EXPLORING ISSUES DURING SPECIAL NEEDS ADOPTIONS AND THE APPLICABILITY OF LIFE CARE PLANS TO ADDRESS THEM

By

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EXPLORING ISSUES DURING SPECIAL NEEDS ADOPTIONS AND THE APPLICABILITY OF LIFE CARE PLANS TO ADDRESS THEM

By

Vicky Patricia Buckles

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The purpose of this study was to identify the barriers associated with the adoption process of children with special needs and the potential of life care planning to address these barriers. At the end of 2009, there were approximately 115,000 children in the United States’ foster care system awaiting adoption. Of these children 60% were diagnosed with emotional, mental, or physical disabilities; conditions collectively referred to as special needs. Despite the disproportionate number of children with special needs, potential parents are more likely to adopt an able-bodied child. As a result, children with special needs tend to remain in foster care longer and experience a greater number of placements. Research has shown that the length and number of foster placements greatly impacts a child’s emotional well-being. As such it is important for these children to find permanent placement that will provide them with stability. The primary method of permanent placement for children in foster care is adoption. Therefore, this study was designed to explore the issues present with special needs adoptions as well as methods of addressing them. Using qualitative focus groups, the researcher explored adoption case managers’ experiences in placing children with
special needs and their opinions on the use of life care plans to aid the adoption process. Additionally, qualitative interviews were conducted with parents with adopted children with special needs in order to gain an understanding from their experience. When examining the data from the adoption case managers a number of themes were identified. From the case managers’ perspective barriers in the process included lack of information/education as well as unrealistic expectations of potential parents. The results from the qualitative interviews revealed a number of themes including decision making characteristics, emotions regarding the adoption process, and challenges in adopting and raising a child with special needs. Both the adoption case managers and parents felt that a life care plan is a useful tool to address some of the issues identified in this study. Future research on the application of life care plans were discussed as well as the impact of the findings on clinical practice.
CHAPTER 1
BACKGROUND

Introduction

At the end of 2009, there were approximately 115,000 children in the United States’ foster care system awaiting adoption (National Data Analysis System, 2009). Of these children, 60% have been diagnosed with emotional, mental, or physical disabilities conditions collectively referred to as special needs (Adamec & Miller, 2007). Specifically, in 2001 of the children awaiting adoption in Florida 96% had special needs (Adamec & Miller, 2007). Despite the disproportionate number of children with special needs, potential parents are more likely to adopt a child without a known disability (Office of Program Policy Analysis & Governmental Accountability, 2008).

The basic concept of adoption has been around for more than 4,000 years, with the first records appearing in Babylonian Code of Hammurabi in 2285 B.C. (Adamec & Miller, 2007). Of course, adoption has evolved since that time and currently is sanctioned as a legal process carried out within the United States court systems (Moe, 2007). Adoption is the legal process of terminating the birth parents rights and obligations, and then bestowing these rights onto the adoptive parents (Zamostny, O’Brien, Baden, & Wiley, 2003). The adoption process is managed through a variety of public and private agencies responsible for matching the child with an adoptive family and then helping the family complete the adoption process (Office of Program Policy Analysis & Governmental Accountability, 2008).

Public vs. Private Adoption Agencies

Potential parents use an agency to assist in completing the adoption process and must decide between private or public agencies. Private adoption agencies are
organizations licensed through the state to manage adoptions (Adoption Florida, 2007). The tax status of the agency may be either for-profit or not-for-profit and they do not receive funding from state or federal tax money. Since federal and state funding is not provided, private adoption agencies often charge a fee for adoption services (Moe, 1998). Furthermore, the lack of funding allows private agencies to make their own requirements for the birth and adoptive parents. Making their own requirements provides the agencies the opportunity to recruit pregnant women who may be considering adoption (Gilman, 2001). Therefore the children who are available through private adoption agencies are often younger, have less traumatic experiences, and fewer special needs (Moe, 1998).

On the other hand, public adoption agencies do receive state and federal tax money to provide adoption services (Moe, 1998). Therefore, the public agencies do not have a fee for adoption services. Furthermore, public adoption agencies receiving monetary support must follow both state and federal adoption laws, thus prohibiting the recruitment of families who are considering placing their children up for adoption (Gilman, 2001). Therefore, the children who are available for adoption through public agencies are often from the state foster care system (Moe, 1998). This means that the children have experienced traumatic events, are older, and often have special needs (Moe, 2005). The public adoption agencies will be the focus of this dissertation, since children with special needs represent the research population.

Foster Care’s Role in the Adoption Process

The foster care system plays a large role in the adoption process because it serves as a shelter for children who are being abused or neglected. Furthermore, children often remain in foster placement until a suitable adoptive home is established.
Determining if a child is being abused or neglected is the first step in deciding if foster placement is the best option for the child. The process of identifying abuse occurs when an allegation is made to the state’s abuse hotline. The abuse hotline is a call center which handles all abuse allegations and determines if they warrant investigation (Moe, 2005). Once an allegation is made, the child welfare investigators will examine the merits of the abuse/neglect claims. If abuse is not confirmed with positive findings the child remains in the birth parents care and the investigation is closed. On the other hand, if abuse allegations are confirmed the child is removed from their birth parents and placed either with available relatives or in foster care. At this point in the process the child is in the custody of the state and a case plan for permanency is developed. The initial goal of the case plan is reunification with the child's birth parents, however if they are unable to complete the case plan a permanency staffing is scheduled. The permanency staffing determines what type of long term placement is in the best interest of the child, including changing the goal of the case plan to adoption. If the permanency staffing determines that adoption is the appropriate goal, the foster care workers initiate the process of terminating birth parents rights and transferring the case to an adoption case manager (Office of Program Policy Analysis & Governmental Accountability, 2008). (Figure 1-1).

Current legislation, Child Safety, Adoption, and Family Enhancement (Child SAFE) Act of 2004, establishes incentives for states that determine long term placement for a child within 12 months of removal from their birth parents. Due to this legislation, the foster care systems attempts to establish the permanency goal within a year, however this does not often occur. The ineffectiveness of the current legislation increases the
number of foster placements and time before a child achieves a sense of belonging. The amount of time a child remains in foster care has a negative impact on the emotional well-being of the child (Powell, 2003).

**Adoption Case Managers**

Individuals who manage the care of the child and aid in the adoption process are referred to as case managers. Case management is simply the process of organizing, facilitating, and managing an individual’s situation (Powell, 2003). The case management process includes assessment, planning, facilitation, and advocacy for options and services to meet an individual’s needs (Case Management Society of America). As such, case management is beneficial in a number of arenas including adoptions. Specifically, adoption case managers advocate and guide the child and potential family through adoption process.

The process has a number of steps in which the potential families must go through in order to finalize the adoption. These steps include an orientation, educational course, home study, matching, placement supervision, and finalization of the adoption. The overall adoption process is shown in Figure 1-2 and will guide the discussion of the role adoption case managers perform. The process of finalizing an adoption requires the case manager to fulfill a number job tasks for both the child and potential parents.

**Case Manager’s Role with Potential Parents**

Potential parents who are interested in adoption must first attend an orientation meeting. The adoption case managers facilitate monthly orientation meetings as a method of recruiting potential families, educating the public on adoption, and advocating for the children who are in their care. If the potential parents are still interested in adopting, they will have to attend an eight week long intensive parenting class called
Model Approach to Partnership in Parenting (MAPP) (Adamec & Miller, 2007). This course provides the potential parents with information on the adoption process, as well as an intensive introduction to parenting skills. Adoption case managers will help the potential parents register for this course and document the completion of the training. Often, one of the agencies adoption case managers will conduct the parenting course as well (Office of Program Policy Analysis & Governmental Accountability, 2008).

The next step in the process is for the potential parents to consent to a home study, which is required by Florida State law (Nolo, 2005). The goal of a home study is to evaluate the potential parents’ desire and commitment to adoption, assess the home environment, and reasons for considering adoption. The assessment is generally conducted by the adoption agency’s case manager and will include interviews with family members, background checks, references, and an in-home evaluation of living conditions (Office of Program Policy Analysis & Governmental Accountability, 2008). After gathering all of the necessary information, the adoption case manager prepares a written report that summarizes the strengths, weaknesses, and overall suitability of the parents for adoption (Adamec & Miller, 2007). The home study will help guide the adoption case managers when completing the matching process.

After the potential adoptive parents have completed parenting classes and a home study, the adoption case manager will attempt to match them with a child. Matching is the process of choosing adoptive parents who are similar to the child. Similarities include appearance, interests, intelligence, personality, and those who will meet any additional needs of the child. The adoption case managers hold match staffing approximately once per week. During the staffing, all of the case managers assess the
incoming home studies and chose a child to match with them (Office of Program Policy Analysis & Governmental Accountability, 2008). Once the family is matched with a child, the case manager will contact the family and schedule a meeting. During this meeting, the case manager presents the potential parents with the child study and file for them to review. Allowing for review of the child’s chart helps the parents understand the background of the child and determine if they want to consider adoption. After providing the potential parent time to review the information, the case manager is available to answer any questions. At the conclusion of the meeting, the parents decide if they want to proceed to supervised placement (Office of Program Policy Analysis & Governmental Accountability, 2008).

When the potential adoptive family is matched with a child, placement supervision begins. The adoption case manager assists the family in preparing for the child as well as addressing any adjustment issues. The family must go through 90 days of supervision to assure that placement is appropriate for the child. During this time the adoption case manager has contact with the family through phone updates as well as weekly visits. Furthermore, the adoption case manager assists the family in completing all necessary paperwork and filing an adoption petition with the circuit court. The adoption petition includes the names, age and address of adoptive parents, the relationship between the adoptive parents and the child, the legal reason that the birthparents’ rights have been terminated, the home study, and a statement that adoption is in the best interest of the child (Nolo, 2005). After filing the adoption petition, the court systems will notify all necessary parties and schedule an adoption hearing. The adoption hearing is held in front of circuit court judge who reviews the
petition and any supporting documentation. The judge determines if the adoption is in the best interest of the child, and will issue an order finalization of the adoption. The final decree of adoption legalizes the new parent-child relationship and legally changes the child’s name (Nolo, 2005).

**Adoption Case Managers Role with the Child**

The adoption case manager becomes involved in the child’s care during the permanency staffing; refer to Figure 1-2. At this time, the case has not been transferred from the foster care worker; however the adoption case manager attends the staffing to obtain an understanding of the child. Gaining an understanding of the child and his or her needs will allow the case manager to start preparing the child for adoption. Moreover, this meeting provides the adoption case manager and foster care worker the opportunity to communicate with each other regarding the case. Often, this collaboration helps smooth the transition between agencies (Office of Program Policy Analysis & Governmental Accountability, 2008).

The adoption case manager truly takes over the child’s care (transfer from foster care worker to adoption case manager) after the judge agrees to the goal of adoption and terminates the biological parents’ rights. The adoption case manager is now responsible for all aspects of care for the individual. As such, it is the responsibility of the case manager to schedule necessary health care appointments, provide transportation, and represent the child’s interest in front of the judge. The adoption case manager basically acts as the child’s parent while he or she are awaiting adoption, furthermore the case manager maintains accurate files on everything that occurs which will allow for this information to be passed onto potential parents. The files should contain a comprehensive history of the child including: available birth records, birth
certificate, social security card, all abuse reports, immunization records, birth parent’s information etc. If any of this information is missing, the case manager has to request the information from the necessary sources to place in the chart (Office of Program Policy Analysis & Governmental Accountability, 2008).

The process of recruiting potential families for a child requires that the case manager present the child to potential parents. One way for the case manager to present the child is through the use of current profiles. The child’s profile is organized and presented in two different methods. The first method is a child study, which is a written narrative containing relevant information about the child and includes reason for removal, medical background, family background, and the child’s interests. The other method of profiling the child is a summary of their basic information that is posted on the states adoption website. This allows potential parents to search and identify children they may be interested in adopting. The adoption case manager is responsible for maintaining accurate profiles of the child.

Once the child is matched with a family, the placement phase begins. The case manager helps prepare the child for meeting his or her new parents. As such, the case manager takes on a supportive role during the process and sets up necessary services to help the child adjust to their new surroundings. Moreover, the case manager talks with the child to assure he or she is happy with current placement before deciding to finalize the adoption. The final responsibility of the case manager is to establish post adoption supports. The case manager arranges for any services that are deemed necessary at the completion of the adoption, which could include counseling, specialty
doctors, primary care physician, and referrals to support groups. At this point the adoption case is closed and removed from the case manager’s caseload.

