Practice

Staff training. Intercountry adoptions are largely facilitated by social workers working at specialized adoption agencies. Professional training is a critical component of competent social work practice and yet adoption workers may not have received training or education on disabilities. The findings of this study suggest the need for specific training or professional development on disabilities for adoption social workers so they are knowledgeable and able to better prepare prospective adoptive parents for the risks associated with adopting a child with a disability. Currently there is no requirement for disability-specific training for adoption social workers.

Pre-adoption preparation. The pre-adoption preparation phase of the adoption process is a critical time during which adoption workers help prospective adoptive parents consider their capacity to parent. As part of this preparation work, a thorough discussion of the likelihood that a child adopted through intercountry adoption may have a disability or has the risk of developing a disability is needed. The findings of this study suggest that prospective adoptive parents are not receiving disability-related pre-adoption preparation. There are three specific recommendations. First, adoption workers could assess the degree to which prospective adoptive parents are accepting or rejecting of difference related to disability, according to Kirk's shared fate theory. Second, workers must facilitate an honest and transparent discussion with prospective adoptive parents regarding the risk of disability. Third, prospective adoptive parents might benefit from a "realistic job preview" by hearing from seasoned adoptive parents, including those with disabilities and/or whose children are in out of home placement, prior to adopting. Some social work positions, such as child protection, are high stress and result in high turnover; realistic job previews help with retention in this sector of the social work profession by offering child welfare students an opportunity to see what the job entails and in a way provides an avenue for opting out. In a similar way, prospective adoptive parents would benefit from seeing a fuller picture of

the challenges involved in parenting a child with a disability as another opportunity to make a fully informed decision.

I suggest a provocative paradigm shift to consider: Siebers (2006) recounts the challenge by some disability activists regarding the vast amounts of research dollars that are spent by the governmental, medical and health researchers aimed at preventing and eliminating disabilities when those funds might be spent on supporting and implementing universal access for everyone – a particularly salient idea as the general population ages and increased numbers of people not born with disabilities will develop a disability as they age. Siebers states that for some in the disability community, “it looks as if the government would rather eradicate people with disabilities than assist them” (p. 66). I argue that if adoption agencies operated under an assumption that every child has or is at risk for developing a disability that more resources could be allocated toward preparing and supporting prospective adoptive parents for parenting a child with a disability.

Implications for Policy

Process. Policies governing intercountry adoption focus on procedure and have a consumer, rather than child welfare, focus. While the Hague Convention on the Protection of Children and Co-operation in Respect of Intercountry Adoption includes guidance for protecting the best interests of children in the intercountry adoption process, the intercountry adoption policies in the U.S. focus on administrative processes and not on ensuring that the best needs of the child adopted to the U.S. are protected. The findings of this study suggest a paradigm shift in which child welfare is the focus of intercountry adoption policy and the central aim is to find families for children rather than a consumer focus where the aim is to find children for families. In addition, standard universal training requirements for workers facilitating intercountry adoption could be implemented for accreditation, particularly training on disability.

Training. An increase in training requirements for prospective adoptive parents is recommended. Currently ten hours of pre-adoption education for prospective parents is the minimum requirement for intercountry adoption under the Hague Convention. These ten hours of training must cover issues of adoption adjustment, race and culture, as well as disabilities; the pre-adoption trainings may also be completed through on-line webinars. There are no minimum training requirements under the Intercountry Adoption Act of 2000. In total, the training is insufficient and if a child welfare focus is the aim of intercountry adoption, an increase in the training hours that must be completed, in person, re-centers the focus of preparing prospective adoptive parents to be able to more sufficiently meet the needs of children with disabilities.

Data. Currently there are no national, centralized mechanisms for collecting adoption data, and adoption agencies are not required to provide data on intercountry adoptions and disabilities or numbers of intercountry adoptions facilitated by their agency that dissolve. While the Intercountry Adoption Act Sec. 205 requires state agencies to collect and report information on all intercountry adopted children who enter state care (including foster care or guardianship) or whose adoption is dissolved, there is no national mechanism for collecting and reporting this data. The findings from this study suggest such data would be useful in providing more robust post-adoption services for intercountry adopted children, and one recommendation would be for either the State Department, as the central authority for the U.S., or the U.S. Children's Bureau to collect and provide a public report of the data to the public.

Future Research

This study explored the experiences of adoptive parents who chose out of home placement for an intercountry adopted child with a disability. Findings from this sample of adoptive parents are limited to this sample. Several aspects of this study suggest further research.

First, this sample included only 19 intercountry adoptive parents that adopted a child born in a country outside of the United States. We do not know whether their constructions about

disability and adoption are similar to other intercountry adoptive parents. A national survey of intercountry adoptive parents would provide additional insight into displacement of intercountry adopted children with disabilities. In addition, we do not know whether intercountry adoptive parents are similar or different from parents that adopt through private domestic agencies or from domestic foster care agencies. A national survey of adoptive parents of children with disabilities would inform adoption practitioners, policymakers and researchers whether certain disabilities are more likely to prompt out of home placement; relationships between type of adoption, disability and out of home placement use; whether geographical or parent demographic differences exist; and whether differences in out of home placements based on type of adoption agency (public, private domestic, intercountry) exist. Testing the Adoption Displacement Decision-Making model would help inform the generalizability of the decision-making pathways of adoptive parents make regarding placing a child in out of home care. Designing and evaluating interventions for 1) preparing prospective adoptive parents and 2) supporting families post-finalization based on the Adoption Displacement Decision-Making model would assist adoption agencies and social service providers in supporting these adoptive families.

Second, this study asked for perspectives of adoptive parents and while many of the parents provided their thoughts about how their child experienced their disability and related out of home placement(s), the child was not interviewed. Therefore perspectives understood are based solely on adoptive parent perspectives. To understand the experience of out of home placement for adopted individuals with disabilities, more research is needed. Finally, the perspectives of adoption agency practitioners are not included in this current study. As the professionals preparing the adoptive parents, conducting the home studies, facilitating the matching of children into families and following up with families post-finalization, their perspectives and understandings about disabilities and adoption displacement and dissolution are important views that are needed.

Limitations

There are some limitations to this study. In terms of sample, it was difficult to find families due to the lack of national registries of adoptive families, and also due to the nature of the topic. Adoptive parents often lose contact with adoption agencies after the adoptions are finalized. Some of the adoption agencies closed their doors, as was the case for five of the families in this study. Other families chose to sever relationships with their adoption agencies. I contacted adoption agencies and asked them to disseminate my call for participants understanding that the agencies may have limited contact with the participants that met the criteria for the study. I also made use of online adoption support groups that consisted of families that met the criteria for this study. In doing so it is possible that a certain type of parent was interested in these online support groups and I may have missed reaching participants that had different views and experiences. One thing in particular that was striking was the high number of parents that followed through with the interviews that had taken on advocacy roles. It may be that these adoptive parents considered participating in the study as a form of advocacy, or that they wanted to share their story as a form of advocacy.

In addition, high profile adoption-related events happened during the course of this study. A media story by the Reuters news organization about re-homing in September 2013 may have made parents more reticent about participating in this study. Also in September 2013, Russia closed its adoption programs to the U.S. as a result of several issues including: 1) denied access by the director of Ranch For Kids residential treatment facility which serves a large Russian adoption population, 2) the death of 19 Russian-born children by their U.S. adoptive parents, and 3) concerns about the re-homing of Russian adopted children. All these events were widely reported in the media and following these events I was unable to recruit

participants for the study.

The consent form includes a mandated reporter disclosure since as a licensed social worker I am mandated to report any knowledge of the abuse of a child. This may have affected potential participant's willingness to be part of the study. Finally, my visibility in the adoption community through my role as a blogger, writer, trainer and professional may also have influenced participants. One participant talked about my professional and advocacy work and shared that she had read my blog. Participants may have chosen to participate or declined to participate based on my visibility.

Another limitation of this study is that the participants were asked to self-report events and many of the questions involved recalling information from several years past (Appendix B). For the three families where spouses or partners participated in the interview together I was able to obtain additional information as the partners would validate or contradict each other in recalling events. This study would have benefitted from having all of the interviews with both parents (if applicable) or for the single parents, with other family or friends that have been a part of the adoption process.

Finally, the study participants self-reported events involving their experiences with adoption agencies, social service agencies, extended families, and their children, and I did not verify these recollections with any of the external persons or organizations that were mentioned.

Conclusion

This study aimed to answer the question of why and how parents choose out of home placement for their intercountry adopted child with a mental health, intellectual or developmental disability. In addition, four sub questions guided this study and these questions included: 1) what were the parent's understanding of disability prior to adopting their child, 2) how do parents

construct disability, 3) what was the parent's experience with accessing and utilizing services, and 4) what has been the impact on the family's lives. This study also sought to understand the gaps that exist between intercountry adoption and domestic child welfare adoption, particularly the impact of the construction of children in foster care as having "special needs" and the construction of children adopted through intercountry adoption as not having "special needs."

The findings of this study show that adoptive parents come in to the adoption process with numerous constructs and ideologies about what it means to adopt a child through intercountry adoption. These constructs and ideologies are internalized through specific intercountry adoption policies that focus more on process than on child welfare. Minimal standards for adoption social worker training on disability do not exist and adoptive parent training requires only ten hours of pre-adoption training, of which disabilities is included.

Adoption social workers in the U.S. are at the forefront of building families through adoption and have great responsibilities. Much of the work adoption social workers do centers on preparing adoptive parents for the responsibilities of parenting children adopted from countries outside the United States. Adoption social workers find themselves in a tough position trying to balance a realistic vision of parenting an intercountry adopted child with a disability while not scaring off potential prospective families. Adoption social workers must conduct honest and transparent conversations with prospective adoptive parents.

This thesis began with the story of young Artyom, the child adopted from Russia and sent back alone due to his "psychological problems" (Cave, 2010). Artyom's mother, Torry Hansen, has never responded publicly to her decision. Until she does, the public will never know if she, as many of the parents in this study described, felt unprepared to adopt a child with a disability. In the time since Artyom's return there have been several significant events in intercountry adoption. Several cases of adopted Russian and Ethiopian child deaths by their adoptive parents made national news. The Ranch For Kids, a residential treatment facility in Montana that

specializes in intercountry adopted children, refused to allow Russian government officials visit that prompted, along with several Russian adoptee deaths, a full closure of Russian adoption to the United States (Radia & Curry, 2012; Volz, 2012). Reuters Investigation published “The Child Exchange” (2013) the results of an in-depth investigation into “re-homing,” the process of adoptive parents using the Internet to find people who will take custody of their adopted child. In the Reuters investigation of a Yahoo discussion group at least 70 percent of the 261 children presented by their adoptive parents seeking to dissolve their adoption over a five-year period were intercountry adoptions.

The actual experiences of the parents in this study differed considerably from their pre-adoption hopes and dreams. The current cultural discourse of intercountry adoption in the United States is all about constructs about orphans and vulnerable children, adoptive parents with good hearts and good intentions, and adoption as a means of mitigating developmental delays. Yet this was not the lived experience of the parents in this study. As Marie said, “You can’t run into a burning building and not get burned yourself.” The parents in this study advocated for a shift in the public and professional conception of intercountry adoption from one that considers it to be a means for a healthy infant to one that recognizes the similarities of the children to those in U.S. foster care. As Lily said,

But if we’re going to bring children here – particularly with international adoption – we’ve gotta make sure that we can be successful when we do that. And it shouldn’t be a business. It’s about child welfare. As a society and as individuals we have to recognize just what a serious thing it is and what a toll it can take on families.