**Training Methods for Adoption Case Managers**

Adoption case managers guide the child and potential family through the adoption process. The process of adoption involves a number of steps and potential obstacles that the case manager must understand and know how to resolve. Therefore, the U.S. adoption systems designed a specific training program that a person must complete before practicing as an adoption case manager. The training is intended to provide the case manager with specialized skills in understanding adoption process, preparing written reports for the court, matching families, completing a home study, and how to help a family through the adoption process. The training program consists of tasks that the case manager will perform within each stage of the adoption process (pre-placement issues, preparation of the child for adoption, presentation of the child, adoption assistance, and placement/post adoption services). Training in each area is achieved through a combination of chart reviews, on the job observations, and a final submission of completed adoption file for review. The training process can last up to six months and during this time the employee is considered on probation. Successful completion of an adoption file will allow the person to start practicing as an adoption case manager while under supervision (Florida Department of Children and Families, 2007).

The current training method of adoption case managers is very intense. The training helps the individual learn the necessary skills to guide the family and child through the process, however there are strengths and weaknesses with the current training curriculum. The training program involves mixed learning methods to assure
the case manager obtains a comprehensive understanding of their role. The program also requires the individual to complete an actual adoption case file to assure they know how to apply the knowledge that they have learned.

The weaknesses of training apply directly to the adoption of children with special needs. The standard training program does not include a component on managing special needs children (Florida Department of Children and Families, 2007). Furthermore, the case manager will probably never come in contact with a chart or observe a child that has special needs until they obtain a regular caseload (Moe, 2005). Since there is not a component covering children with special needs, the case managers remain unaware of the types of services and additional needs necessary. This leaves the case manager in an unfamiliar and difficult position when planning the adoption process, recruiting, or matching for a child with special needs. This becomes a disadvantage for the children who have special needs, because they may not be placed in an environment that affords them the best opportunity for permanency.

Considering the highest rate of failed adoptions is with children who have special needs, improvements to the training requirements are necessary to provide adoption case managers with a more comprehensive understanding regarding the aspect of special needs (Adamec & Miller, 2007).

**Barriers within the Adoption System**

Adoption is a complex process and the adoption case managers must understand all aspects in which potential parents must complete. For this reason the lack of specialized training regarding special needs adoption creates a large barrier towards successful placement of children with special needs. Moreover, research has revealed a number of issues in relation to the adoption process (Nolo, 2005). Florida’s Office of
Program Policy Analysis & Governmental Accountability (OPPAGA) recently published a review of the state’s child welfare system. This report revealed that Florida consistently lagged behind national standards in the total number of successful adoptions. The report discussed some of the major barriers contributing to the lack of adoptions. The number one barrier identified by adoption agencies was locating families who are willing to adopt children with special needs. The agencies felt that a number of the children in their care had either medical or behavioral issues that deterred potential parents from considering adoption. Another issue preventing adoption was that potential adoptive parent felt they were unable to obtain adequate information regarding the child’s needs to feel comfortable with becoming responsible for the child’s care (Office of Program Policy Analysis & Governmental Accountability, 2008).

Another issue to consider when examining adoption is the dissolution rate. Dissolution of adoption occurs when the adoptive parents decide the adoption is not going to work and the child is returned to foster care (Moe, 2005). The adoption agency must keep records on the number of failed adoptions and revealing that up to 20% of special needs adoptions result in dissolution. This is compared to 3% dissolution rate for all other adoptions (Smith & Howard, 1999). As a result of high adoption dissolution, research started focusing on the factors that contribute to a parent deciding to disrupt the adoption. One of the prominent reasons documented by more than ten research studies is the number and severity of the child’s needs at the time of adoptive placement (Adamec & Miller, 2007). Parents often report that the child having any emotional, cognitive, or physical problems was too difficult to handle (Mallon & Hess, 2008).
2005). Another major reason for dissolution expressed by adoptive parents is the lack of information regarding the extent of the child’s care prior to adoption. The parents felt that they were not prepared for what was expected of them, resulting in the decision to dissolve the adoption (Mallon & Hess, 2005).

**Provision of Healthcare for Adopted Children with Disabilities**

Financial support for meeting the disability related needs of an adopted child is most often provided by state Medicaid. The Medicaid program was enacted in 1965 under Title XIX of the social security act and is funded through a state and federal partnership. According to the legislation, the Medicaid plan is administered by each state in accordance to their individual state plans. The goal of the Medicaid program is to improve the health coverage of those who otherwise might not be able to afford their medical care, therefore under the Medicaid plan the state reimburses providers for medical services rendered to qualified individuals. Each recipient must meet specific eligibility requirements to be covered under Medicaid, which are determined by federal and state legislation. The eligibility criteria and more on Medicaid will be discussed in Chapter 2.

**Life Care Planning**

One potential method of addressing the barriers within the state adoption system, including limitation in training and case manager’s knowledge base, is through the use of life care plans. Life care plans are dynamic documents that organize a concise plan for the current and future needs of individuals with disabilities (Weed, 2004). The plans are created for both children as well as adults and examine the disability through life expectancy. Each life care plan is based upon published standards of practice, comprehensive assessments, data analysis, and research (NARPPS, 2004).
Specifically, the life care planner makes recommendations on the medical, psychological, social, and environmental needs based on the person’s functional abilities as well as published standards of care (Weed, 2004). The plan explains the frequency, duration, rationale, and cost of the necessary recommendations. Organization of the plan can vary between life care planners, however they generally cover 16 basic areas: projected evaluation, projected therapeutic modalities, diagnostic test/education, wheelchair needs, wheelchair accessories, orthopedic/prosthetic, home furnishings and accessories, aids for independent functioning, medication, supply needs, home care/facility care, projected routine medical care, aggressive medical care, transportation needs, architectural renovations, leisure or recreational equipment (Deutsch & Sawyer, 2002). The life care planner uses a consistent methodology when establishing recommendations to assure valid and reliable plans that will meet the individual’s needs. A discussion of the specific steps in developing a life care plan will be included in Chapter 2.

Life care plans are currently used in personal injury and other types of litigation cases in order to educate their audiences (Weed, 2004). Education regarding the accurate disability related needs is one of the primary goals of LCPs. For this reason LCPs would be an organized and concise method for adoption case managers to communicate the disability related needs when attempting to place a child with special needs.

**Research Methods**

As stated earlier, LCPs are a comprehensive tool that predicts the disability related needs through life expectancy, and as such it is difficult to obtain valuable information regarding the use of life care plans when employing short term quantitative research.
The use of either longitudinal quantitative or in-depth qualitative methods will provide the best information. This study aims to explore the use of LCPs with special needs adoption, and therefore uses an in-depth qualitative method which will be discussed in Chapter 3.

**Goal of the Research**

The primary goal of this dissertation was to conduct a qualitative study to analyze the use of Life Care Plans within the adoption system. This research will lead to the development of a specialized model of Life Care Planning for use in the adoption of children with special needs.

**Question #1**

What are the perceptions of adoptive parents of children with special needs regarding the use of life care plans during the adoption process?

**Question #2**

What are adoption case managers' perceptions regarding the use of life care plans with a special needs adoption?
Figure 1-1. Foster care process
Figure 1-2. Adoption process
CHAPTER 2
LITERATURE REVIEW

Issues of Special needs Adoptions

In 2007 there were 8,000 children in the Florida foster care system (AFARCS, 2009). These children remain in foster care until a suitable adoptive placement is found, however for many children this takes years or may never occur (Moe, 2005). The average length of stay for children awaiting adoption is greater than two years (AFARCS, 2008). The extended length of time in foster care is due to the fact that foster care adoptions are consistently lower than adoptions from private or international agencies; furthermore disabilities are overrepresented in foster care system versus the general population (AFARCS, 2008; Moe, 2005). The combination of these two characteristics means that children often linger in the foster care system for an extended period of time.

People who consider adoption are less likely to be willing to adopt a child who is in the foster care system (Dave Thomas Foundation, 2007). This is evident when examining the statistics regarding adoption because in 2001 a total of 8,435 children were adopted in the state of Florida (Child Welfare Gateway, 2005). Of those adoptions only 17% or 1,466 were from the public foster care system (AFARCS, 2005). These numbers are consistent with national statistics with only 39% of all adoptions occurring from foster care (Child Welfare Gateway, 2005).

Research on adoption explains some of the reasons regarding the lower number of adoptions. The Dave Thomas Foundation (2007) conducted a survey regarding Americans opinions on adoption. A total of 1,166 participants took part in the survey that explored the perceptions people held regarding adoption. Specifically the study
focused on identifying the number of people who were actively considering adoption as well as the children they would be willing to adopt. Of particular interest were the questions that addressed if the families considering adoption felt that foster care was an option. Only 30% of respondents noted that they had considered adopting a child from the foster care system. Another study conducted by Macomber and colleagues (2005) shows similar results with only 33% of the families considering foster care adoption.

The second issue pertains to the larger number of children within the foster care system who have special needs. Children with special needs account for 96% of the foster care population in the state of Florida. This presents a major barrier, because potential parents are not as willing to adopt children who have additional needs. The survey conducted by the Dave Thomas Foundation (2007) found that only 34% of respondents would consider adopting a child who had special needs. Macomber and colleagues (2005) also conducted a survey examining women’s interest in adoptions. The researchers collected data from a nationally representative sample for the National Survey of Family Growth. Women were surveyed about their willingness to adopt a child who had special needs, and found that only 31% of the sample would consider this type of adoption. The study also noted that the willingness decreased with the increase number of mental, emotional, or physical problems the child displayed (Macomber, et al., 2005).

Another study commissioned by the Department of Health (2005) regarding the barriers to adoption also found similar interests pertaining to special needs adoptions. The researchers interviewed 200 families in various stages of the adoption process and found that the special needs of a child were a major determining factor on whether to
adopt. The study specifically examined the willingness of potential parents to consider a child with physical disabilities, medically fragile, sexual acting out, or had multiple disabilities. The results showed that a high percentage of families were unwilling to adopt children with these types of diagnoses including: 44% for physical disability, 50% regarding medically fragile, 68% if the child is sexual acting out, and 78% if the child had multiple disabilities. The research shows that potential parents are less likely to consider adopting a child with special needs, and therefore not as willing to consider foster care adoptions (U.S. Department of Health, 2005).

**Legislation and the Adoption Process**

Establishing a foster care system and public adoption process is the responsibility of each state. As such, each state’s individual legislation establishes the framework for the child welfare system. However, the states’ legislation must comply with federal guidelines thus establishing both state and federal regulations of the adoption process. Since this dissertation focuses on the state of Florida, the discussion will be on Florida’s legislation establishing adoption.

The process of foster care and adoption was briefly discussed in Chapter One and is mandated by the state legislation. Florida’s legislation regarding child welfare is under Title V Chapter 39 of the Judicial Branch. Areas specific to the adoption process include 39.601, 39.701, 39.01 (18), 39.621, 39.802, and 39.806 (Florida Statutes and Constitution, 2009). The process the child goes through to be available for adoption will guide the discussion of Florida’s laws establishing the Child Welfare system.

The state sheltering a child occurs when abuse/neglect is confirmed by an investigator with the Department of Children and Families. Once this occurs a case plan is developed for the parents to follow in order for reunification to occur. The
The purpose of a case plan is to outline the services, treatment, and modifications the parents must meet in order to assure that they will be able to provide a safe environment if the child is returned. Florida Statute 39.601 establishes guidelines for the case plan which allow the foster care worker, family of origin, and the courts know the permanency goal as well as the steps to completing it. As stated in Chapter 1, the initial permanency goal is generally reunification with the family of origin, however may change to adoption if reunification is no longer an option.

The biological parents must agree to the case plan and take the necessary steps to initiate the required services. According to Statute 39.701 the family’s progress on completing the case plan objectives towards the goals is to be reviewed by the circuit court judge on a periodic basis. The first judicial review is held six months post removal with continuing reviews every six months until achieving permanency. The judicial review allows the courts to determine suitability of the case plan’s goal and accommodate for any changes that occur.

Allowing concurrent planning for permanency of a child is provided by Florida Statute 39.01 (18). This means that while establishing a case plan with all reasonable efforts to reunify the child with the parent is necessary, the foster care worker will also consider establishing another permanency goal including adoption. Once reunification is determined inappropriate for the child, Statute 39.621 gives the courts the power to determine the most appropriate goal. Commonly the primary permanency option available to the court is adoption.

If the biological parents are unable to meet the expectations of the case plan to provide a safe environment for the child, the Child Welfare system will seek to terminate
parental rights. The final two Statutes both address the termination of biological parent’s rights in order to allow the child to be adopted. First, Statute 39.802 establishes the guidelines the state must follow when terminating parental rights. Initiating termination of parental rights requires that the department file an original petition with the clerk of courts who will schedule an advisory hearing. The petition must be in writing, explain the grounds for termination, and be signed by the petitioner or a representative of the department. The advisory hearing will finalize the termination of the parents’ rights. Statute 39.806 establishes the grounds for terminating parental rights and includes: voluntary surrender, abandonment, whether the child is at risk for continued abuse, or if the parent is incarcerated for a substantial portion of the child’s life. The Statutes described above are specific to Florida’s Child Welfare System; however Florida like all other states must also follow the Federal Legislation and guidelines as well.

**Federal Legislation**

The goal of federal laws is to improve the welfare of children and promote permanency (Adamec & Miller, 2007). The first federal law impacting welfare of children was the Child Abuse Prevention and Treatment Act of 1974 (CAPTA). This law was passed in response to the increasing findings from medical reports revealing that a large number of children were being abused or neglected. The goal of the legislation was to shed light on child abuse and encourage states to establish foster care practices in response (Adamec & Miller, 2007). A number of amendments to the CAPTA legislation (1978, 1984, 1988, 1992, and 1996) have occurred with the most recent being the reauthorization of the act occurring through the Keeping Children and Families Safe Act. The 1978 amendment is important because it was the first
legislation to address the needs for permanency of children with special needs by establishing the Adoption Opportunities program (Moe, 2005). The 1984 amendment established guidelines for foster care workers to search for adoptive placement even for children with disabilities or terminal conditions (Adamec & Miller, 2007). Finally, the 1988 amendment sought to expand the Adoption Opportunities Program to include post adoption support services for families who adopted children with special needs. This legislation and its amendments were the first to examine the unique issues faced by children with special needs and recognize the importance of permanency (Gilman, 2001).

In 2003 CAPTA was reauthorized under the Keeping Children and Families Safe Act of 2003 (KCFSA, 2003). This piece of legislation kept intact the majority of the provision under CAPTA, but sought to implement programs that will increase the adoption of children with special needs. KCFSA (2003) also establishes grants for programs that eliminate barriers toward placing children across jurisdictions. The main goal of KCFSA is to improve placement options for children with special needs. (Moe, 2005)

Probably the most widely known and impactful child welfare legislation in recent years is the Adoptions and Safe Families Act of 1997 (ASFA). This legislation was passed by President Clinton with the goal of promoting timely permanency. Provision within the legislation included acceleration of permanent placements, implementation of shorter time limits for making decisions about permanent placement, safety for abused and neglected children, promotion of adoptions, and increased accountability. The provision to accelerate permanent placement means that states must initiate court
proceeding to free a child for adoption no later than fifteen months after the removal from their parents. Prior to this legislation many children would linger in the system for greater than two years with the case plan goal remaining reunification with the biological parents. The idea of freeing children for adoption quicker allows the case workers to seek suitable placement for the child in an expedited manner. The legislation also establishes shorter time limits for determining the most appropriate permanency goal for the child. States must hold a permanency hearing no later than twelve months after the child entered foster care. This guideline is six months prior to the previous standards which were to hold permanency hearings at eighteen months post removal (Moe, 2005)

The provision of safety for abused and neglected children means that the words “safety of the child” is to be included in every step of the case plan and review process (Adamec & Miller, 2007). Furthermore, this provision requires criminal background checks to be a part of the approval process for both foster and adoptive parents. The portion of the legislation focusing on adoption aims to increase the amount adoptions completed within each state. In order to encourage adoption, ASFA establishes incentive funds for those states that increase the rate of adoptions. Furthermore, this portion of the legislation also establishes state funding healthcare (Medicaid) for children with special needs. ASAFA states that the child will maintain Medicaid eligibility regardless of the adoptive parents’ income or geographical location. (Adamec & Miller 2007)

The final role of ASAFA is to increase accountability of the state welfare system. In response to this the Department of Health and Human Services became accountable for monitoring and establishing outcome measures for each state. Starting in 1999 and
each year after the states must report the statistics on the various outcome measures including: number of children awaiting adoptions, demographics of awaiting children, and the number of adoptions completed. (Moe, 2005). AFARCS is then responsible for compiling and reporting the status of the nation’s child welfare system. The goal of data collection is to impact policy and procedures at both the state and federal level (Moe, 2005).

**Health Coverage for Adopted Children**

The federal legislation ASFA establishes health care for children who are adopted from the state foster care system and assures that they maintain state funded Medicaid. As discussed in Chapter 1 Medicaid is a state and federal partnership to provide health coverage for qualified individuals. Determining eligibility for Medicaid services is completed by the state’s Department of Children and Families (DCF) and can be accomplished in four ways. First, the person may become eligible through Qualified Designated Providers. Here a practitioner recommends the person for Medicaid coverage based on a health condition. The most common qualified individuals in this category are women who are pregnant. The next path of eligibility is low income families as determined by DCF. Low income families are determined by the number of members as well as the family’s income including assets. The third method of meeting criteria for Medicaid services is to be approved for disability by Social Security Administration. These individuals have a disability that significantly impacts their ability to function in society and maintain employment. According to the federal legislation ASFA 1997, children who have special needs and are adopted from the foster care system maintain Medicaid coverage until the age of 18. This is the final category of
individuals who are determined eligible for Medicaid services (State of Florida Medicaid Program, 2009).

Medicaid is a program that helps qualified individuals receive necessary medical services; however like most insurance policies Medicaid has limitations on the type and amount of services that are covered by the plan (Florida Department of Health, 2009). The limitations of benefits are determined by state legislation, therefore vary between states. In response to the general limitations in coverage, supplemental plans have been developed by some states. The goal of the supplementary plans is to cover additional services for people who have extraordinary medical needs. Extraordinary medical need is any person who has a diagnosable emotional or physical disability that would require additional supplies or treatment. Based on the eligible plans in the state of Florida, the following two would apply to a number of children in the adoption system and include: Children’s Medical Services (CMS) and the Developmental Disability Waiver (Agency for Health Care Administration, Developmental Disability Waiver, 2007).

Children’s Medical Services (CMS) is under Florida’s Title V, and serves the state’s children with special health care needs. The program is a supplementary managed care plan under the state of Florida’s Medicaid program, and is designed to provide eligible children with integrated medical services. Eligible children are those who are under the age of 21, who qualify for state Medicaid, and who have serious or chronic physical, developmental or behavioral conditions that require extensive preventive and maintenance care beyond that required by typically healthy children. (CMS Network, 2008)
The other supplementary plan that will apply to children in the foster care system is the Developmental Disabilities Waiver (DDW). The waiver is a Medicaid program that is designed to provide home and community-based services to people with developmental disabilities, including cerebral palsy. The goal of this program is to promote, maintain, and restore the health of recipients in order to minimize the effects of the disability and promote optimal independent functioning. Participants must be covered under the state Medicaid benefits, in order to be eligible for the DDW program (Agency for Health Care Administration, Developmental Disability Waiver, 2007).

**Impact of Long Term Foster Care Placement**

As discussed in Chapter 1, the state foster care system shelters children while they await a permanent home. While this is extremely important for the child, the dynamics of the system also presents challenges for the child (Bruhn, 2003). The first challenge is that the foster care system is dependent upon families who decide to become certified foster homes. The number of children needing foster placement is often greater than the number of qualified homes available (AFARCS, 2007). Differences between available homes and the number of children often lead to multiple short term placements while seeking permanency for the child (Rubin, O'Reilly, Luan, & Lacalio, 2007). It is more difficult to find foster placement for children with special needs due to the additional certifications required to qualify a foster home as medically needy. When a suitable home is not immediately available for the child, they go to group home or shelters until a suitable home is located. Therefore, children with special needs often experience more instability in their placement (Rubin, O’Reilly, Luan, & Lacalio, 2007).

The second issue for children in foster care is the length of time until permanency is achieved (Bruhn, 2003). While a number of people consider adopting children, the
frequency of adoptions from the foster care system are consistently lower. In 2001, 127,000 children were adopted in the United States and only 39% of these adoptions were from the public foster care system (Child Welfare Information Gateway, 2004). Considering there are currently 130,000 children awaiting adoption in foster care system, the lower adoption rate will mean these children remain in state foster care longer (AFARCS, 2009).

The public foster care system does not assure stability for the child or how long the child will remain in foster placement awaiting permanency (Bruhn, 2003). Legislation, such as ASFA 1997, has sought to correct some of these issues; however permanent placement has remained largely unsuccessful (Rubin & et al., 2007). Currently, the average length of stay for children awaiting permanency is greater than two years (AFCARS, 2008). During this time the child will experience approximately four to six different placements and the number of placements is greater for children with disabilities or behavioral issues with an average of ten to fifteen different placements (Bruhn, 2003). The lack of stability for the child impacts both their emotional and physical development (Lawrence, Carlson, & Egeland, 2006). The specific impact on children has been the focus for a number of research studies. Overall, the research consistently shows that continuing foster placement has a negative impact on the child and as such interventions should be developed to encourage permanency (Lawrence, Carlson, & Egeland, 2006; Bruhn, 2003, Rubin, O’Reily, Mekonnen, Luan, & Localio, 2008).

Bada and colleagues (2008) evaluated whether living arrangements of children was associated with their behavioral and adaptive outcomes. The study followed 1092
children from 1 month of age to 3 years old collecting information on living arrangement and developmental outcomes at each clinic visit. At the age of three the researchers administered instruments to examine behavioral problems as well as adaptive functioning. The results of the study revealed a significant increase in behavioral problems with each move per year as well as each year of involvement in child protective custody. These findings support that long term foster placement is detrimental to the child and as such the child protection agency should work towards permanency as quickly as possible.

Rubin and colleagues (2007) researched the impact of placement stability on behavioral outcomes for children in foster care. The researchers collected information on 729 children from the National Survey of Child and Adolescent Well-being who had been in foster care for at least 18 months. The study sought to control for extraneous variables that may impact the child’s behaviors to determine the direct effect of instability. The main extraneous variable controlled for was behavioral issues at the time of foster care placement; therefore the researchers only examined children who did not have behavioral issues at the time of removal. Each participant was categorized according to the length of time required to establish stability. The categories were early stability (stable placement within 45 days), late stability (stable placement beyond 45 days), and unstable (never achieving stability). Researchers used a child behavioral checklist to determine behavioral well-being of each participant and then compared the findings between each category. The results of the study showed the probability of behavioral issues among early stabilizers was 22%, compared to 36% in children who were unstable. This showed a 63% increase in behavioral issues related to instability.
alone. Therefore, the results of the study supported the need for interventions that promote placement stability as a means of improving the outcomes of children in the foster care system.

Lawrence and colleagues (2006) examined the impact of foster placement on the child’s behaviors as well as psychological functioning. The goal of the study was to explore the pre and post placement adaptation of children in foster care, and the long-term consequences of foster care on behavior problems, overall emotional health, and psychopathology in adolescence. The researchers gathered a total of 189 participants from the Minnesota Longitudinal Study of Parents and Children. From the total sample, the researchers identified three subgroups: children who entered foster care (46); children who were maltreated but remained at home (46); and children who did not experience maltreatment or foster care (97). For the children who were in foster care a pre-placement baseline was collected by assessing the child’s functioning and developmental adaptation during infancy, toddlerhood, preschool years and kindergarten. The researchers used various instruments to gather information on the following variables: attachment quality; toddler-caregiver experience rating; persistence and ego control rating; and emotional health rank. All sub-groups were assessed using the Child Behavior Checklist and Kiddie Schedule for Affective Disorders and Schizophrenia Ratings. The results of the study showed that children who were in foster care had significant changes in behavioral scores pre and post placement, with a higher ranking of behavioral issues upon leaving foster care. Further analysis, also revealed that there was a significant difference between the foster care group and the control group (no maltreatment/foster placement) in the number of behavioral issues.
present. The study also noted a significant difference in psychopathology diagnoses between the foster care group and control group, with the foster care group showing a higher prevalence. Overall, the results of the research supported the belief that foster care increases the behavioral problems in children. Furthermore, the study demonstrated that the increase in behavioral issues was beyond the effects associated with abuse history, baseline adaptation, and socioeconomic status of the individual.