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Appendix

Appendix A: Consent form

CONSENT FORM

Placement Stability for Intercountry Adoptees with Disabilities

You are invited to be in a research study of adoptive parents to better understand the pre- and post-adoption needs and experiences of adoptive families. You were selected as a possible participant because you responded to a call for participants for this study. We ask that you read this form and ask any questions you may have before agreeing to be in the study.

This study is being conducted by: JaeRan Kim, doctoral candidate at the School of Social Work at the University of Minnesota for her doctoral dissertation. You may contact JaeRan Kim at blev0001@umn.edu or 612-626-3831 or the faculty adviser, Dr. David Hollister at dhollist@umn.edu.

Background Information

The purpose of this study is to better understand the pre-and post adoption needs and experiences of adoptive parents of internationally adopted children with disabilities.

Procedures:

During this study, you will be asked to answer some questions about how you define disabilities, about your experiences with adoption, parenting a child with disabilities, and choosing out-of-home placement options for your child. This interview was designed to be approximately one to one and a half hours in length. The interview will be audiotaped.

After this interview, I will send you a summary of the interview and you will have the opportunity to clarify, change and validate your interview. You will receive a follow-up phone call (or in-person meeting if you prefer) with me to discuss the interview summary. This follow-up conversation may be 15 minutes to a half hour in length, depending on the your wishes. At any time during or after the interview, you may decide to stop the interview or withdraw consent with no repercussions.

Risks and Benefits of being in the Study

Talking about difficult times that your family has experienced may be stressful or bring up emotions for you. If you experience such emotion or stress, we can pause or end the interview at any time. Your participation will be anonymous and your personal information will be completely protected.

While there are no individual personal benefits to participants of this study, participants in this study have the opportunity to have your experiences and stories inform practice, policy and research on adoptive families.

Finally, I do not anticipate that in the course of our interview there will be any reason that you will disclose information about the abuse or neglect of a child. However, as a licensed social worker, I am mandated to report any information about the abuse or neglect of a child to the appropriate child welfare agency.

Compensation:

As a token of my appreciation, you will receive a \$25 gift card to a discount store (Target or Wal-Mart).

Confidentiality:

The records of this study will be kept private. In any sort of report we might publish, we will not include any information that will make it possible to identify a subject. Research records will be stored securely and only researchers will have access to the records. Study data will be encrypted according to current University policy for protection of confidentiality. Audio recordings will be destroyed once they are transcribed.

Voluntary Nature of the Study:

Participation in this study is voluntary. Your decision whether or not to participate will not affect your current or future relations with the University of Minnesota. If you decide to participate, you are free to not answer any question or withdraw at any time without affecting those relationships.

Contacts and Questions:

The researcher conducting this study is JaeRan Kim. You may ask any questions you have now. If you have questions later, **you are encouraged** to contact me at blev0001@umn.edu or 612-626-3831 or the faculty adviser, Dr. David Hollister at dhollist@umn.edu.

If you have any questions or concerns regarding this study and would like to talk to someone other than the researcher(s), **you are encouraged** to contact the Research Subjects' Advocate Line, D528 Mayo, 420 Delaware St. Southeast, Minneapolis, Minnesota 55455; (612) 625-1650.

You will be given a copy of this information to keep for your records.

Statement of Consent:

I have read the above information. I have asked questions and have received answers. I consent to participate in the study.

Signature: _____ Date: _____

Signature of Interviewer: _____ Date: _____

Appendix B: Interview guide

Interview Protocol

[Inform the participant of the nature of the study, the known benefits and risks, and obtain consent. Explain confidentiality; have the participants choose a name they would like to be referred to in the study. Ask for permission to tape the interview]

This first question is to get a general sense of who you are and to get to know you and your family.

Question 1. Tell me a little bit about your family. [Do a genogram; have parents give pseudonyms for children if they want to include “names” and year of birth and year of adoption]

Question 1b. Describe for me how you came to adopt your child.

[Prompts: Did something in particular prompt this decision? How did you come to the choice to adopt internationally?]

These next few questions are so I can get an understanding of your understanding of disabilities, both before and after you adopted your child.

Question 2a. What does the word “disability” mean to you?

Question 2b. What did you know about intellectual and/or developmental disabilities or mental health disabilities in general prior to adopting your child?

Question 2c. How did your adoption agency present or discuss the potential risks of adopting a child with a mental health or intellectual or developmental disability?

Question 2d. How did this information affect your decision to adopt?

[Prompt: Did you discuss what potential disabilities you were willing or able to accept? Did it make you change your mind about where to adopt? Were you open to adopting a child with disabilities? Did you turn down children because of their disability or risk of disability]

These next few questions are so I can get an understanding of your experience of parenting this child with diagnosed disability

Question 3a. Describe for me what disability or disabilities your child has been diagnosed with.

Question 3b. Describe for me what it is like parenting a child with an intellectual and/or developmental disability or mental health disability.

[Prompts: What have been some of the surprises? What have been some of the challenges?]

The next few questions are about your experiences with out-of-home placement services.

Question 4a. How did you come to make the decision about seeking out-of-home placement services?

Question 4b. Tell me about your experiences of having your child in out-of-home placement.

[Prompts: How has this experience affected your family? What helped? What did not help?]

Question 4c. What does the future look like in terms of your relationship with your child at this point?

The last few questions are to elicit parent expertise about the experience of placing an internationally adopted child with MH or I/DD in out-of-home placement.

Question 5a. What would you like people who do not have your experiences know or understand about adopting a child with MH or I/DD?

Question 5b. What advice do you have for adoption agencies about ways they could or should prepare and/or support families who have adopted children with MH and I/DD?

Thank you so much for taking the time to talk with me today. Is there anything else you would like for me to know about your experiences?

[Follow up with any references, information for the family, etc.]

Appendix C: Codes, categories and constructs

INITIAL CODE	SECOND CODING	CATEGORY	FINAL CATEGORY
<ul style="list-style-type: none"> • DESCRIBING FAMILY • HAVING ADOPTION IN FAMILY • HAVING FRIENDS WHO ADOPTED • DOING FOSTER CARE 	DESCRIBING FAMILY	CONSTRUCTING FAMILY	CONSTRUCTS
<ul style="list-style-type: none"> • RECEIVING FAMILY SUPPORT • LACKING FAMILY SUPPORT • RECEIVING NEGATIVE FEEDBACK ABOUT ADOPTING • BEING SUPPORTED IN DESIRE TO ADOPT • CARING FOR A NON-BIO CHILD 	REACTION TO ADOPTION PLAN	RELATIONAL COSTS	COSTS
<ul style="list-style-type: none"> • WANTING TO PARENT • TRYING HALF-HEARTEDLY TO HAVE BIO KIDS • WASN'T GETTING PREGNANT 	WANTING TO PARENT	CHOOSING TO HAVE A FAMILY	CHOICES
<ul style="list-style-type: none"> • CHOOSING TO ADOPT • ADOPTING A RELATIVE CHILD • WANTED TO ADOPT • PLANNING TO ADOPT SOME DAY • THINKING "IT'S A SIGN" • SEEING THE NEED • WANTING A CHILD THAT NEEDED PARENTS • ADOPTING FROM A DISSOLUTION • CHOOSING NOT TO HAVE BIOLOGICAL CHILD • WANTING BIO KIDS • BEING OLDER • BEING SINGLE • HAVING A DISABILITY • BEING INFERTILE • WANTING SIBLING FOR ANOTHER CHILD • WAITING UNTIL BIO CHILDREN WERE OLDER 	CHOOSING TO ADOPT	CHOOSING TO ADOPT <ul style="list-style-type: none"> • Infertility • Humanitarianism • Knowing someone who had adopted • Feeling it was only choice 	CHOICES
<ul style="list-style-type: none"> • CHOOSING INTERNATIONAL ADOPTION • CONSIDERING DOMESTIC ADOPTION • FEARING BIRTH FAMILY • FEARING "SPECIAL NEEDS" • DISQUALIFYING FOR 	CHOOSING INTERNATIONAL ADOPTION	CONSTRUCTING ICA Avoiding domestic <ul style="list-style-type: none"> • Birth parent issues • Special needs 	CONSTRUCTS

<p>DOMESTIC ADOPTION</p> <ul style="list-style-type: none"> • FEELING “SWEPT INTO” ICA • WANTING MORE CONTROL/CHOICE 		<p>foster care</p> <ul style="list-style-type: none"> • Chances of being chosen were slim <p>Choosing country</p> <ul style="list-style-type: none"> • Shortest wait • Easiest process • Prior connection to country • Country chose them 	
<ul style="list-style-type: none"> • CHOOSING A COUNTRY • CONSIDERING ANOTHER COUNTRY FIRST • SPEAKING LANGUAGE OF CHILD’S COUNTRY • HAVING WORKED/LIVED IN CHILD’S COUNTRY • HAVING VISITED COUNTRY • HAVING CONNECTIONS IN COUNTRY • LIKING CULTURE • BEING OPEN TO RACE & COUNTRY • HAVING COUNTRY CHOSEN FOR YOU • DISQUALIFYING FOR SOME PROGRAMS • MEETING CRITERIA FOR PROGRAM • LONGSTANDING PROGRAM WITH AGENCY • GOING WITH A NEW COUNTRY/PROGRAM • LOOKING FOR SHORT WAIT TIMES • LOOKING FOR EASIEST PROCESS • THINKING COUNTRY HAD HEALTHIER BABIES • SWITCHING PROGRAMS • RESEARCHING DIFFERENT PROGRAMS • RECOGNIZING COUNTRY CONTEXTS ARE DIFFERENT 	<p>CHOOSING A COUNTRY</p>	<p>CHOOSING ICA</p>	<p>CHOICES</p>
<ul style="list-style-type: none"> • CHOOSING A CHILD • WANTING AN INFANT • WANTING A SPECIFIC CHILD • WANTING A YOUNGER CHILD • WANTING A SPECIFIC RACE OR GENDER • WANTING AN OLDER CHILD • WANTING CHILD TO “MATCH” SIBLING • FINDING CHILD ON 	<p>CHOOSING A CHILD</p>	<p>CONSTRUCTING ADOPTION</p> <p>Choosing “healthy” child</p> <ul style="list-style-type: none"> • Completing a “Willing to consider form • Discussing risk of disability with agency • Choosing a 	<p>CONSTRUCTS</p>

<p>INTERNET</p> <ul style="list-style-type: none"> • NAVIGATING RACE IN ADOPTION • RECEIVING REFERRAL • WAITING FOR A LONG TIME • FALLING IN LOVE WITH A PHOTO/VIDEO • CHOOSING FROM A SELECTION OF OPTIONS • CONSIDERING A SPECIAL NEEDS CHILD • WANTING A “HEALTHY” CHILD • FEELING CONFIDENT IN GETTING HEALTHY CHILD • HAVING STARS IN MY EYES • RECEIVING CHILD’S HX • LOOKING “NORMAL” • BEING CAUTIONED BY ORPHANAGE WORKERS • HAVING ORPHANAGE MINIMIZE BEHAVIORS • SEEING RED FLAGS • UNDERSTANDING RISKS EXIST • HAVING LIMITED OPTIONS • TAKING A LEAP OF FAITH • MINIMIZING EXTENT OF POTENTIAL RISKS • CONSULTING WITH INTERNATIONAL ADOPTION EXPERTS • LACKING IMPORTANT INFORMATION ON CHILD • CONSIDERING A REFERRAL • DISCUSSING CHILD’S ISSUES • SAYING YES TO ADOPTING THEIR CHILD • DECIDING NOT TO ADOPT A CHILD • FEELING THEY COULDN’T SAY NO • FEELING LIKE THEY WERE SHOPPING • WANTING TO BE MORE OPEN • BEING OPTIMISTIC 		<p>specific, identified child</p> <ul style="list-style-type: none"> • Saying yes to a referral <p>Falling in love with photo/video</p> <ul style="list-style-type: none"> • Looking normal • Receiving background history • -Minimizing risk • -Red flags • -Having stars in my eyes 	
<ul style="list-style-type: none"> • MEETING BIRTH FAMILY • WISHING HAD CONNECTION W BIRTH FAMILY • SEARCHING FOR BIRTH FAMILY • CONNECTING WITH BIRTH RELATIVE 	MEETING BIRTH FAMILY	CONSTRUCTING ICA Child has birth family	CONSTRUCT
<ul style="list-style-type: none"> • MEETING CHILD • TRAVELING TO COUNTRY 	MEETING CHILD	CHOOSING CHILD	CHOICE