Literature has also identified the emotional and psychological impact that long term foster care has on a child. One study examined the psychiatric morbidity and risks for suicide among children who were once placed in foster care (Vinnerljung, Hjern, & Lindblad, 2006). The study found that those children who were in foster care had a four to five times greater chance of being hospitalized for suicide attempt. Furthermore, the results of the study also showed that children in foster care were five to eight times more likely to be treated for a serious psychiatric disorder in their teens. Delilah Bruskas (2008) completed a review of the literature regarding the experiences associated with foster care. The synthesis of the literature showed that children placed in foster care often experience feelings of confusion, fear, apprehension of the unknown, loss, sadness, anxiety, and stress. Furthermore, it is noted that these feelings often interfered with the child’s developmental and mental stability. The author suggested that implementing a systemic orientation for all children entering care will help address some of these emotional concerns.

**Ecological Perspective of Adoption**

The ecological systems theory proposes that the developing person is impacted by the interactions of four separate ecological systems (Bronfenbrenner, 1979). The model defines the environment as a “set of nested structures, each inside the next.”

(Bronfenbrenner, 1979, pg. 3). At the core of the model is the developing person with the four ecological systems, micro, meso, exo, and macro systems, expanding outward. The level of influence on the developing person lessens as you expand outward. Therefore, the level of the environment with the most impact of the person would be the micro system and the least impact is the macro system. Regardless of the level influence, it is important to understand the characteristics which compose each environment in order to grasp the concepts of the developing person’s behaviors.

The first ecological system described by Bronfenbrenner (1979) is the microsystem. The microsystem represents the immediate environment in which the developing person lives. This system may include family, work, school, as well as other areas the person interacts with directly. The mesosystem, the second environment expanding outward, is defined as the linkage or interaction between two or more microsystems (Anderson & Mohr, 2003; Bronfenbrenner & Morris, 1998). The theory proposes that the linkage between different microsystems will create modifications in the developing person’s behaviors and thoughts, which impact the microsystem (Bronfenbrenner & Morris, 1998). For example, a child may interact between two different microsystems such as the family unit and school. The model proposes that modification occur as the child interacts with the teacher, therefore affecting the child’s interactions with their parents (Bronfenbrenner, 1998; Trawick-Smith, 2003). A child may do something wrong, be disciplined by a teacher, and thus develop a negative attitude toward school. The child then returns to the family microsystem and displays that same negative attitude, therefore demonstrating how things that occur in one microsystem will modify the child’s behaviors in another microsystem.
The third ecological system described by Bronfenbrenner is the exosystem. This system includes settings that the developing person may not directly interact with, however influence them. This system is comprised of extended family, neighbors, work place, and more. The final level of the environment that impacts the developing person is the macrosystem. The macrosystem encompasses all the other systems, and is composed of cultural attitudes as well as laws and regulations that impact the shaping of the microsystem (Schweiger & O’Brien, 2005; Bronfenbrenner, 1979; Bronfenbrenner, 1998; Palacios, 2009).

The ecological model provides a method of conceptualizing the impact of a person’s environment on their behaviors and development. Therefore, Schweiger and O’Brien (2005) utilized this model to examine the adoption process as well as the impact of the interaction from each ecological system. The ecological perspective of adoption places the adopted child at the core of the environment. The next level of the environment, the microsystem, contains the child’s experiences is their adoptive family. When viewing the microsystem of adoption it is important to maintain awareness that the child enters a family with established patterns of interactions. The family’s interactional patterns impact the child’s microsystem. Furthermore, the adopted child enters the new microsystem with their own relationship history which often includes abuse and neglect (Schweiger & O’Brien, 2005). Based on the ecological systems theory the parents and child are impacted by each other, and as such this interaction within the microsystem provides an explanation for the attachment difficulties commonly witnessed by adoptive families (Schweiger & O’Brien, 2005). Rushton and colleagues (2000) examined the impact of the parent/child relationship and identified a correlation
between parenting and child characteristics including attachment. The study specifically found that children who were more active and distractible were less likely to form secure attachments with the adoptive parents, thus impacting the microsystem (Rushton, Dance, & Quinton, 2000).

According to the ecological theory, relationships are another important aspect within the microsystem (Schweiger & O'Brien, 2005; Palacios, 2009). Therefore, relationships amongst siblings as well as spousal relationships are an integral component of the adopted child’s microsystem. Adopted children often enter families who either have biological children or previously adopted children, therefore the reactions between the siblings will impact the adjustment and development of the adopted child (Schweiger & O’Brien, 2005). Based on this interactional understanding of the child’s microsystem, it is recommended that social workers prepare siblings for the placement of an adoptive child (Schweiger & O’Brien, 2005; Mullin & Johnson, 1999). Furthermore, this ecological view of the adoption process helps highlight the importance of sibling relationships on the successful placement of the child. This will provide potential parents with an awareness of the potential issues that may need to be addressed in order to promote successful integration of the adopted child. The spousal relationship between adoptive parents is also a consideration of the microsystem. According to the ecological model, difficulties in a marriage may impact the child just as issues with the child can impact a marriage. The ecological model provides a framework to both conceptualize this interaction as well as highlight the needs for interventions (Schweiger & O’Brien, 2005).
As stated earlier, the mesosystem defines the interactions between the microsystems in which the developing person interacts within (Bronfenbrenner & Morris, 1998). According to the ecological systems theory, the interactions defined within the mesosystem help understand the relationships within the microsystem. Furthermore, the model theorizes that the child’s interactions outside of the microsystem (adoptive family) impact their perceptions and behaviors therefore influencing the way they act with adoptive parents and siblings. The influences within the mesosystem often go unrecognized by the members within the microsystem; however have a huge impact on family relationships (Schweiger & O’Brien, 2005). The mesosystem of an adopted child includes the family of origin, as well as peers and school interactions.

The ecological view of adoption provides a method to conceptualize the impact that the child’s previous history has on the immediate microsystem, adoptive family. The child’s family of origin is a microsystem in which they have spent developmental time within. As stated earlier the average age of child adopted from the foster care system is nine years old. A nine-year-old child will have memories and experiences from their family of origin. These experiences are often negative or emotionally difficult for the child, and therefore will impact the adoptive microsystem (Schweiger & O’Brien, 2005). The linkage between the family of origin and the adoptive family microsystems is defined within the mesosystem of the developing child. The mesosystem recognizes that the adoptive parents did not and do not participate in these experiences, however the adoptive parents relationship with the child will be affected by these past experiences (Schweiger & O’Brien, 2005). The effects of linkage on the adoptive family is often witnessed through the ability of the child to form attachments with their adoptive
parents (Derdeyn & Graves, 1998). A child’s sense of abandonment by their family of origin is often expressed as anger and disruptive behaviors towards the adoptive parents, thus negatively impacting the relationship.

Another linkage of microsystems occurs between peer relationships, educational environment, and the adoptive family. Commonly, a child with special needs experiences multiple disruptions in placements while awaiting adoption, and therefore experiences changes in school as well as peer groups. These experiences shape the child’s behaviors and perceptions which will impact adjustment into the adoptive family and their new educational environment. Based on the mesosystem of the ecological theory, the quality of the parent/child relationship affects the child’s school adjustment and peer relationships (Schweiger & O’Brien, 2005). Research shows that children of parents who are warmer and more supportive tend to have stronger and more positive peer relationships (O’Connor, Jenkins, Hewitt, DeFries, & Plomin, 2001). These findings support the concept of linkages between microsystems defined within the mesosystem. Moreover, the linkage between the child’s peer groups also impacts the microsystem of the adoptive family; therefore, inclusion of the adoptive child within a supportive peer group contributes to more positive parental relationships (Schweiger & O’Brien, 2005).

The adoption process requires the parents to become a part of a larger environment that impacts their behaviors and decisions. This environment is the social service agency and by definition this interaction is a part of the exosystem. The social service agency is responsible for helping the potential parents complete the legal aspects of adoption. The adoption process is discussed in Chapter 1.
The final component of the ecological perspective of adoption is the macrosystem. When defining the macrosystem of adoption the first thing to consider is the definition of family. While a family is often composed of terms such as mother, father, sister, brother, there is also a larger societal and culture definition. Commonly, the societal and cultural definition establishes what a family should look like, the relationship among its members, how family is formed, as well as who can call themselves a part of the family (Schweiger & O’Brien, 2005). This cultural definition falls within the macrosystem and according to the ecological theory impacts the adoptive person. Adoptive families often do not meet the societal expectations of family, therefore impacting the formation and cohesion of the family unit (Schweiger & O’Brien, 2005).

The other aspect of the macrosystem is legislation. Legislation is an integral part of adoption and establishes all of the policy and procedures. Based on the ecological theory, the current legislation as well as any changes in legislation impacts the adoptive person. First, without legislation establishing the adoption process, the adoptive child at the core of this model would not exist. Prior to legislation children would linger within the foster care system until they became old enough to care for themselves (McKenzie, 1993). The next issue is how changes in legislation impact the adoptive person. For example, the passage of Adoptions and Safe Families Act of 1997 impacted the adoptive person by implementing Medicaid insurance for each child within the adoption system. The implementation of insurance changes the adoptive person as well as their other environments by providing access to medical care.

The ecological perspective of adoption provides a method of conceptualizing the adoptive child’s environment. Furthermore, this model assists in understanding how the
child’s behaviors are formed, molded, and potentially changed. This understanding assists in gaining perspective on adoption as well as how to modify the system in order to achieve changes in the adoptive child.

**Issues within the Adoption System**

As mentioned earlier the number of adoptions finalized from the public foster care system is lower than those from private or international adoption facilities (Child Welfare Information Gateway, 2004). Research has sought to explore some of the issues that make potential parents less willing to consider foster care adoption. The literature demonstrates a number of issues related to both the structural process of adoption as well as the characteristics of the children available for adoption from the foster care system.

The U.S. Department of Health and Human Services commissioned researchers to develop a study to explore the barriers present at each stage of the adoption process. The researchers recruited 200 families seeking to adopt children with special needs from the public foster care system to participate. Each participant took part in in-depth interviews regarding their experiences and opinions on the adoption process. The goal of the interview was to determine the actual and potential barriers of completing the adoption process. In order to collect information on each stage of the process researchers classified the interviews in five different groups according to where the family was in the adoption process. The five groups were as follows: 1) initial contact and orientation with the adoption agency, 2) families who completed an application but discontinued prior to approval, 3) families who completed their home study and training but never had a child placed with them, 4) families who had a child placed but did not
follow through with the finalization of adoption, and 5) families who completed the adoption process (U.S. Department of Health and Human Services, 2005).

In order analyze the data the researchers coded the family’s experience of the adoption process to assess child, family, and agency barriers encountered. Categorization of the codes was placed under the labels of child, family, or agency factors. The child factors included the child’s ability to attach to adoptive families, foster care experiences and history, behavior, health, mental health, educational needs, and demographics. The family factors were family commitment, ability to interact with the system, available support, preparation and expectations, family dynamics, child integration, parenting abilities, personal circumstances, and family distress. The final category, agency factors, were availability of services; agency emotional support; availability of financial support; adoption process; legal system interactions; family assessment; level of agency bias and cultural competence; and agency communication or responsiveness (information sharing and disclosure). The analysis of the interviews showed that child factors were overall a major barrier to families in all steps of the process. Specifically, 77% of families in group four and 40% of the families in group 5 noted this to be of particular concern to them. The study also noted that the most frequently reported child factor was the child’s mental health. The category of family factors was most commonly seen reported in groups 1 and 2 which exited the adoption process in the early stages. Families who completed the adoption process (group 5) reported the least amount of family issues. Families within all five groups reported agency factors as a barrier to their overall experience: 80% of families in group 1; 93% of the families in group 2; and 100% or all of the families in groups 3, 4, and 5. The
most common agency factor was the logistics of adoption process, as reported by 93% of the families. A second most common factor was the lack of information provided to the families by the adoption agency as reported by 80% of the families. The study shed light on the issues that are present in the public foster care system.

The U.S. Department of Health and Human Services (2008) also commissioned research on adoption staff members’ perceptions of the barriers to adoption. The researchers recruited a nationwide sample of private and public adoption agency staff. The participants were given a 29 item survey to assess agency and system barriers, family and child barriers, solutions to overcome barriers, and child’s preparation for adoption. Each respondent was asked to rate the survey factor on a scale of one to five depending on how strongly they felt the factor was a barrier. The scale started at one (not a barrier) and went up to five (indicating a major barrier). The researchers sent out 1,659 surveys in both hard and electronic forms to adoption agency across 34 states and Washington, D.C. Ultimately, 382 surveys from staff located in 29 different states and Washington, D.C. were returned. The survey indicated that 67% of the participants felt that an inadequate pool of families interested in adopting children with special needs is major barrier. Participants also felt that the availability of post-adoption services and lack of respite care was another agency barrier, as reported by 42% of the respondents. Some of the family barriers identified were the prospective parents’ specificity in the type of child desired; the parents inability or unwillingness to accept certain characteristics in the child’s history; parents unwillingness to access services or community resources; and the lack of experience with children who have special needs. Sixty seven percent of respondents noted that specificity in type of child desired was a
major barrier. The participant felt that the parents seeking to adopt from the foster care system have an unreal expectation about the type of children available as well as the behavioral expectations of children with special needs. Specifically, respondents reported that parents were looking for a young child with minimal special needs. Parents being unwilling to accept characteristics of the child’s background were identified as a major barrier by 45% of the respondents. These respondents noted that potential parents were uneducated and confused regarding the power of a loving family. The unwillingness of a family to access services was noted by 44% of the people surveyed. The final family barrier noted was lack of experience with special needs children and was identified by 41% of the participants. The respondents noted that the lack of experience reinforced the unrealistic expectation regarding the child’s behavior and abilities.

The final category of barriers assessed was characteristics of the child. The results of the survey show that 84% of respondents identified the age of the child as a major barrier. If a child was engaging in sexual behaviors 81% reported that this was a major barrier. Seventy eight percent of the respondents noted that sexually acting out was a major barrier when parents consider adoption. Finally 50% of the respondents stated that the child displaying behavior problems in the home was a major barrier in the completion of the adoption process. Overall the study revealed how important a number of these issues were in the completion of the adoption process. The researchers recommended that increased education, awareness training, and recruitment of families would help reduce the impact of these issues.
As discussed in Chapter 1, the state of Florida’s adoption system has reviewed the perceived barriers within its foster care system as well (OPPAGA, 2008). Similar to the literature on the barriers, Florida has identified a lack of families willing to adopt children with special needs as the number one challenge that the states foster care system faces. The review also identified a lack of information and support from the adoption agency as major barrier as well. Due to the barriers facing the foster care system, an intervention to help increase the number of permanent placements should be addressed.

**Life Care Planning**

Life care planning is a rapidly growing subspecialty within the professional field of rehabilitation (Weed, 2004). The field of life care planning was first introduced in 1981 through the legal publication Damages in Tort Actions (Deutsch & Raffa, 1981). The publication proposed the use of life care plans as a method of establishing guidelines to determine damages in civil litigation. The use of life care plans in civil cases became one of the primary functions of the document; however life care plans held great potential for other venues. In addition to civil litigation, life care plans were introduced to the health care industry in 1985 through the publication of Guide to Rehabilitation (Deutsch & Sawyer, 1985). The development and use of life care plans within the health care arena provides rehabilitation professionals with established guidelines for assessing the patient’s disability related needs through life expectancy (Riddick-Grisham, 2004). Since the introduction of life care plans for use in civil litigation and in the health arena, life care planning has grown to be a widely accepted and valued tool within the rehabilitation field (Weed, 2004). With the growing popularity, professionals started creating life care plans using in a variety of different methods as well as using
plans in ways that were not initially intended (Weed, 2004). In response to growing development and use of life care plans, there became need for standardization of life care planning to create a uniform practice.

In 1992, leaders within the life care planning field met to discuss the needs for training on a universal method of creating life care plans (Weed, 2004). They established an intensive sixteen day training course which would teach rehabilitation professionals the methods and effective uses of a life care plan. Since that time, the field of life care planning continues to grow and now there are multiple training programs designed for both novice and advanced practitioners (Riddick-Grisham, 2004). Establishing a training program opened the door for the subspecialty of life care planning to consider developing a board certification process. In 2003 the Commission on Health Care Certification (CHCC), established the Certified Life Care Planner. With a standardized education and certification system, the once fragmented field merged to form the professional organization of International Academy of Life Care Planners. In 2003 this organization published a standard definition of a life care plan as well as Standards of Practice for life care planners to follow (International Academy of Life Care Planners, 2003). The collaboration of leaders and the organization agreed upon the following definition:

A Life Care Plan is a dynamic document based upon published standards of practice, comprehensive assessment, data analysis and research, which provides an organized concise plan for current and future needs with associated costs, for individuals who have experienced catastrophic injury or have chronic health care needs. (International Academy of Life Care Planners, 2003).

The Standards of Practice is regularly updated with the most recent publication occurring in 2006. A life care planner practices within the guidelines of the
organizations published standards. These standards define the life care planner’s role and provide guidance for the completion of the life care planning process (International Academy of Life Care Planner, 2006).

**Role of a Life Care Planner**

Life care planning is a multidisciplinary specialty ranging from nurses to rehabilitation counselors who develop life care plans. Therefore, it is important for the life care planner to establish a philosophical basis regarding their role in the life care planning process (Deutsch & Sawyer, 2002). When establishing a philosophical basis, a life care planner should examine the scope of practice, professional standards, and basic procedural tenets (Deutsch, 2007). These guidelines establish the life care planner as primarily an objective educator, regardless of the purpose in which the life care plan is being developed. It is the role of a life care planner to educate their audience and their tool is the life care plan (Deutsch, 2006). Although, being an educator is the primary responsibility of a life care planner; they may take on a number of different roles throughout the life care planning process in order to obtain the necessary information. Coordination and communication with appropriate team members is a vital role for a life care planner (Riddick-Grisham, 2004). It is essential whenever possible for the life care planner to consult with team members for the individual in order to gain an understanding of the routine care the person will require. Sometimes, the life care planner may even take on the subsequent role of managing the patient’s care (Riddick-Grisham, 2004).

The life care planning standards establish eight primary functions of a life care planner regardless of their roles (International Academy of Life Care Planners, 2003). The first function is data collection. The life care planner compiles data in a systematic,
comprehensive, and accurate method from published resources as well as medical records. The second function is assessment, which includes analysis of the data to determine the individual's future needs. The next primary function is planning. Planning is the development of the life care plan recommendations utilizing a consistent methodology along with the completion of the written plan. Collaboration, being the fourth function, is an important part of the life care planning process because it allows the life care planner to obtain professional opinions when formulating recommendations. The fifth function is plan development research, which establishes the rationale and support for the recommendation in the life care plan. The life care planner can achieve this by researching standards of care or peer reviewed information. The sixth function is facilitation, which includes remaining objective to resolve any disagreements about appropriate recommendations for the life care plan. Furthermore, facilitation includes educating the involved parties on the process of life care planning in order to elicit their participation. The seventh function is evaluation, which is reviewing and revising the life care plan to assure internal consistency. The final function of a life care planner is testimony and completion of this function is dependent upon the reason for the development of the life care plan. These functions are evident throughout the process of life care planning (International Academy of Life Care Planners, 2006).

**Process of Life Care Planning**

While the philosophical basis of the life care planner is an educator, it is their responsibility to develop the life care plan. The field of life care planning has 14 recognized tenets that establish the basis to develop an effective life care plan. Table 1 displays a listing of these tenets. When developing a life care plan, it is essential to follow the recognized tents to assure a consistent methodology. A uniform approach to
developing the life care plan allows the professional to establish valid and effective strategies for each individual (Riddick-Grisham, 2004).

After the life care planner has a good understanding of the tenets pertaining to life care planning, the process of developing the plan can begin. Of course, the process of life care planning begins with a referral or some determined need to develop a plan. It is important for the life care planner to review the referral and determine the following: time frame in which the plan has to be completed, billing agreements, and any retainer information that is applicable to the case (Weed, 2004).

The next step is to obtain a complete set of medical records. The life care planner wants medical records to be as complete as possible and includes “nurses’ notes physicians’ order, ambulance report, consultant’s report, admission and discharge summaries, home care notes, as well as any laboratory or radiographic reports” (Weed, 2004, pg. 25). The life care planner obtains the records from the various sources and then completes a thorough review noting any important information regarding the individual’s catastrophic injury. Information obtained from the medical records includes; primary and secondary diagnosis, problem lists, current providers, frequency, duration, treatment complications; medication usage and response; along with any rehabilitation outcomes (Riddick-Grisham, 2004). The life care planner completes the review of medical records by writing a summary. The summary of medical records helps develop questions for the initial interview with the individual.

The next step in gathering valuable information regarding the individual’s disability related needs, is the initial interview. The initial interview is usually conducted at the individual’s home so as to provide a better understanding of the person’s needs and
current level of functioning (O’Keefe, 2001). The first interview can last anywhere from three to five hours and will help the life care planner gain an understanding of the patient’s daily care requirements (amount of time, equipment, level of assistance needed, as well as identify those providing care) (Riddick-Grisham, 2004). When available, it is important to include any family or other members that may be caring for this individual to obtain additional perspectives regarding the impact of the disability on the person’s functioning (O’Keefe, 2001). Since the interview is very lengthy and it is necessary to obtain large amounts of information, many life care planners use check lists or interview forms to guide the process (Weed, 2004). The interview process will obtain information regarding the individual’s medical history, treatment plan, therapy team, education, work history, medications, supplies, adjustment to disability, daily schedule, and transportation needs. Furthermore, while completing the interview process the life care planner may obtain pictures of any equipment, medicines, or necessary accommodation in order to support recommendations of the life care plan (Weed, 2004; Riddick-Grisham, 2004).

As previously noted, one of the important roles of a life care planner is that of a team coordinator. As a team coordinator, it is the responsibility of the life care planner to consult with other allied health professionals involved in the routine care of the individual (Riddick-Grisham, 2004). The consultation can occur either through writing or personal contact. Some life care planners choose to write letters and include questions for the professional to complete in his or her own time and return to the life care planner. Whereas, other life care planners choose to either schedule phone or in-person meetings to obtain the necessary information. The method in which consultation
occurs depends on the preference of the individual developing the life care plan. Once the life care planner accesses the treatment team for consultation, it becomes a very valuable step of the process. The consultation allows the life care planner to obtain professional opinions regarding the future needs of the individual, such as the type and frequency of services necessary. This collaboration of information assists the life care planner in establishing a medical basis for their recommendations (Riddick-Grisham, 2004). In order to gain additional information and support, the life care planner may also reference published standards of care or other peer reviewed journal/book sources.

At this point in the process, the life care planner should have a preliminary idea of the recommendations the life care plan will propose (Woods, 2004). With the preliminary plan in mind, the life care planner must complete evidence based research (Riddick-Grisham, 2004). Evidence based research is another important part of the process, as it provides further rationale and support for the recommendations. The life care planner should be aware of the necessary research methods, as well as have an understanding of peer reviewed information (Deutsch, 2006). Research is conducted to obtain information in two areas: evidential support and cost analysis. Gathering evidential support includes identifying articles, standards of care, or other reputable sources that provide rationale for the recommendation in each area of the life care plan (Woods, 2004). For example, the life care planner is completing a plan for a person with cerebral palsy and the plan recommends a baclofen pump. The question then becomes why this person needs the equipment. The research documentation regarding the effectiveness of this treatment for muscle spasticity will answer why the baclofen pump was included. The use of research to support recommendations helps the life
care plan answer questions regarding disability related needs, rather than creating new ones. This follows tenet four of the life care planning process.