<ul style="list-style-type: none"> • VISITING AT ORPHANAGE • FALLING APART AT AIRPORT 			
<ul style="list-style-type: none"> • IMAGINING ADOPTED CHILD • COMPARING TO PREGNANCY • ANTICIPATING DREAM CHILD • WORRYING ABOUT CHILD HAVING SPECIAL NEEDS 	IMAGINING ADOPTED CHILD	<p>CONSTRUCTING ADOPTION: Adoption is like having child by birth</p> <p>Child will be like birth child</p>	CONSTRUCTS
<ul style="list-style-type: none"> • WORKING WITH ADOPTION AGENCY • CHOOSING ADOPTION AGENCY • GOING TO INFORMATION MEETING • GOING THROUGH HOME STUDY PROCESS • WORKING WITH OTHER COUNTRY • BEING ASKED TO ADOPT CHILD'S SIBLING • WANTING AN ETHICAL ADOPTION • RECEIVING PRE-ADOPTION EDUCATION • DISCUSSING RISK OF DISABILITY W AGENCY • HAVING AGENCY MINIMIZE RISK OF DISABILITY • COMPLETING "WILLING TO CONSIDER" CHECKLIST • WANTING TO LOOK GOOD FOR AGENCY 	WORKING WITH ADOPTION AGENCY	<p>CHOOSING TO ADOPT Adopting is less risky than having child by birth</p> <ul style="list-style-type: none"> • can control risks • choose the child <p>Agency is honest and transparent about risk of a child having a disability</p> <ul style="list-style-type: none"> • Willing to consider form gives parent ability to choose type of child they want 	CHOICES
<ul style="list-style-type: none"> • PREPARING TO ADOPT • JOINING AP GROUPS • READING & LEARNING ABOUT ADOPTION • RESEARCHING ADOPTION 	PREPARING TO ADOPT	CONSTRUCTIONS ABOUT ADOPTION	CONSTRUCTS
<ul style="list-style-type: none"> • BEING DISSOLUTIONED ABOUT ICA OR AGENCY • MARKETING ADOPTION (AGENCY PERSPECTIVE) • THINKING AGENCY COULD HAVE DONE BETTER • COMPARING TRAINING TO FOSTER CARE TRAINING • INFORMING AGENCY CLOSED DOWN • REALIZING AGENCY LIED/CONCEALED INFORMATION • REALIZING AGENCY'S POOR PRACTICES 	BEING DISSOLUTIONED ABOUT ICA OR ADOPTION AGENCY	EMOTIONAL CONSEQUENCES:	CONSEQUENCES

<ul style="list-style-type: none"> • SEEING UNETHICAL ADOPTIONS HAPPENING • FEELING MISLED BY ADOPTION AGENCY • FEELING MISLED BY COUNTRY • LEARNING OF COUNTRY'S CORRUPTION • RECONSIDERING PREVIOUS CHOICES OR ATTITUDES • BEING UNPREPARED • FEELING NAÏVE • LOOKING BEYOND GOOD INTENTIONS • SENSING HIGHER RATE OF SPECIAL NEEDS IN ICA NOW • SEEING THE "GOOD, BAD & UGLY" IN ICA 			
<ul style="list-style-type: none"> • CONSTRUCTING DISABILITIES • KNOWING ABOUT DISABILITIES • LEARNING ABOUT DISABILITIES • LACKING KNOWLEDGE ABOUT DISABILITIES • RE-DEFINING DISABILITY BECAUSE OF CHILD • DISCLOSING OWN (PARENT) DISABILITY • DISCLOSING FAMILY'S DISABILITY • KNOWING CHILDREN W DISABILITIES • THINKING ENVIRONMENT REDUCES DISABILITY • CONSIDERING IMPACT OF CHILD'S HISTORY 	DEFINING/CONSTRUCTING DISABILITIES	<p>CONSTRUCTING DISABILITIES</p> <ul style="list-style-type: none"> • Disability is physical • Disability is visible • Disability is having "difficulty" or an "inability" to do something "others" can do • Disability is more than developmental delay • Disability is not bad or negative • Disability "gets in the way" <p>CONSTRUCTING NORMAL</p> <ul style="list-style-type: none"> • Disability is not "normal" • "Like the rest of us" • "Like their peers" 	CONSTRUCTS
<ul style="list-style-type: none"> • PARENTING A CHILD WITH A DISABILITY • ADJUSTING TO ADOPTION • HAVING ROSE COLORED GLASSES • TRYING TO MANAGE BEHAVIORS • ACTING OUT AT HOME • LIVING WITH VIOLENCE • WORRYING ABOUT SAFETY • WORRYING ABOUT HURTING CHILD 	PARENTING A CHILD WITH A DISABILITY		COSTS

<ul style="list-style-type: none"> • PARENTING OUT OF DUTY, NOT LOVE • BEING BLAMED BY CHILD • BEING TARGET OF CHILD'S ANGER • CHANGING LIFE TO ACCOMMODATE CHILD • REALIZING OWN LIMITATIONS • LEARNING TO BE THE PARENT CHILD NEEDS • QUESTIONING PARENTING SKILLS • OVERESTIMATING PARENTING SKILLS • EDUCATING SELF ABOUT CHILD'S DISABILITY • UNDERSTANDING CHILD'S NEEDS • TRYING TO FIGURE OUT WHAT IS NORMAL AND WHAT IS DISABILITY • RECOGNIZING CHILD'S GIFTS AND TALENTS • LEARNING FROM CHILD OR EXPERIENCES (PERSONAL GROWTH) • COMMITTING TO CHILD • BEING AN OPEN BOOK • BECOMING AN EXPERT IN CHILD'S DISABILITY • CONSIDERING DIFFERENCE IN DEVELOPMENTAL VS CHRON AGE • DEALING WITH LEGAL ISSUES (FOR CHILD – ARRESTED) • FILING A LAWSUIT OR COMPLAINT • TAKING THOSE BULLETS FOR CHILD • DOING THIS IS FULL TIME JOB • MISSING WORK • TRYING TO WORK • STRUGGLING TO WORK BECAUSE OF THE DEMANDS • NEEDING TIME AWAY • LACKING OTHER AP'S OR SUPPORT GROUPS IN AREA • BEING UNABLE TO ATTEND SUPPORT GROUPS • WANTING SUPPORT • LACKING FAMILY SUPPORT • LACKING RESPITE WHO CAN MANAGE CHILD'S BEHAVIORS • STRUGGLING WITH FAMILY'S DENIAL OF THE PROBLEM 			
--	--	--	--

<ul style="list-style-type: none"> • STRUGGLING WITH FAMILY'S LACK OF SUPPORT • WANTING TO BE PROACTIVE 			
<ul style="list-style-type: none"> • COPING • FINDING SUPPORT • GETTING THERAPY (PARENT) • BEING A SUPPORT TO OTHERS • JOINING ADOPTION SUPPORT GROUP • CONNECTING WITH OTHER AP'S • RELYING ON FAITH • HAVING A SENSE OF HUMOR • TAKING IT ONE DAY AT A TIME • ACCEPTING I'VE TRIED MY BEST • FOCUSING ON THOSE HAPPY MOMENTS • THINKING IT COULD BE WORSE • BEING STRONGER THAN WE THOUGHT • DENYING HOW HARD IT WAS • MAKING TIME FOR EACH OTHER • WORKING TOGETHER TO GET THROUGH • LETTING GO OF EXPECTATIONS/GIVING UP CONTROL • BECOMING AN ADVOCATE • BEING A CAREGIVER • FEELING BONDED/ATTACHED TO CHILD • LOVING CHILD • TAKING PARENTING PLEDGE SERIOUSLY • TRYING TO STAY A STEP AHEAD OF KIDS 	TRYING TO COPE	PERSONAL COSTS	COSTS
<ul style="list-style-type: none"> • FEELING HOPEFUL/OPTIMISTIC • CONSIDERING CHILD A GIFT • EMPATHIZING WITH CHILD • FEELING HOPELESS • FEELING GUILT • \$\$ HAVING SPENT SO MUCH MONEY ON ADOPTING • RECOGNIZING PRIVILEGE • FEELING IF THEY DIDN'T ADOPT, WHO WOULD? 	FEELINGS ABOUT EXPERIENCES	PERSONAL COSTS Toll on personal well being <ul style="list-style-type: none"> • Toll on personal health • Toll on personal mental health Feelings of grief and guilt	COSTS

<ul style="list-style-type: none"> • FEELING GOOD IN KNOWING YOU'RE PROVIDING A BETTER LIFE • FEELING CALLED • FEELING FAMILY WAS "MEANT TO BE" • FEELING LUCKY/FORTUNATE TO BE CHILD'S PARENT • FORGETTING WHAT "NORMAL" IS • FEELING THERE ARE NO OPTIONS • FEELING POWERLESS TO HELP • FEELING MISUNDERSTOOD • HAVING A HARD TIME ASKING FOR HELP • ACKNOWLEDGING TOLL ON PERSONAL WELL BEING • BEING OVERWHELMED • BRINGING UP OWN UNRESOLVED ISSUES • EXPERIENCING STIGMA • DEALING WITH PUBLIC'S IGNORANCE • EXPERIENCING PITY • BEING ISOLATED • BEING JUDGED • BEING LONELY • BEING EXHAUSTED • FEELING DEPLETED • FEELING SHAME FOR ASKING FOR HELP • EXPERIENCING OWN PTSD/ STRESS/DEPRESSION • FEELING LIKE HAD TO CONTROL IT ALL • BEING ANGRY WITH CHILD • LOSING CONTROL 		<p>Grieving fantasy child</p> <p>SOCIAL COSTS</p> <ul style="list-style-type: none"> • Being isolated and lonely 	
<ul style="list-style-type: none"> • LIVING WITH DISABILITY • NOTICING DIFFERENCE • BEING SELF-CONSCIOUS • BEING STIGMATIZED FOR DISABILITY • HATING HAVING DISABILITY • FEELING LIKE A BAD KID • FEELING SINGLED OUT • FEELING SHAMED • GETTING FURTHER BEHIND • TRYING TO KEEP IT TOGETHER IN PUBLIC • FEELING SUICIDAL • FEELING HOMICIDAL • OVERDOSING • FEELING/SEEING DIFFERENCE ON MEDS • BEING GLAD TO HAVE A 	<p>LIVING WITH DISABILITY (CHILD'S VIEW)</p>	<p>COSTS TO CHILD</p>	<p>COSTS</p>

<ul style="list-style-type: none"> DISABILITY BEING RESILIENT 			
<ul style="list-style-type: none"> BEING ON TRACK DEVELOPMENTALLY NOTICING THINGS DEVELOPING SYMPTOMS/BEHAVIORS DESCRIBING BEHAVIORS KNOWING SOMETHING IS WRONG HAVING ROSE COLORED GLASSES REALIZING SERIOUSNESS OF ISSUES SEEING BEHAVIORS WORSEN RECEIVING AN INTERVENTION THINKING THEY'D JUST HAVE TO DEAL WITH IT RECEIVING DIAGNOSIS GETTING ASSESSMENTS TRYING TO FIGURE OUT DIAGNOSIS ACCEPTING DIAGNOSIS QUESTIONING DIAGNOSIS DEALING WITH MEDICATIONS BEING A PUZZLE 	DESCRIBING CHILD'S DISABILITY	<p>CONSTRUCTING DISABILITY</p> <p>Something more than developmental delays</p> <p>Having something to "hang stuff on"</p> <p>"Real" disabilities n not "adoption stuff"</p>	CONSTRUCTS
	FIGURING OUT DIAGNOSES	<p>CHOOSING ASSESSMENTS</p> <p>Getting assessments</p> <p>Considering diagnoses</p> <p>Being a puzzle</p>	CHOICES
<ul style="list-style-type: none"> STRUGGLING TO FIND RESOURCES FINDING TIME TO ACCESS RESOURCES LACKING RESOURCES ASKING FOR HELP GETTING ADVICE FROM OTHER AP'S LOOKING FOR RESOURCES ACCESSING RESOURCES RESEARCHING OPTIONS GETTING REFERRALS WAITING TO GET SERVICES INTERVENING EARLY USING PCA'S GETTING RESPITE TRYING TO FIND ADOPTION COMPETENT PROVIDERS CONSULTING WITH MEDICAL SPECIALISTS CONSULTING WITH A SPECIALIZED ADOPTION CLINIC LEARNING HOW LIMITED RESOURCES ARE ADVOCATING FOR MY CHILD CONNECTING W OTHER AP'S 	FINDING RESOURCES	<p>CHOOSING SERVICES</p> <p>Considering the symptoms and behaviors</p> <p>Managing safety</p>	CHOICES

<ul style="list-style-type: none"> • BALANCING CONFLICTING ADVICE/OPINIONS • NEEDING ADVICE ON HOW TO MANAGE • BEING STABLE FOR A WHILE 			
<ul style="list-style-type: none"> • RECEIVING AGENCY POST ADOPTION SERVICES • CALLING AGENCY FOR HELP • GETTING POST ADOPTION VISITS • HAVING AGENCY BE UNHELPFUL • FINDING AGENCY'S POST-ADOPT SERVICES HELPFUL • DOING POST-ADOPT REPORTS • BEING UNAWARE OF AGENCY'S POST ADOPT SERVICES • FINDING POST-ADOPT FOCUS ON CULTURE • FEELING STIGMA FROM AGENCY'S 	RECEIVING AGENCY'S POST-ADOPTION SERVICES	CHOOSING SERVICES	CHOICES
<ul style="list-style-type: none"> • WORKING WITH MENTAL HEALTH PROFESSIONAL • GOING TO A THERAPIST • SWITCHING THERAPISTS • BEING OUT OF THEIR DEPTH (THERAPISTS) • GETTING THE RIGHT THERAPIST • FINDING APPROPRIATE THERAPISTS/THERAPY • TRYING NEW STRATEGIES • HOPING CURRENT TREATMENT WORKS • LOSING CONTROL IN THERAPIST OFFICE • QUESTIONING THERAPISTS' COMPETENCE 	WORKING WITH THERAPISTS AND/OR MENTAL HEALTH PROFESSIONALS	CHOOSING SERVICES	CHOICES
<ul style="list-style-type: none"> • WORKING WITH OTHER PROFESSIONALS • PUTTING PROFESSIONALS UP ON PEDASTALS • TRUSTING PROFESSIONALS • BEING DISCOUNTED BY PROFESSIONALS • HAVING MORE KNOWLEDGE THAN PROFESSIONALS • WORKING WITH PEDIATRICIANS • WORKING WITH HOSPITAL STAFF/DOCTORS/PSYCHIATRISTS 	WORKING WITH OTHER PROFESSIONALS	CHOOSING SERVICES	CHOICES

<ul style="list-style-type: none"> • WORKING WITH CORRECTIONS 			
<ul style="list-style-type: none"> • DEALING WITH SCHOOLS • STARTING SCHOOL • STRUGGLING IN SCHOOL • HAVING A GOOD TEACHER • GETTING ACCOMMODATIONS • SWITCHING SCHOOLS • THREATENING OTHERS AT SCHOOL • DISRUPTING CLASSES • BATTLING WITH SCHOOL • DISAGREEING WITH SCHOOL • GETTING IEP • TRANSFERRING TO SPECIAL ED CLASSROOM • DEALING WITH PROBLEM TEACHERS/ADMIN • GETTING KICKED OUT OF SCHOOL • BEING PULLED OUT OF CLASS • GETTING RESTRAINED 	DEALING WITH SCHOOLS	SOCIAL COSTS Being judged	COSTS
<ul style="list-style-type: none"> • BEING IN CRISIS • GOING TO THE EMERGENCY ROOM/HOSPITAL • CALLING THE POLICE • WORKING WITH POLICE 	BEING IN CRISIS	CHOOSING OUT OF HOME PLACEMENT	CHOICES
<ul style="list-style-type: none"> • CHOOSING OUT-OF-HOOME PLACEMENT BEING ENCOURAGED TO PLACE CHILD IN OHP • CONSIDERING TREATMENT • REALIZING CHILD NEEDED OHP • FINDING APPROPRIATE OHP • PLACING CHILD IN OHP • WAITING FOR PLACEMENT • HAVING CHILD ARRESTED • BEING IN JD • HAVING NO SAY IN CHILD'S TX • REALIZING OHP IS NOT GOOD FOR CHILD • VISITING CHILD IN OHP • WORKING WITH STAFF AT RESIDENTIAL TREATMENT • RESISTING OHP (CHILD'S VIEW) • INVOLVING FAMILY IN OHP TX • KNOWING CHILD WAS NOT READY TO COME HOME • EVALUATING EFFECTIVENESS OF OUT OF HOME PLACEMENT 	CHOOSING OUT-OF-HOME PLACEMENT	CHOOSING OUT OF HOME PLACEMENT Considering effectiveness Getting recommendations Working with staff	CHOICES

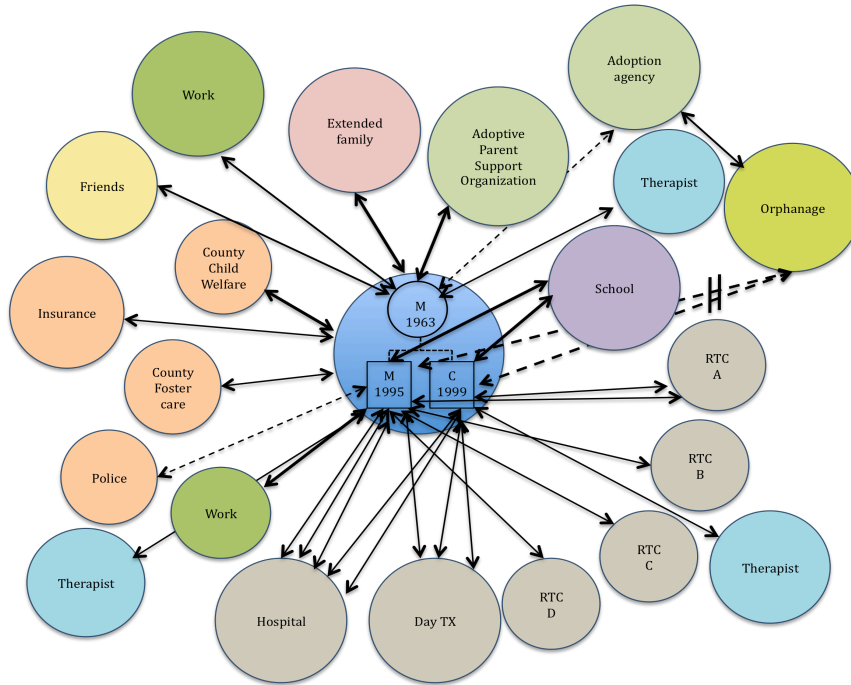
<ul style="list-style-type: none"> • REINTEGRATING CHILD BACK HOME • STRUGGLING IN OHP • GETTING KICKED OUT OF OHP BC OF BEHAVIORS • BEING DISCHARGED BC INSURANCE WOULDN'T PAY • LOSING IT AFTER HOME VISIT • CONSIDERING IT WAS WORTH IT • PAYING FOR TREATMENT • GETTING RESPITE WHEN CHILD IN OHP • FEELING LIKE THEY ABANDONED CHILD IN OHP 			
<ul style="list-style-type: none"> • CONSIDERIN DISSOLUTION • KNOWING DISSOLUTION WOULD HARM CHILD • FINDING A POTENTIAL ADOPTIVE HOME • TERMINATING PARENTAL RIGHTS 	CONSIDERING DISSOLUTION	CHOOSING TO DISSOLVE OR COMMIT Considering commitment	CHOICES
<ul style="list-style-type: none"> • NAVIGATING BUREAUCRACY • NAVIGATING IMMIGRATION • WORKING WITH INSURANCE COMPANIES • SWITCHING ISNRUANCE COMPANES • BEING TOLD INSURANCE NO LONGER WOULD PAY • APPEALING INSURANCE COMPANY DECISION • WORKING WITH THE SYSTEM • WORKING WITH COUNTY SERVICES • BEING CAUGHT BETWEEN SYSTEMS • BEING BLAMED BY COUNTY • TRANSFERING GUARDIANSHIP TO STATE • WORKING WITH MEDICAID • GETTING DD SERVICES/WAIVERS/SSI • NEEDING IQ<70 FOR DD SERVICES • NOT EXACTLY FITTING ALL THE CRITERIA • LEARNING NO ONE WILL TELL YOU HOW TO GET SERVICES • APPEALING FOR WAIVERS • BEING PART OF A MULTIDISCIPLINARY TEAM 	NAVIGATING BUREAUCRACY	COSTS Financial costs	COSTS
<ul style="list-style-type: none"> • IMAGINING THE FUTURE 	IMAGINING THE FUTURE	SOCIAL COSTS	COSTS AND

<ul style="list-style-type: none"> • LAUNCHING CHILD INTO INDEPENDENCE • BELIEVING CHILD CAN BE INDEPENDENT • FINDING HOUSING FOR CHILD • PLANNING TRANSITION • FILING FOR GUARDIANSHIP • COMING TO TERMS • RE-EVALUATING EVERYTHING • GRIEVING THE FANTASY/DREAM CHILD • WORRYING ABOUT THE FUTURE • WORRYING ABOUT CHILD BEING SAFE • WORRYING THINGS MIGHT GET WORSE • BEING UNCERTAIN ABOUT THE FUTURE • BEING REALISTIC ABOUT FUTURE • WANTING CHILD TO FEEL CAPABLE • SEEING POTENTIAL • THINKING ABOUT FUTURE ROLE • LETTING GO • MAKING PROGRESS 		<p>Being unable to do family things</p> <p>REDEFINING FAMILY</p> <p>REDEFINING DISABILITY</p>	CONSTRUCTS
<ul style="list-style-type: none"> • EMPATHIZING WITH FAMILIES 	EMPATHIZING WITH FAMILIES	EMOTIONAL CONSEQUENCES	CONSEQUENCES
<ul style="list-style-type: none"> • DESCRIBING OTHER ADOPTIVE PARENTS 	DESCRIBING OTHER ADOPTIVE PARENTS	EMOTIONAL CONSEQUENCES	CONSEQUENCES
<ul style="list-style-type: none"> • IMPACT ON FAMILY • BEING A FAMILY • REDEFINING “FAMILY” • BEING ON SAME PAGE WITH CO-PARENT • EXPERIENCING MARRIAGE/RELATIONSHIP STRESS • MANAGING IMPACT OF DISABILITY ON SIBLINGS • CAUSING SIBLING TO BE MORE EMPATHETIC • IMPACTING PARENTING OTHER CHILDREN • MINIMIZING SIBLING’S ISSUES • BEING EMBARRASSED BY SIBLING • BEING ANGRY AT SIBLING • MANAGING IMPACT ON OTHER FAMILY MEMBERS • BEING UNABLE TO DO THINGS 	IMPACT ON FAMILY	<p>RELATIONAL COSTS</p> <p>Managing impact on siblings</p> <p>Costs to marriages or partnerships</p> <p>Costs to relationships with extended family</p>	COSTS
<ul style="list-style-type: none"> • RECOGNIZING CHILD’S 	MANAGING OTHER	CHILD’S COSTS	COSTS