The second area in which the life care planner will gather necessary research is through establishing the cost of each treatment, medications, supplies, and equipment recommended in the life care plan (Weed, 2004). While assessing the cost of supplies or services, it is important to follow specific procedures. As described in tenet five of the life care planning process, it is important to not depend on one source to determine cost. Therefore, the life care planner will need to obtain prices from multiple sources to determine the cost that will be included in the life care plan. Sources on pricing come from product catalogs, supplier websites, flyers, or local service providers. One important issue to note while determining cost within a life care plan is tenet twelve, which states that all potential complications and future technologies are not considered in the cost of the life care plan (Riddick-Grisham, 2004). The last step in the life care planning process is the presentation of the life care plan. The life care plan is an organized method of presenting the information obtained throughout the life care planning process. Each life care planner chooses their method of displaying the information, however the plans should contain documentation of the need for and cost of each given item, the expected duration of that need, and the projected frequency and cost of the item’s replacement (Riddick-Sherman, 2004). Furthermore, there are standard areas in which each individual’s needs are assessed. The broad areas are listed in Table 2 with an example of some of the recommendations within each area.

The life care planning process has a number of consistent steps in order to achieve the final product and is necessary to assure consistent methodology when
approaching the organization of disability related needs. This process assures that the life care plan establishes a medical, rehabilitation, case management, and psychological foundation for the plan, thus assuring a valid rationale and basis (Deutsch, 2006).

**Unique Considerations to the Life Care Planning Process**

When completing the life care planning process, there are some issues that the life care planner must continually address. First, is the fact that the life care plan is a multi-dimensional document, and therefore the areas of the life care plan and their recommendations interact with each other (Deutsch & Sawyer, 2002). This interaction is important to recognize and avoid because it will result in an overlap of the services that are recommended for the individual. As an example, if a life care recommends a week long therapeutic camp, it is important to recognize the effect this will have on the amount of home aid care and regular therapeutic services necessary. Therefore, if the child is gone for a week, the life care planner will subtract this amount of time from the necessary areas.

Another matter of importance is how the life care planner assesses the cost of services based on frequency. This is an issue because it is reasonable to assume that therapeutic services and the professional will not be available 365 days a year due to holidays, vacations, or sick leave. Keeping this in mind, a guideline for assessing frequency is to use the concept of a therapy year which has 48 weeks. Using the therapy year will assure the life care plan does not over estimate the amount or cost of therapeutic services necessary (Deutsch, 2006).

A life care plan is needs driven and not funding driven. However, it is important for the life care planner to be conscious of collateral sources (Deutsch & Sawyer, 2002).
Collateral sources are any other programs that may fund or provide the services that are recommended within the life care plan. A life care plan does not depend on the collateral sources although, it is important for the plan to make note of the available sources when applicable. One of the major collateral sources to consider is the federal legislation of Individuals with Disabilities Education Act (IDEA). Under IDEA, the school systems provide educationally related therapeutic services to the individual at no cost (IDEA, 2004). This would impact the recommendation in the areas of projected therapeutic evaluations and projected therapeutic services, which should be noted within the plan.

The final unique issue this paper will review is the considerations given to the area of home care versus facility based needs. The recommendations in this area may not always be clear to the life care planner. A number of factors must be considered including the availability of familial support, geographical area, and the progressive needs of the individual as they age.

To address these multiple issues, the life care planner may propose different options of care for the individual. The options often include ways to keep the individual functioning independently as well as assisted living or facility based care when necessary. The life care plan will identify and assess the cost for each option individually. The proposal of multiple options allows the plan to adjust to the changing needs of the individual.

**Preliminary Research**

To determine the barriers to adoption and the feasibility of life care plans to address the problems with special needs adoptions, three pilot studies were performed. The goal of the first study was to identify the barriers adoption case managers
experience when attempting to place a child who has special needs. The second research study examined the feasibility of developing a Medicaid based life care plan. The third study explored the perceptions of parents who adopted children with special needs, and the barriers they confronted. The preliminary findings of these three studies establish the framework to explore the use of life care plans in the process of adoption.

In order to explore the experiences of adoption case managers, the researcher employed qualitative methods that included semi-structured interviews with five adoption case managers. Each participant was actively working within the adoption field and had both past and present experience with special needs adoptions. A number of themes emerged from the interviews including: lack of information regarding disabilities, uncertainty of the child’s future, and fear of caring for the child. It was determined that these barriers limit the adoption of children with disabilities.

The first theme was the lack of knowledge about and understanding of disabilities the potential parents had, resulting in an inability to grasp a realistic picture of the needs of the child. This theme or adoption barrier was exacerbated by the case managers’ lack of understanding regarding disabilities as well; therefore the case managers were unable to answer potential parent’s questions regarding the child’s disability related needs. Another barrier related to the lack of knowledge is the assumed uncertainty of the child’s future. The case managers stated that potential parents often expressed concerns regarding the quality of the future of a child with a disability. Finally, the case managers stated that the lack of information and understanding of the child’s needs created fear and insecurities about potential parent’s abilities to adequately manage the care of the child. Life care planning is a tool that can address all the themes that were
identified by the case managers, thus reducing the barriers associated with special needs adoptions.

As stated earlier, children who are adopted from the public adoption system maintain Medicaid for all their health needs. Therefore, an important step in determining the feasibility of life care planning in the adoption system was to examine if Medicaid would cover the necessary expenses. This study focused on determining if a Medicaid based life care plan was feasible. The principal investigator reviewed a life care plan obtained from an experienced planner. The life care plan was developed for a five year old child who was born with cerebral palsy. The first step in the comparison process was to determine all state based insurance programs that the child was eligible for. Based on eligibility requirements, the child would have been covered by state Medicaid, Children’s Medical Services, and Developmental Disability Waiver. Each section of the life care plan was compared to what Medicaid and the supplemental insurance programs would cover.

Overall, the comparison between the sample life care plan and the services provided by state Medicaid showed that the majority of the child’s needs were covered by at least one of three Medicaid programs the child was eligible for. The researcher reviewed all sections of the life care plan, and specifically identified the similarities and differences of services. There were only two sections of the life care plan where none of the recommendations were covered by Medicaid programs including: leisure time and aids for independent functioning. Under each of these section recommendations for adaptive toys, assistive computers, and summer camp were included. Since the majority of the child’s medically based needs are reimbursable through the state
insurance programs, the researcher concluded that a Medicaid based life care plan was a feasible method of outlining a person’s needs.

The third study explored the barriers in the adoption process from the perspective of parents who adopted children with special needs. The idea is that life care plans will may help in the adoption process so it was essential to gather insight on parents felt some of the problems where. Therefore, the researcher employed qualitative methods due to the exploratory the opinions of parents who have adopted children with special needs. The participants took part in in-depth interviews aimed at gathering information regarding their perceptions of the barriers. A total of eight participants were interviewed and the child’s diagnosis ranged from emotional to physical disabilities. A number of themes emerged from the interviews at each step of the process. The themes were categorized according to which step the barrier was present and included: initial contact; adoption process; and post adoption placement.

The parents expressed a number of different themes related to initial contact with the adoption agency. Some of the participants felt that they were jumping through hurdles in order to be eligible to adopt a child. The families noted that they had to take part in multiple interviews and a home study in order to show the agency that they were an appropriate placement for the child. The barriers noted in this stage of the process were the amount time, frustration, and familial intrusion.

The adoption process itself presented a number of issues for the families. The biggest problem expressed was the lack of information provided on the child’s physical and emotional health. A number of participants felt that the adoptions agency left information out or did not provide enough information to get an accurate picture of the
child. One participant stated, “You wonder why don’t they give you this information are they afraid you are not going to adopt the child.” The final category of post adoption placement revealed a number of issues and emotions the families experienced. Feelings of shock, abandonment, frustration, and loneliness were all things expressed by the parents. The participants expressed that the agency provided nothing to them upon finalization. This left the parents feeling lost and confused as to how to get help for the issues their children were having. A number of participants stated they felt abandon by the adoption agency, because clearly the children had issues prior to the adoption that were not brought up. Furthermore, some of the parents discussed calling the agency seeking help and were told that there was nothing that could be done. Again this creating a feeling of abandonment, frustration, and being all alone. In describing their experiences with adoption a number of the parents stated that it was challenging and frustrating because there was no support available. This research highlights the need for parents to have guidance in understanding their child’s disability once the adoption is finalized.

The preliminary studies showed that there were a number of perceived barriers when placing children with special needs. Life care planning has the potential to help overcome many of these barriers. Since children who are adopted in the state of Florida maintain Medicaid, a life care plan has to be organized around this funding source. The feasibility of establishing a Medicaid based life care plan was confirmed through research. Therefore, the use of life care plans within the adoption system could serve as a valuable tool to help promote special needs adoptions.
Table 2-1. Tenets of life care planning

<table>
<thead>
<tr>
<th>Tenet</th>
<th>Description</th>
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</thead>
<tbody>
<tr>
<td>1</td>
<td>First and foremost, life care planners are rehabilitation professionals and educators</td>
</tr>
<tr>
<td>2</td>
<td>All plan recommendation should clearly relate to patient-specific evaluation data</td>
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<tr>
<td>3</td>
<td>Assume the probability of success of recommendations</td>
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<td>4</td>
<td>Life care plans are designed to answer questions, not raise them</td>
</tr>
<tr>
<td></td>
<td>Life care plans specify provisions throughout life expectancy and cannot depend on any one individual, service, or supplier to fulfill plan recommendations</td>
</tr>
<tr>
<td>5</td>
<td>Recommendation must consider disability, individual, family, and regional factors</td>
</tr>
<tr>
<td>6</td>
<td>Attend to details</td>
</tr>
<tr>
<td>7</td>
<td>Recommendations are proactive, not reactive</td>
</tr>
<tr>
<td>8</td>
<td>Recognize the benefits of maximizing patient potential</td>
</tr>
<tr>
<td>9</td>
<td>Life care planning is multidimensional</td>
</tr>
<tr>
<td>10</td>
<td>Consider the entire cost of each recommendation</td>
</tr>
<tr>
<td>11</td>
<td>The costs provided in a life care plan do not include two important categories: potential complications and future technology</td>
</tr>
<tr>
<td>12</td>
<td>Consider the psychological effects of the injury and disability</td>
</tr>
<tr>
<td>13</td>
<td>Disability interacts with age to produce additional concerns</td>
</tr>
</tbody>
</table>
Table 2-2. Areas of the life care plan

<table>
<thead>
<tr>
<th>Area of Life Care Plan</th>
<th>Types of Recommendation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Projected Evaluation</td>
<td>Health related professional evaluation (PT, OT, RT, etc.)</td>
</tr>
<tr>
<td>Projected Therapeutic Modalities</td>
<td>Displays type, schedule, frequency, &amp; duration of planned therapies. For example, PT, OT, etc.</td>
</tr>
<tr>
<td>Diagnostic Testing and Education</td>
<td>Educational testing requirements, special ed. needs, vocation training, or college education programs</td>
</tr>
<tr>
<td>Assessment</td>
<td></td>
</tr>
<tr>
<td>Wheelchair Needs</td>
<td>Various wheelchair types (electric, manual, sports, etc.)</td>
</tr>
<tr>
<td>Wheelchair Accessories and Maintenance</td>
<td>Includes bags, cushions, trays, batteries, etc. As well as maintenance of any recommended chair.</td>
</tr>
<tr>
<td>Orthopedic or Prosthetic Requirements</td>
<td>Any upper/lower splinting, etc.</td>
</tr>
<tr>
<td>Home Furnishings and Accessories</td>
<td>Furnishing from hand held showers to lift recliners that will improve the quality of life of the person.</td>
</tr>
<tr>
<td>Aids for Independent Function</td>
<td>Any assistive technology that is medically needed.</td>
</tr>
<tr>
<td>Medication</td>
<td>Includes prescription and over the counter disability related medications.</td>
</tr>
<tr>
<td>Supply Needs</td>
<td>Latex gloves, gauze, cauterization supplies, etc.</td>
</tr>
<tr>
<td>Home Care or Facility-Based Care Needs</td>
<td>Within home (respite care, house cleaners, home health aides) or the choice for residential setting</td>
</tr>
<tr>
<td>Projected Routine Medical Care</td>
<td>Any anticipated medical needs based on the treatment team.</td>
</tr>
<tr>
<td>Aggressive Medical Care</td>
<td>Surgeries, hospitalizations, etc.</td>
</tr>
<tr>
<td>Transportation Needs</td>
<td>Necessary adaptation to vehicles</td>
</tr>
<tr>
<td>Architectural Renovations</td>
<td>All adaptation to the home made necessary by the disability</td>
</tr>
<tr>
<td>Leisure or Recreational Equipment</td>
<td>Camps for kids, organization memberships, or subscriptions to magazines etc.</td>
</tr>
</tbody>
</table>

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CHAPTER 3
METHODOLOGY

Research Goals

The goal of this study is to explore the potential use of life care planning during the adoption process of children with special needs. When considering research methods, the nature of exploration helps determine the design of the study. Specifically, careful consideration is necessary when employing new techniques; therefore these research questions are often answered better with the use of qualitative methods as opposed to quantitative techniques (Patton, 1990). Researchers employ qualitative research techniques to develop concepts and obtain a better understanding of social phenomena in a natural rather than experimental setting. Furthermore, qualitative methods place an emphasis on the meanings, experiences, and views of participants. (Pope & May, 2000). The final advantage of qualitative methods is that it allows for the exploration and discovery of the chosen phenomena (Patton, 1990).