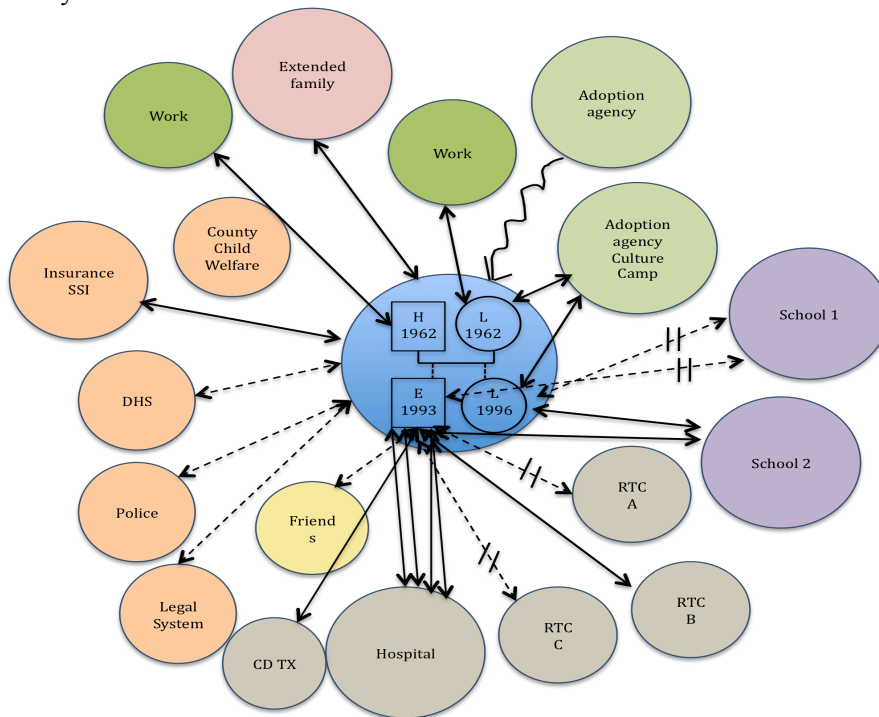
<p>SADNESS/TRAUMA/GRIEF</p> <ul style="list-style-type: none"> • RECOGNIZING ADOPTION ISSUES • NAVIGATING CULTURAL ISSUES • DISCUSSING RACIAL IDENTITY • THINKING ABOUT RACE 	ADOPTION ISSUES		
<ul style="list-style-type: none"> • ADVOCATING FOR CHANGE • ADVISING PROSPECTIVE ADOPTIVE PARENTS • IMPROVING ADOPTION AGENCY PRACTICES • IMPROVING POST-ADOPTION SERVICES • IMPROVING AWARENESS • PROMOTING EDUCATION ABOUT DISABILITIES • TRAINING, SPEAKING, EDUCATING • SUGGESTING A BETTER SOLUTION 	ADVOCATING FOR CHANGE	BEHAVIORAL CONSEQUENCES	CONSEQUENCES

Appendix D: Ecomaps

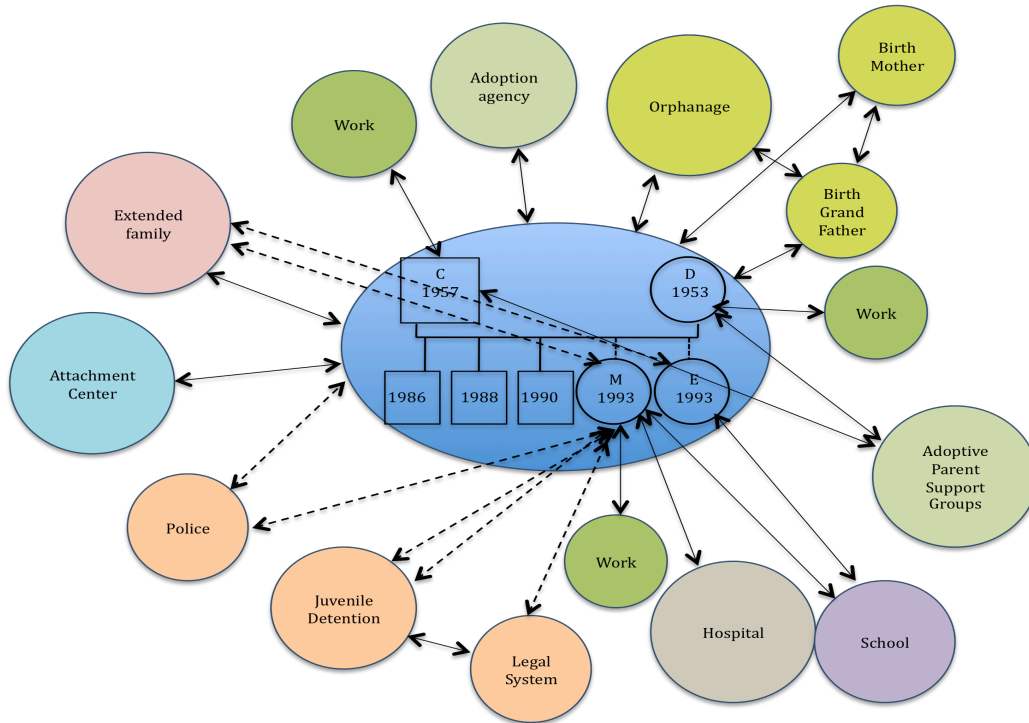
1. Mary



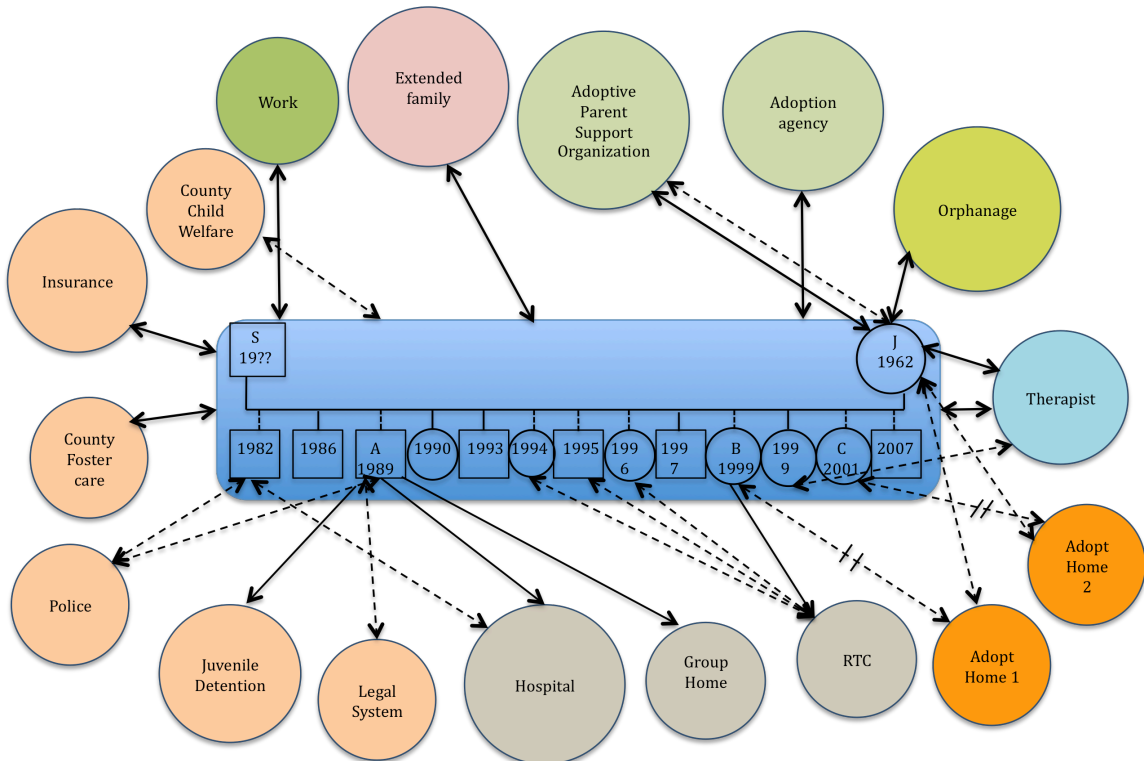
2. Lily



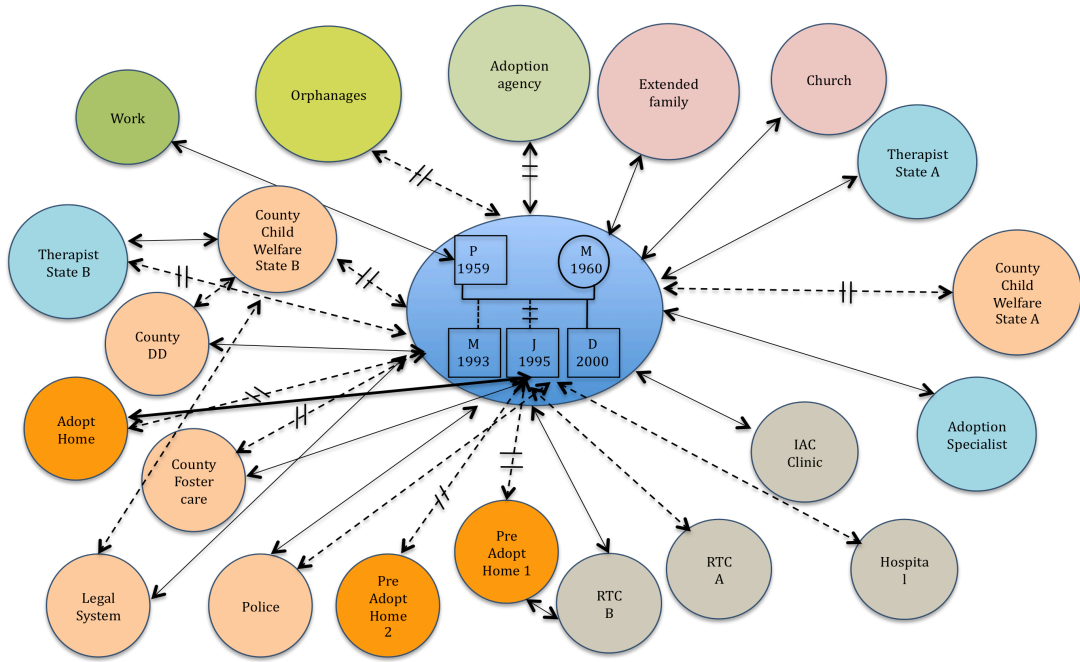
3. Chris and Debra



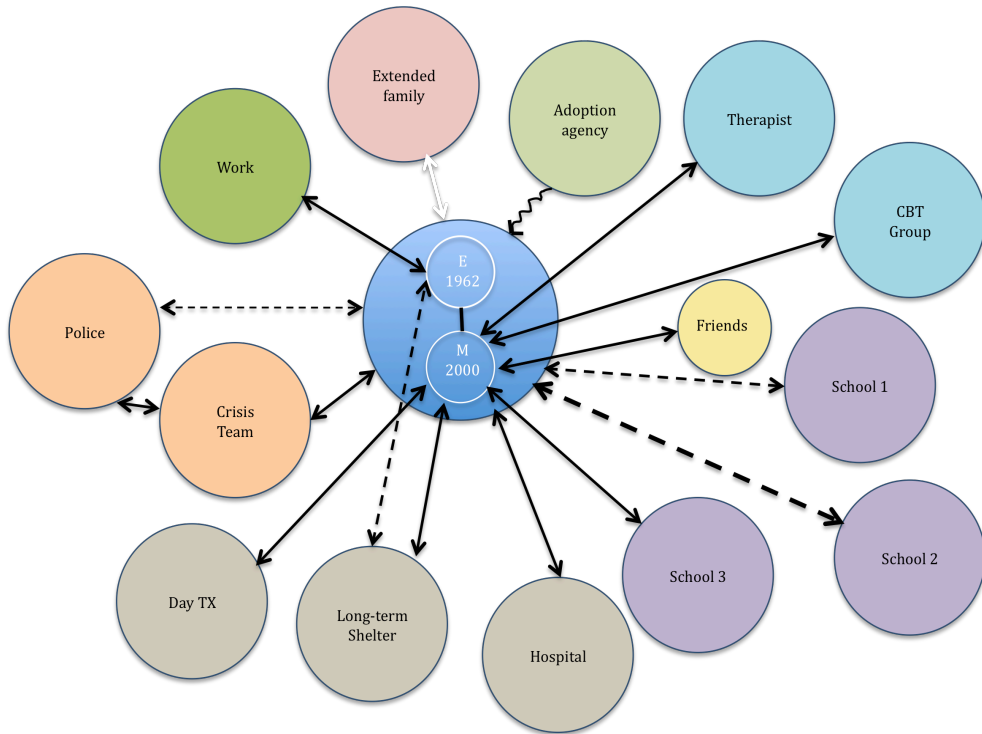
4. Janet



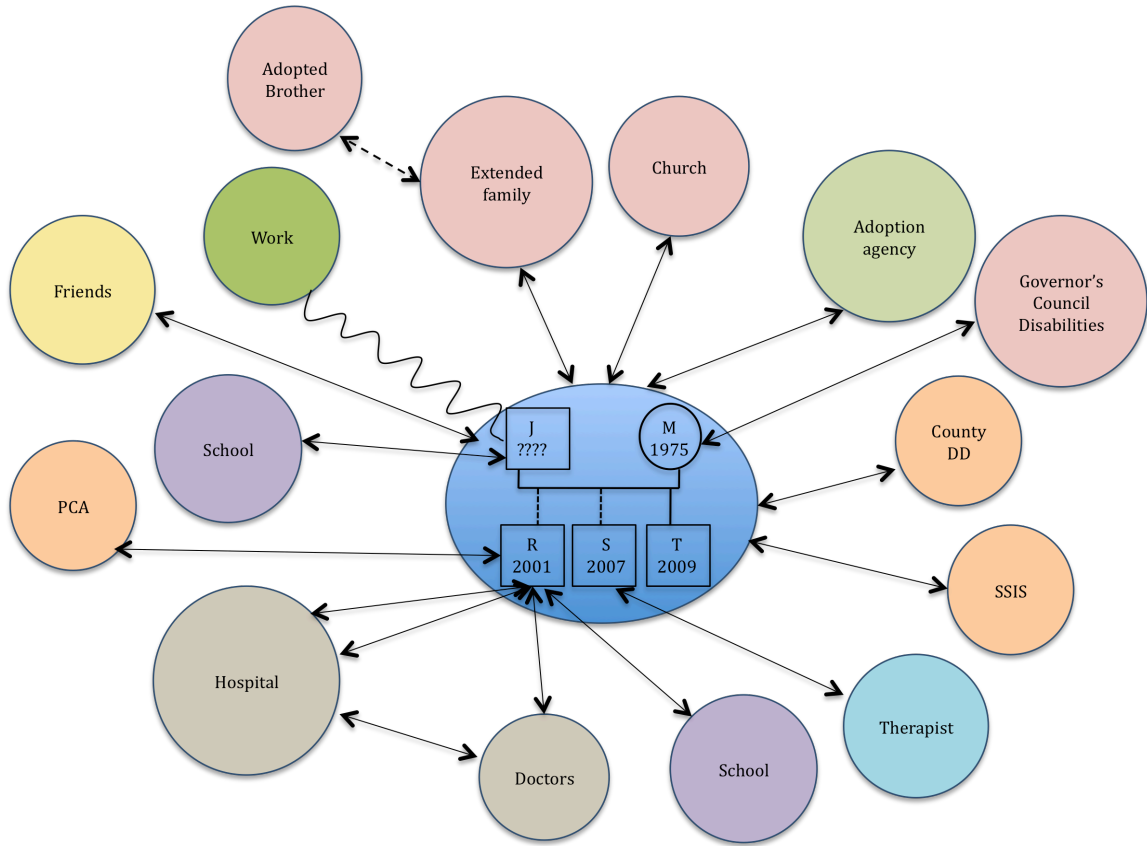
5. Patrick and Marie



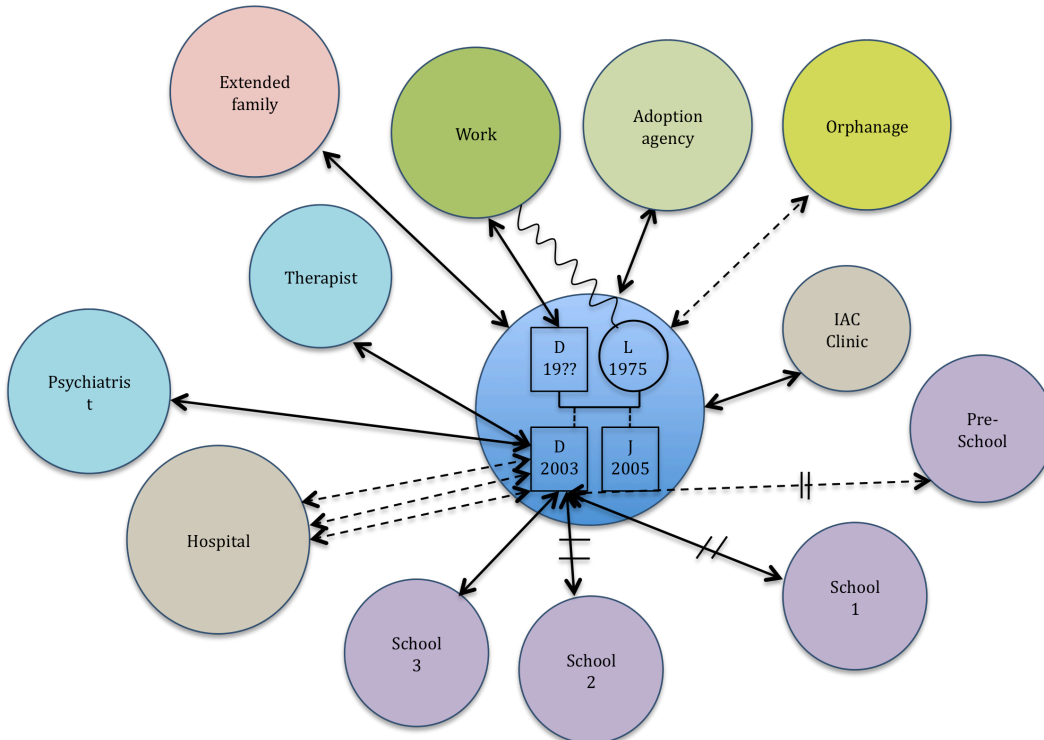
6. Eleanor



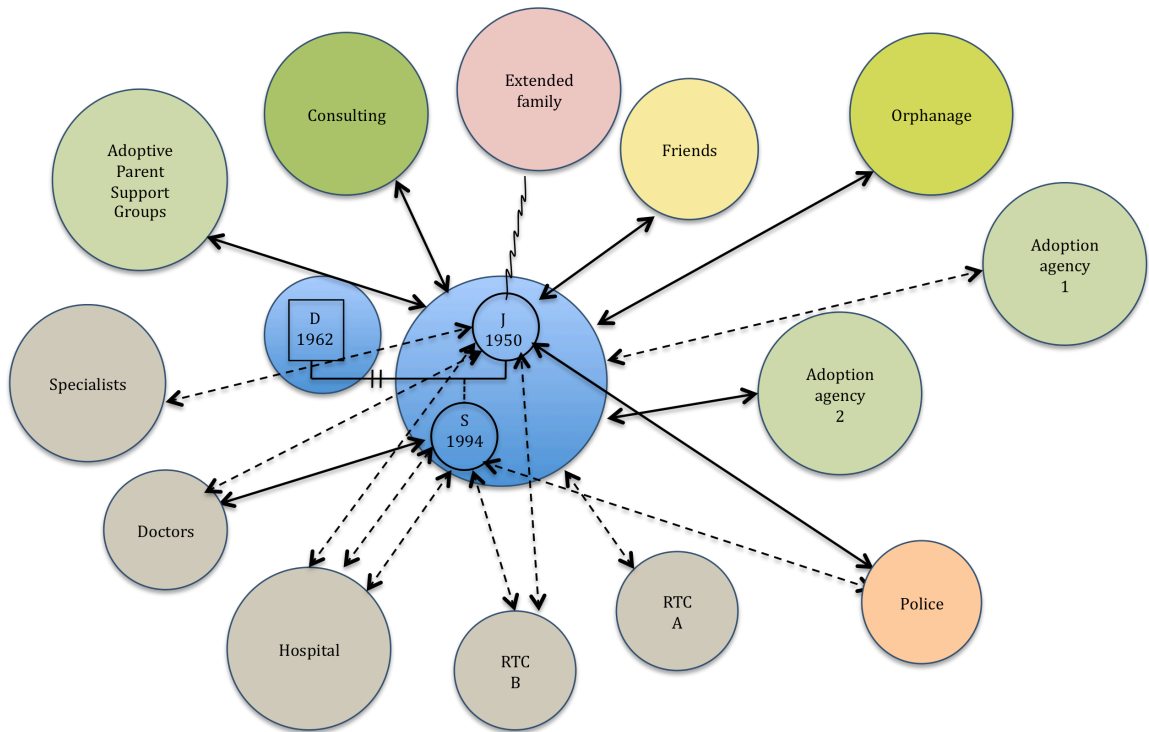
7. Melissa



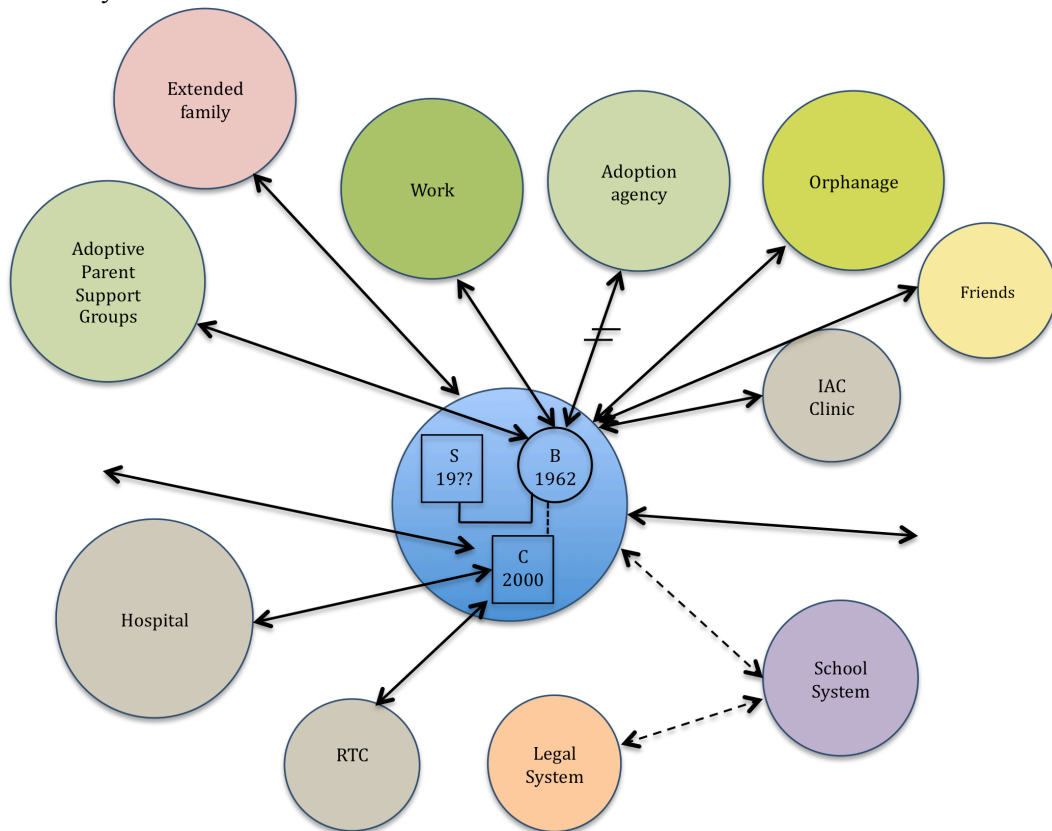
8. Laura



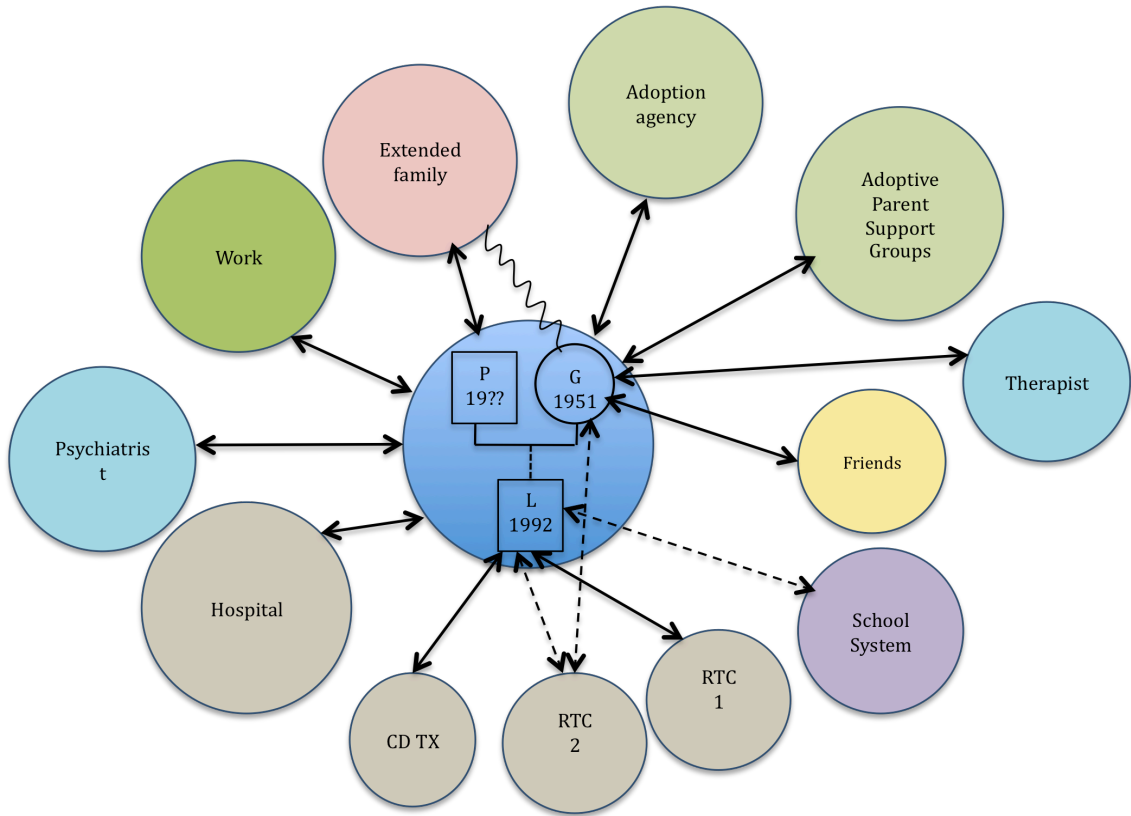
9. Jane



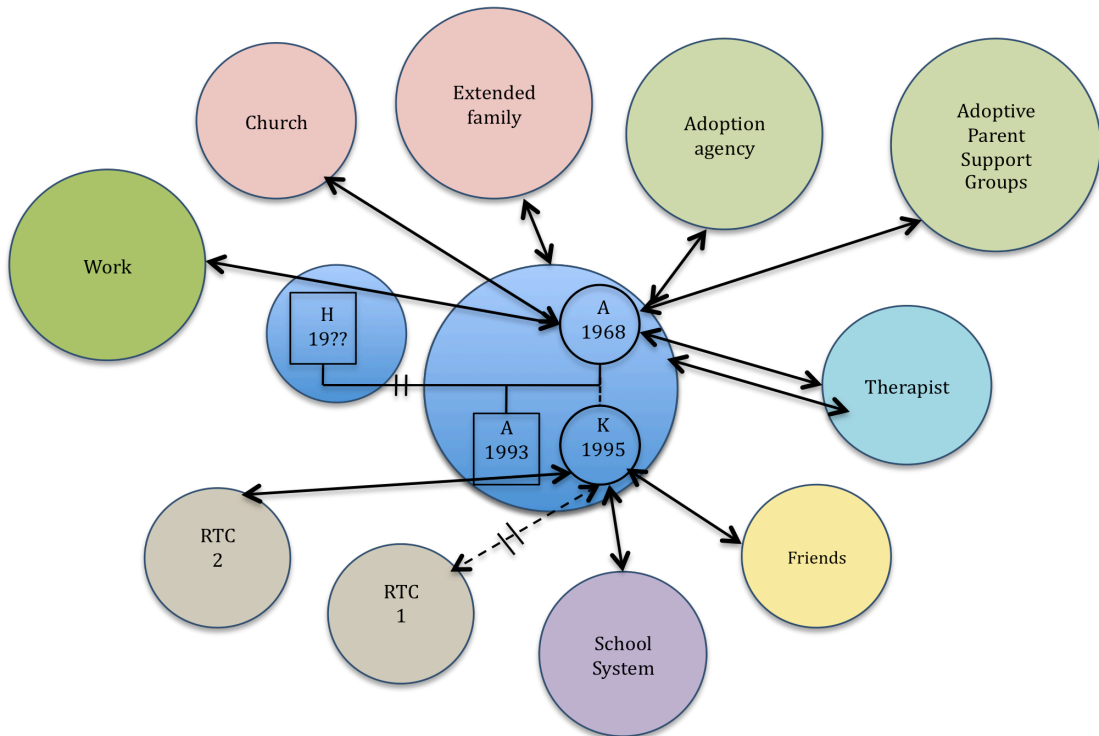
10. Becky



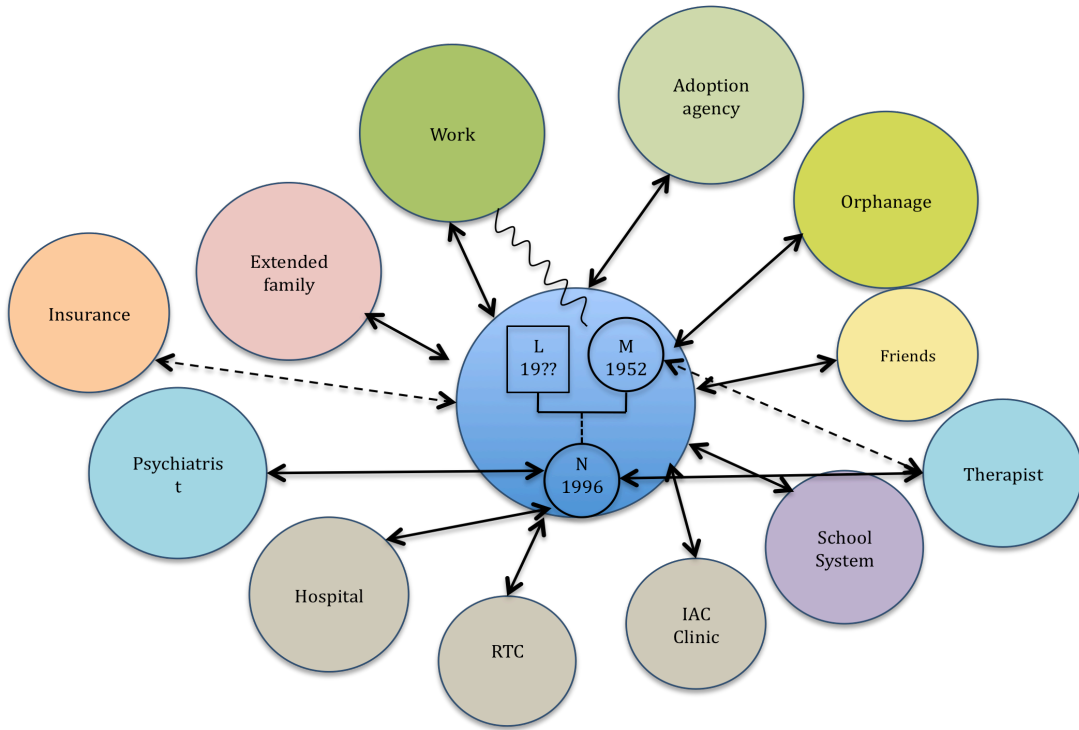
11. Grace



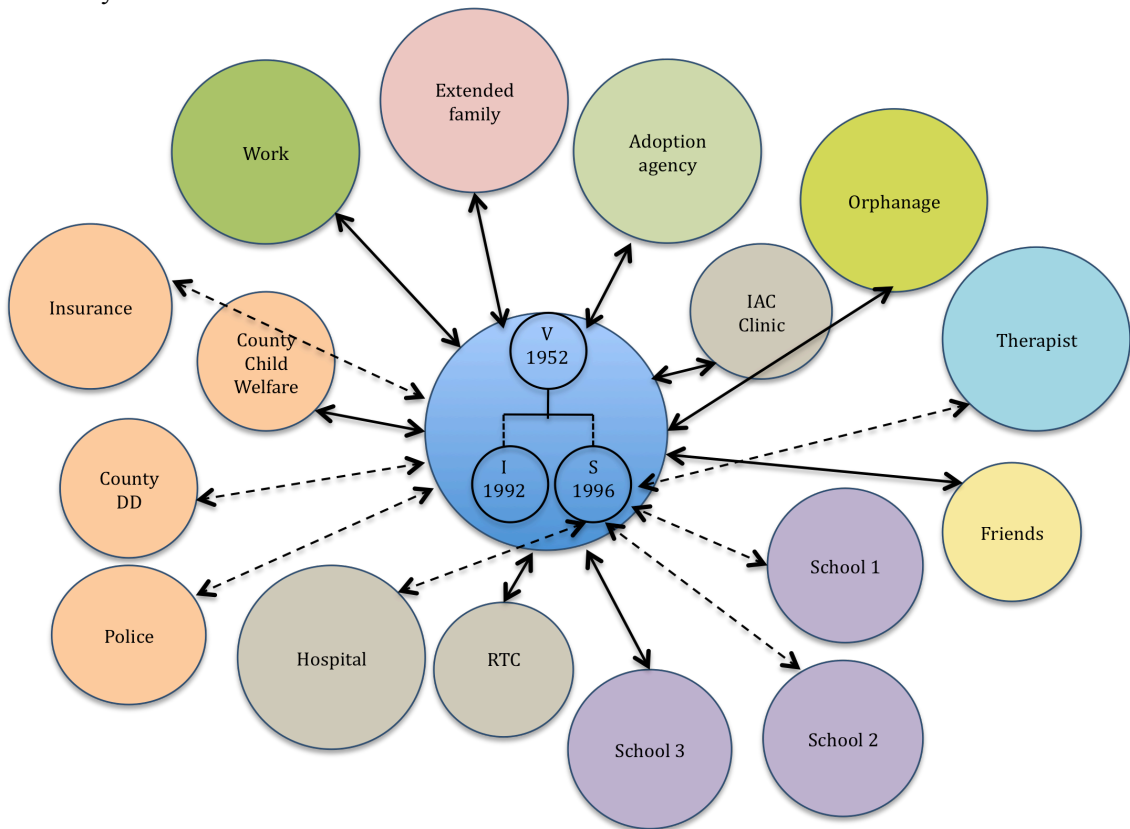
12. Anne



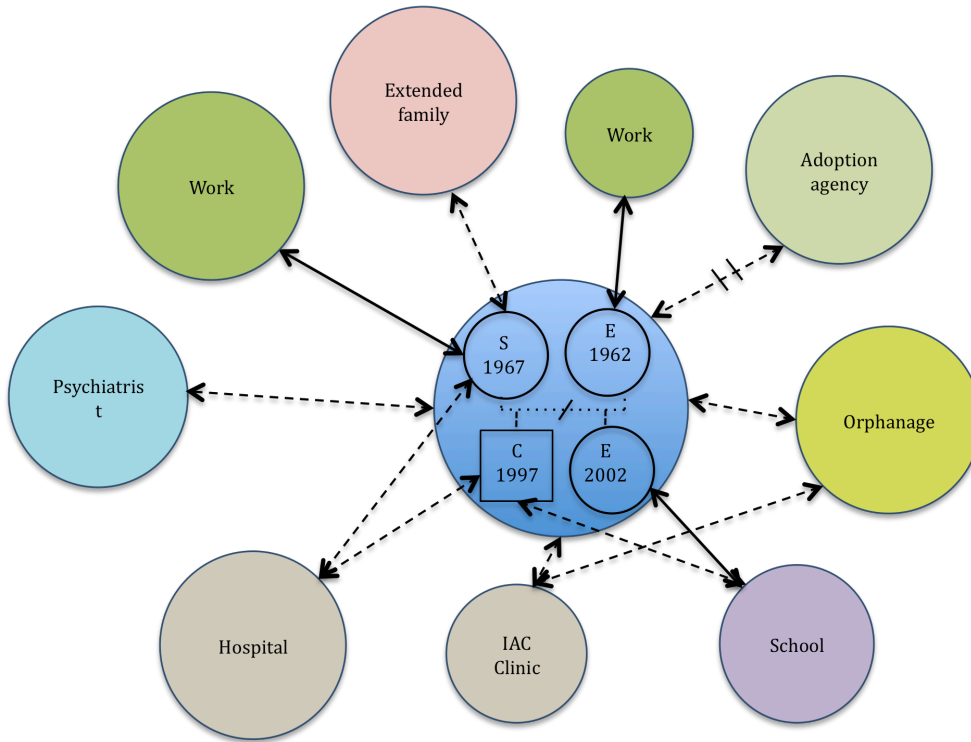
13. Mama



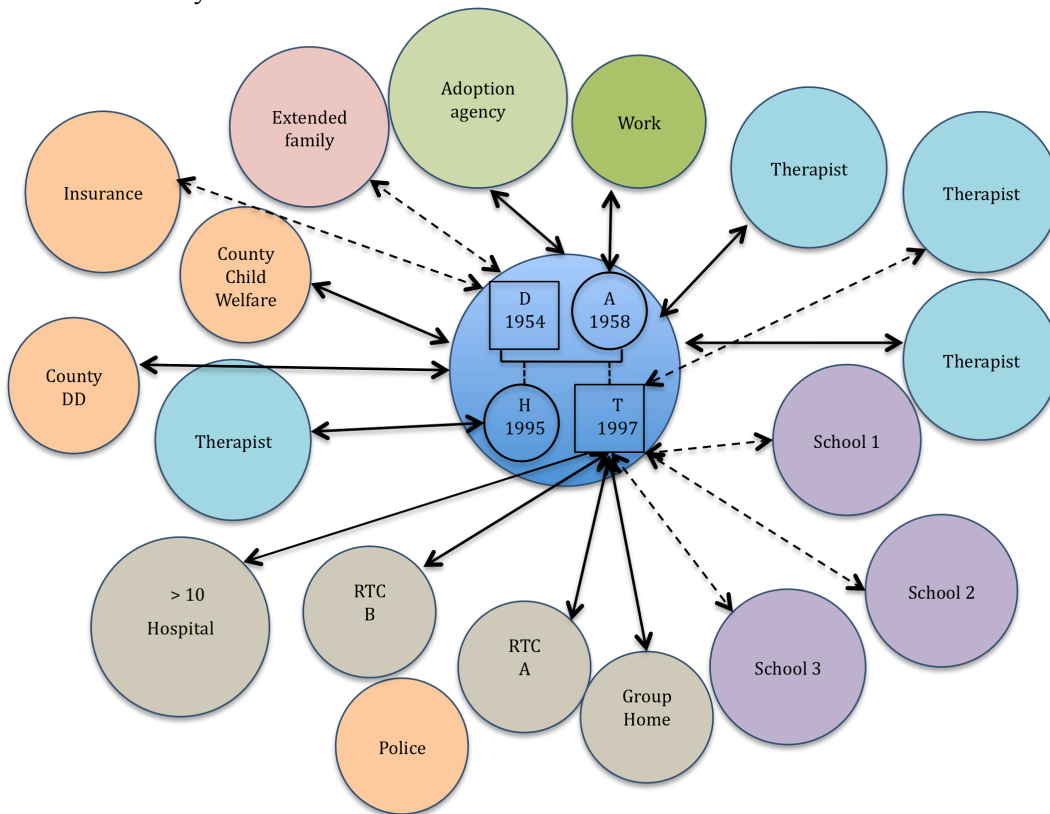
14. Vicky



15. Sarah



16. Dan and Amy



Appendix E: Parent Demographic Form

|Interview participant demographic information - Parent Information

Interview pseudonym: _____

Year of birth: _____ Gender: _____ Race: _____ Interview with spouse/partner? Yes No

Marital status: Married/Civil Union Divorced Single

Highest degree: High school or GED Some college AA BA/BS MA/MS PhD

Current state of residence: _____

Children Information – Please fill out the information below for each child

Year of birth	Gender	If adopted year of adoption	Country of birth if adopted	Disability/Diagnosis
_____	_____	_____	_____	_____
_____	_____	_____	_____	_____
_____	_____	_____	_____	_____
_____	_____	_____	_____	_____
_____	_____	_____	_____	_____
_____	_____	_____	_____	_____
_____	_____	_____	_____	_____
_____	_____	_____	_____	_____

Appendix F: Contact Summary Form

Contact:

Contact date:

Description of location and contact:

What were the main issues or themes that struck you in this contact?

Summarize the information you received (or failed to receive) on each of the target questions you had for this question:

Question 1. Tell me a little bit about your family.

Question 1b. Describe for me how you came to adopt your child.

Question 2a. What does the word “disability” mean to you?

Question 2b. What did you know about intellectual and/or developmental disabilities or mental health disabilities in general prior to adopting your child?

Question 2c. How did your adoption agency present or discuss the potential risks of adopting a child with a mental health or intellectual or developmental disability?

Question 2d. How did this information affect your decision to adopt?

Question 3a. Describe for me what disability or disabilities your child has been diagnosed with.