Lincoln and Guba (1985) identified three factors for determining the suitability of the research question when choosing qualitative methods. These factors are: 1) the focus of inquiry, 2) the fit of the inquiry paradigm to the focus, and 3) the ability of the paradigm to substantiate the theory guiding the inquiry. As discussed in Chapter 2, there has been little research examining the problems faced by case managers and potential parents when completing special needs adoption and no research exploring the use of life care plans to improve the outcomes following special needs adoptions. Given the exploratory nature of this study, the inquiry fits qualitative research methods.

The researcher must also consider the paradigm that best fits the theoretical background of the research in question (Givens, 2008). A paradigm is a set of
assumptions and perceptual orientations shared by members of a research community that helps determine how to view the phenomena and the type of research methods to employ (Givens, 2008; Patton, 1990). Both research questions in the study utilize qualitative tools but from two different paradigms according to the chosen methods. Each method and paradigm will be discussed below.

**Research Question 1**

What are the perceptions of adoptive parents of children with special needs regarding the use of life care plans during the adoption process?

**Rationale**

Very little research is available that examines parents’ perspective of their experience when adopting and raising a child with special needs (Adamec & Miller, 2007). The primary goal of the current study is to explore the potential of life care planning in the adoption system. The purpose of using life care plans is to provide parents with a disability-related tool to assist in understanding the child’s needs. Parents have firsthand experience regarding the challenges associated with adopting children with disability and as such will provide essential insight into the current problem and potential use life care planning.

**Methods**

This research question is exploratory in nature, due to the lack of research available on parents’ experiences adopting and raising children with special needs. Therefore, the principal investigator chose to employ qualitative methods guided by grounded theory (Glaser & Strauss, 1967). The grounded theory approach is particularly useful when answering research questions with an exploratory focus that are aimed at understanding phenomena involving personal experiences about which
little is known (Glaser & Strauss, 1967). Grounded theory researchers seek to discover and ground the phenomena in theory that is based on reality, therefore believing that theory emerges from the data collected (Corbin & Strauss, 1990). This is particularly useful when researching a phenomenon that has little to no prior theoretical background to support the research questions (Given, 2008).

**Inquiry Paradigm**

The constructivist paradigm of inquiry assumes that individuals “construct” knowledge from their social interactions and experiences. People who ascribe to this paradigm believe that research is aimed at understanding the phenomena by constructing meaning from the subjective realities of informants (Denzin & Lincoln, 2000). The constructivist paradigm will help corroborate the grounded theory emerging from the data, since both are grounded in the assumption that understanding phenomena is achieved through perceptions of others. One method of constructing grounded theory is through constant comparative analysis. Constant comparative analysis involves the development of conceptual model by comparing data in order to identify similarities or differences (Givens, 2008; Glaser & Strauss, 1967). This method will be discussed further in the data analysis sections later.

**Sampling Technique**

This investigator employed semi-structured qualitative interviews in order to fully understand the current problems with special needs adoptions. In accordance with the constructivist paradigm, the researcher chose to use criterion based purposeful sampling techniques (Surridge, 2007). Purposeful sampling involved the strategic selection of individuals who would provide information rich data on the phenomena of special needs (Patton, 2002). Since there is little knowledge about the potential
applicability of life care plans in the adoption process, purposeful sampling provided the best strategy to gather the necessary exploratory information (Patton, 2002). The criterion used to recruit participants was adoption of a child classified as having special needs at the time of adoption, and adopted the child at least five years prior to the interview.

**Recruitment Methods**

For the purpose of this study the researcher developed a flyer that was distributed at mental health, and social services agencies located in a rural community in North Central Florida. The flyer solicited parents who had adopted a child with special needs and were interested in participating in a qualitative interview. The interested parents would then contact the researcher who would screen them to determine their eligibility for participation in the study.

**Participants**

For qualitative studies sample size is determined by a couple of factors including: the purpose of the study, the goal of researcher, the depth of data sought, and feasibility given available time and resources (Patton, 1990). The primary goal of qualitative research is to gain an in-depth and highly contextualized understanding of the phenomena being studied. Therefore qualitative studies, like this one, are well-suited to a small sample size (Given, 2008). Based on small sample sizes, qualitative studies commonly depend upon theoretical saturation or redundancy of data to determine the appropriate sample size (Patton, 1990). Saturation is achieved when the interviews no longer generate new information (Given, 2008). Specifically for this study, theoretical saturation was achieved at nine participants.
The researcher recruited a total of nine participants who adopted children with special needs. Based on the criterion established prior to recruitment all of the participants had adopted a child classified as having special needs at least five years prior to the interview. Also considered in recruitment efforts was the type of special needs with which participants' children were diagnosed. This consideration yielded three participants in each of the following categories physical disability, emotional disability, and combination of both.

**Procedures**

This investigator decided that using semi-structured qualitative interviews would be the best method for fully understanding the current problems with special needs adoptions. By utilizing qualitative methods the researcher was able obtain data that provided a deeper understanding of the rationale, process, and contexts of special needs adoptions (Lehoux et al., 2006). Semi-structured interviews are a common method when collecting qualitative data and are consistent with grounded theory. The use of qualitative interviews allowed the researcher to obtain data on the thoughts and feelings of participants related to all aspects of adopting and caring for children with special needs. Further, qualitative interviews are a powerful tool because they assist the researcher in obtaining diverse opinions from the research participants (Given, 2008).

An interview guide was developed and used to help facilitate the face-to-face interviews with the participants (Appendix B). The interview guide consisted of a set of ten open-ended questions, which helps summarize the content which the researcher covers during the interviews (Given, 2008). The questions included in the interview guide were carefully worded with the purpose of allowing each respondent the
opportunity to answer the same questions with essentially the same wording. Using an interview guide ensured that the same basic lines of inquiry were pursued with each person, therefore increasing the comparability of responses (Patton, 1990). Furthermore, the development and implementation of an interview guide helped assure that the interviewer carefully determined the best method of utilizing the limited time available during an interview (Patton, 2002).

After the participants were screened and determined eligible for participation in the study, the researcher scheduled a time with them to complete the face-to-face interview. All of the interviews were conducted in a quiet and private location of the participant’s choosing. This included locations such as the researcher’s office, the participant’s home, or the office of the participant. Prior to each interview the participants were informed of their rights as a research subject and required to sign an informed consent form. All of the interviews were audio recorded for later transcription and analysis. All of the interviews started with an introduction of the life care planning process and the participants were provided with a copy of an actual life care plan for reference (Appendix C). After a brief introduction of life care plans, the interviewer followed the interview guide in order to the gather the necessary information. All digital audio recordings were transferred onto a storage device and transcribed into Word® documents for analysis.

Data Analysis

The researcher chose to use Microsoft Word® software as a method of managing and organizing the large amount of information collected from the nine interviews. Utilization of Microsoft Word® during the data analysis process provided the researcher the opportunity to identify commonalities amongst the data. These commonalities were
labeled using codes and organized to establish a coding tree. The program allows for the researcher to browse themes, electronically code data, develop coding framework, and create displays of the theoretical framework. The researcher established date and time codes within the program to track the changes to the coding framework, thereby creating an “audit trail” for anyone accessing the data electronically.

According to grounded theory, data collection, analysis, and theory formation is an ongoing and simultaneous process (Glaser & Strauss, 1967; Patton, 1990; Glesne, 1999; Denzin & Lincoln, 2000). Therefore, data analysis began when the interviews were transcribed. Transcription requires listening to the audio recording and creating a word for word document that encompasses the participants’ responses to the interview guide. This process was completed using Microsoft Word® and resulted in a comprehensive document that was used for data analysis. The researcher immediately began to analyze/interpret the data to form a coding framework. The immediate analysis of the interview is necessary because the interpretive information collected is then used to guide the next interview. This process ensured that the investigator would not miss any salient information throughout the interviews (Corbin & Strauss, 1990).

**Constant comparative method and coding**

In keeping with the grounded theory and the constructivist paradigm the researcher used constant comparative methods to analyze the data. This approach combines specific coding procedures with theory development and encourages the comparison of codes across data sources (Glaser & Strauss, 1967). The comparative analysis method provided the researcher the opportunity to refine the coding framework, ensure codes were representative of the data, and minimize redundancies in codes. The comparison of codes within and across nodes allowed the researcher to compare
data across study participants and modify coding as necessary, therefore assuring that the final coding framework is representative of the participants’ experiences. (Glaser & Strauss, 1967)

Another advantage of using constant comparative methods is the ability to uncover theory from the data. According Corbin and Glaser (1990), this method can lead to the attainment of complex theory that will correspond with the data, because constant comparisons force the analyst to consider much “diversity” in the data. The “diversity” in data refers to the comparison of each incident with other incidents in terms of similarities and differences. Making such comparisons helps the researcher overcome bias since concepts can be compared amongst all the participants (Corbin & Strauss, 1990).

The process of coding began with reading the transcripts repeatedly to achieve immersion and obtain a sense of the whole (Tesch, 1990). The next step was to read each line of the transcript in order to derive codes by highlighting the words from the text that appear to capture important expressions regarding the topic of interest. As themes or concepts emerged they were added to the coding framework and given a descriptive label. Each line of the transcript was analyzed according to the coding framework and labeled accordingly. The codes were then added to the theoretical framework as necessary. This process continued for each interview until the final theoretical framework was achieved.

**Research bias**

A concern regarding qualitative research is the extent to which predispositions or biases of the evaluator may affect data analysis and interpretations (Patton, 2002). Regardless of the research methodology, often data from and about humans inevitably
represent some degree of individual perspective rather than the absolute truth (Patton, 2002). As such it is important for the research design to account for these concerns. In order to overcome research bias, this investigator included methods to maintain “reflexivity” during the research and analysis process. According to Malterud (2001), “reflexivity” is assuring that the researcher attends systematically to the context of knowledge construction throughout the research process. This was especially important when examining the effects of the researcher and her biases during every step of the research. Furthermore, Malterud (2001) states that once reflexivity is maintained that personal knowledge and biases are a valuable resource to research process.

Minimizing the effects of researcher bias was achieved through the researcher taking many steps to maintain awareness of the context of knowledge and construction at every stage of the research process. The first step used to minimize researcher bias was through taking applicable coursework in qualitative methods from professors experienced in conducting this type of research. Through this coursework, the researcher developed an understanding of basic qualitative research methods, theoretical frameworks, how to develop discussion guides, and conduct interviews. The next step used to maintain reflexivity was being trained on the utilization of software for analyzing qualitative data. This step was crucial for not only providing an understanding of how to use software program, but for facilitating the understanding of coding techniques commonly used in qualitative research. Furthermore, the trained qualitative researcher was available for consultation throughout the researcher process.
Another method which assured accuracy of the coding was to have other researchers review the codes and obtain congruence among the codes. This investigator frequently met with her chairperson in order to review the analysis. This step allowed for continual validation of the research findings. Finally, this researcher maintains awareness that her personal bias and experiential background may influence the qualitative process. A personal bias statement is discussed below and helps the researcher maintain reflexivity throughout the process.

**Research Question 2**

What are adoption case managers’ perceptions regarding the use of life care plans with special needs adoptions?

**Rationale**

As discussed in Chapter 2, previous research demonstrates that there are a number of barriers when completing special needs adoptions. These barriers included lack of information regarding disabilities, uncertainty of the child’s future, and fear of caring for the child. One possible tool to address these issues is the use of a life care plan. The life care plan outlines the child’s needs and the type of funding sources available to meet such needs. To date, there has been a lack of research into the potential uses of life care plans in the field of adoptions.