Question 3b. Describe for me what it is like parenting a child with an intellectual and/or developmental disability or mental health disability.

Question 4a. How did you come to make the decision about seeking out-of-home placement services?

Question 4b. Tell me about your experiences of having your child in out-of-home placement.

Question 4c. What does the future look like in terms of your relationship with your child at this point?

Question 5a. What would you like people who do not have your experiences know or understand about adopting a child with MH or I/DD?

Question 5b. What advice do you have for adoption agencies about ways they could or should prepare and/or support families who have adopted children with MH and I/DD?

Anything else that struck you as salient, interesting, illuminating or important?

What new (or remaining) target questions do you have in considering the next contact with this person?

Appendix G: Recruitment Flyer

Are you an adoptive parent of an internationally adopted child between 6-21 years old with a disability? Has the child lived – either temporarily or permanently – in a group home, residential treatment center, foster care or another adoptive family?



Adopting a child with disabilities can be both challenging and rewarding. Parents who have adopted children from outside the United States with mental health and intellectual/developmental disabilities sometimes struggle to find appropriate pre- adoption education and/or post-adoption support to help them manage the challenges of parenting a child with a disability.

The purpose of this study is to inform adoption practices and improve adoption supports for families that adopted children with disabilities.

What is involved: I am asking adoptive parents in the United States for about 60 to 90 minutes of their time to interview them about their experiences. Interviews may be conducted in-person or through video conferencing. Participation is voluntary and your information will be protected and confidential. Your participation in this study will never be disclosed.

Who: Adoptive parents whose internationally adopted child:

- Is currently between 6 and 21 years of age
- Has a disability (including physical, developmental, and mental health)
- Is currently, or has in the past, been placed in any of the following (other than for respite or a 72-hour hold):
 - Shelter
 - Foster care
 - Residential treatment center
 - Group home
 - Hospital treatment center
 - With another caregiver (in legal or informal transfer of custody)
 - With another adoptive family after a dissolution of the adoption

To participate in this study, or to find out more information about this study, please contact JaeRan Kim at blev0001@umn.edu or visit my website at jaerankimresearch.wordpress.com.

Appendix F: Recruitment Scripts

To agencies and organizations (email and/or letter):

Dear [Agency],

My name is JaeRan Kim and I am a doctoral candidate at the School of Social Work at the University of Minnesota. I am contacting you today to ask for your assistance in my dissertation research.

In my research, I hope to understand and learn how parents who have adopted children from outside the United States with disabilities (including mental health and intellectual/developmental disabilities) manage the challenges of parenting a child with a disability. I am hoping to look specifically at families where the parents have made the difficult choice to place their internationally-adopted child in temporary or permanent placements outside of the adoptive home.

I am looking for adoptive parents who would be willing to be interviewed and who would share their experiences. Your agency works with adoptive parents that may fit the criteria for my study. Would your agency be willing to help spread the flyer that I have attached to this email on my behalf? I am happy to meet with you in person or by phone to answer any questions you may have about me and my research.

Best,

JaeRan Kim

To electronic parent organization lists (i.e. Discussion boards, list-serves, and facebook groups):

Dear administrator of [GROUP],

My name is JaeRan Kim and I am a doctoral candidate at the School of Social Work at the University of Minnesota. I am contacting you today to ask for your assistance in my dissertation research.

In my research, I hope to understand and learn how parents who have adopted children from outside the United States with disabilities (including mental health and intellectual/developmental disabilities) manage the challenges of parenting a child with a disability. I am hoping to look specifically at families where the parents have made the difficult choice to place their internationally-adopted child in temporary or permanent placements outside of the adoptive home.

I am looking for adoptive parents who would be willing to be interviewed and who would share their experiences. Your [group] consists of adoptive parents that may fit the criteria for my study. Would you be willing to publish my *Call for Participants* notice that I have attached to this [email/inquiry] on my behalf? I am happy to talk further with you to answer any questions you may have about me and my research.

Best,

JaeRan Kim