**Inquiry Paradigm**

The naturalistic paradigm assumes that there are multiple interpretations of reality. The multiple realities are based on differences among people’s perceptions and experiences. The purpose of the naturalistic paradigm in qualitative research is to discover meaning and beliefs, understand the actions of others, as well as generate theory (Lincoln & Guba, 1985). One method to obtain an understanding of participant’s
realities is through content analysis (Heuseng & Shannon, 2005). Conventional content analysis method was used in this study to obtain an interpretation of the data collected and is discussed in further detail in data analysis portion.

**Sampling Technique**

One sampling technique commonly utilized under the naturalistic paradigm is purposeful sampling (Surridge, 2007). As stated earlier, purposeful sampling involves the strategic selection of individuals who will provide information rich data on the phenomena of interest (Patton, 2002). Therefore, purposeful sampling is well suited for inquiries where the focus is on a phenomena in which little knowledge is available. Since there is limited knowledge about the case managers' views of the applicability of life care plans in the adoption process, purposeful sampling techniques were employed. Specifically, this study employed criterion based purposeful sampling where the participants are recruited based on a set criterion (Patton, 2002). The criterion established prior to recruitment was 1) actively work as an adoption case manager, and 2) personal experience placing children with special needs in adoptive homes.

**Recruitment Methods**

Similar to recruitment methods for the individual interviews, the researcher chose to also recruit participants using a flyer. For the purpose of the focus groups the researcher developed a flyer which was distributed to several of public adoptions agencies. The flyer solicited case managers who had worked in the field for at least three years and had personal experience in placing a child with special needs. The interested case manager would then contact the researcher who would screen them to determine their eligibility for participation in the study.
Participants

The researcher completed a total of two focus groups with six case managers within each group, for a total of twelve participants. The decision to conduct two focus was based on standardized methods of focus groups and included the following steps. When deciding how many focus groups to conduct in order to adequately address the research question, the investigator used the research goals to help make the decision. In general research projects that are exploratory in nature conduct focus groups until saturation is achieved. A research study achieves saturation when the moderator is able to anticipate what the next group will say. For this study saturation occurred within two focus groups (Morgan, 1988). Exploratory studies, such as this one, often require fewer focus groups due to the broad nature of the research questions (Morgan, 1988). Another characteristic which determined the rate in which saturation was achieved was the homogeneity of the participants in each group. Since the two groups were composed of adoption case managers’ with similar work backgrounds, age, race, and experience saturation was achieved with fewer focuses groups. (Morgan, 1988; Patton 2002; Morgan, 1996)

When determining sample size, factors to consider include: the purpose of the study, the goal of the researcher, what depth of data will be useful, and what is feasible given available time and resources (Patton, 1990). For qualitative studies, the goal is to use a sample size that will lead to theoretical saturation or redundancy of data (Patton, 1990). Furthermore, Morgan (1992) noted that a smaller group size was more appropriate with emotionally charged topics such as this one, and allows for greater participant involvement. Based on these guidelines the investigator chose to include six people within each focus group.
Procedures

This investigator chose to employ qualitative focus groups to fully explore the implication of life care plans in the adoption process. Qualitative methods allow the researcher to obtain a deeper understanding of the rationale, process, and contexts of a chosen phenomenon (Lehoux et al., 2006). Common methods in collecting qualitative data are individual interviews and participant observations; however this investigator chose qualitative focus groups because they combine elements of both approaches and allow access to interaction and social data that is not easily obtained with other methods (Morgan, 1988). The organization of the focus groups involved gathering participants with particular characteristics and collecting data through the group interaction (Hollander, 2004; Morgan, 2002). The main intent of using groups was to encourage participants in the session to interact with each other in order to enhance the quality of the data obtained (Greenbaum, 2000).

The standardized approach of semi-structured focus groups as described by Greenbaum (2000) was employed. Focus groups included the participants (described earlier), a moderator, and an observer. The moderator was responsible for facilitating each focus group. Facilitation of the focus group included introducing the topic, assisting in the continuation of discussion, and promoting a safe environment for participant interactions and self-disclosure (Morgan, 1988; Greenbaum, 2000). It was important for the moderator to intervene in the discussion as little as possible, due to the impact that this would have on the group interactions (Morgan, 1996). Therefore, the moderator of the group was aware of this dynamic and carefully considered each interaction within the group. The moderator took some notes during the focus groups, but for the most part listened to the discussion.
The other person involved in the focus group is an observer. The observer was present during each focus group and was responsible for taking field notes. The observer recorded interactions between the group members, as well as interactions between the group and the moderator. This process was valuable since the main goal of focus groups was to gather information through group interactions. The observations obtained from the moderator as well as the observer were transcribed and included in the data analysis.

According to Greenbaum (2000) developing a discussion guide for the focus group is an important part of the process. The discussion guide will be a tool to help the moderator initiate the group as well as maintain and encourage the flow of the discussion. The discussion guide consisted of an introduction, questions carefully worded and arranged, as well as probing questions to encourage further exploration of the topic if necessary (Appendix B). The use of the discussion guide guaranteed that each focus group responds to the same questions through the same sequence, therefore establishing continuity between groups and increase comparability of responses.

First, the discussion guide provided a scripted introduction to the participants and included: the moderator introducing herself as well as explaining her role, the purpose of the group, and administrative details such as rules and audio/video taping. After the introductions the moderate encouraged participants to introduce themselves to each other. The next section of the discussion guide is the presentation of the topic(s) to be discussed. The discussion guide then had pre-scripted questions for the moderator in order to elicit information from the participants.
Each participant met with the principal investigator prior to the focus group. During this meeting the participants were provided with the purpose of the study and expectations if they chose to participate. The investigator was available to answer any questions and assure IRB-approved informed consent is obtained from each person. The other goal achieved during this initial meeting was to obtain demographic information from each individual participant. This data allowed the investigator to describe the research population.

The focus groups were held in a large room that allow for both verbal and nonverbal interactions amongst all participants. Each session was both audio and video recorded in order to collect the necessary data. A digital audio recorder was utilized to tape the discussion and transferred to a storage drive for transcription. The discussion groups were also video recorded in order to assure accurate transcription of audio records and to include observational data for analysis. Each video tape was viewed by two people and the observations of the interactions recorded. These notes were transcribed to also be included in the analysis.

The last 15 to 20 minutes of each focus group was dedicated to debriefing. The debriefing allowed the moderator to summarize some of the initial impressions of the group discussion and receive feedback from the participant. This time provided the moderator an opportunity to determine the extent to which there is agreement on the initial findings (Greenbaum, 2000).

**Data Analysis**

The audio recordings, observational notes, and field notes were all transcribed into Word® documents and each transcription was checked for accuracy. The transcripts were then ready for data analysis process. Word® was also used by the researcher to
assist in the organization and development of coding scheme. In order to answer the current research questions the investigator utilized line-by-line coding to identify prominent themes and relationships.

**Content Analysis and Coding**

In keeping with the naturalistic paradigm, this researcher chose to analyze the data using content analysis (Morgan, 1988; Hsieh & Shannon, 2005). Content analysis is a methodology of studying the content of communication and categorizing its meaning (Neuendorf, 2001). According to Ole Holsti (1969), a number of different techniques have been classified as content analysis, however for this study the researcher chose to use conventional content analysis through the framework approach (Hsieh, & Shannon, 2005). The conventional approach of content analysis was chosen due to the limited empirical literature and lack of theoretical framework on the phenomenon (Moen, et al., 2009). In accordance with the lack of literature, no preconceived categories were utilized when coding the data. Therefore the coding categories and their labels came directly from the participants (Moen, et al., 2009). The primary advantage of conventional content analysis is to gain direct information from study participants without forcing the data to fit into preconceived categories (Moen, et al., 2009).

Coding began with reading the transcripts repeatedly to achieve immersion and obtain a sense of the whole (Tesch, 1990). The next step was to read each line of the transcript in order to derive codes by highlighting the words from the text that appear to capture important expressions regarding the topic of interest. During this process the investigator recorded her first impressions, thoughts, and initial analysis of the chosen text. As the process continues codes that were consistent across participants started to emerge and became the initial coding scheme. The codes were then sorted into
categories which organize them into meaningful cluster according to their relationship to each other (Patton, 2002). Finally the researcher defined each category, subcategory, and codes from the information gathered during the analysis process.

**Personal Bias Statement**

Five years ago I graduated from the University of Florida with a Master's Degree in Rehabilitation Counseling. My educational training provides me with a comprehensive understanding of disabilities, the challenges that people with disabilities face, as well as the psychosocial factors influencing participation. It is this understanding that I held onto when entering the field of mental health counseling. I work as a children’s therapist in the local mental health agency. Throughout the years, I have worked directly with children who have been abused, neglected, and left within the foster care system to either be adopted or age out of the system. These experiences allowed me to gain a personal understanding of the hardships that children with emotional and physical disabilities face when trying to find an adoptive home. Furthermore, I have also had children on my caseload who have special needs and were adopted. By working with these parents I was able to hear about their challenges and frustration with the adoption system and lack of services provided. My experiences in the field is what led to my desire to research this population in order to figure out what might be done to help encourage families to adopt, as well as support those families who have chosen to adopt a child with special needs. I truly believe that children with special needs deserve a loving home and that with the appropriate services in place this would be possible.

The combination of special needs adoptions and life care planning occurred through my doctoral training. The training provided me with an understanding of the process of life care planning and the potentials it holds for people with disabilities. I am
going to be seeking certification in the field of life care planning as well. The combination of my experience with children and my training in life care planning may influence my interpretation of the qualitative data examining people’s experiences.
CHAPTER 4
PARTICIPANT CASE SUMMARIES

Overview

The goal of this chapter is to provide perspective to the data analysis of this study. In order to do so, a description regarding some of the participants’ backgrounds is included below. These descriptions will provide context for understanding the findings from the data. Each of the parents who were interviewed as a part of this study had their own unique set of circumstances and expectations when entering the adoption process. These circumstances and expectations shaped their experiences of adoptions and therefore provide context for the presentation of theoretical framework and data in Chapter 5.

Participant Demographics

Nine interviews were conducted with parents who have adopted children with special needs. Specific demographic information is described in Table 4-1. Eight of the participants were female and one was male with ages ranging from 45 to 65. All of the participants were Caucasian and lived in a small rural communities in North Central Florida. The number of years since adoption ranged from five to twenty-eight years, and the special needs of the adopted child included: physical (3 participants), mental/emotional (3 participants), and a combination of both (3 participants). Prior to making the decision to adopt, seven of the nine parents interviewed had biological children who did not have disabilities. Furthermore, seven participants had experience either in the medical or social services field, while one other participant had contact with her children who worked in the medical field. Only one participant had no experience or contact with anyone who had prior knowledge of the system or disabilities themselves.
All of the participants were well educated with education levels ranging from some college education to obtaining a master’s degree. Finally, five of the nine participants were foster families prior to choosing to adopt the child.

Table 4-1. Participant demographics

<table>
<thead>
<tr>
<th>Participant</th>
<th>Gender</th>
<th>Age</th>
<th>Special Needs</th>
<th>Years Since Adoption</th>
</tr>
</thead>
<tbody>
<tr>
<td>P1</td>
<td>F</td>
<td>60</td>
<td>Mental/emotional</td>
<td>14 years</td>
</tr>
<tr>
<td>P2</td>
<td>F</td>
<td>58</td>
<td>Combination</td>
<td>26 years</td>
</tr>
<tr>
<td>P3</td>
<td>F</td>
<td>59</td>
<td>Mental/emotional</td>
<td>14 years</td>
</tr>
<tr>
<td>P4</td>
<td>F</td>
<td>45</td>
<td>Physical</td>
<td>5 years</td>
</tr>
<tr>
<td>P5</td>
<td>F</td>
<td>58</td>
<td>Combination</td>
<td>10 years</td>
</tr>
<tr>
<td>P6</td>
<td>F</td>
<td>65</td>
<td>Physical</td>
<td>28 years</td>
</tr>
<tr>
<td>P7</td>
<td>M</td>
<td>63</td>
<td>Physical</td>
<td>26 years</td>
</tr>
<tr>
<td>P8</td>
<td>F</td>
<td>50</td>
<td>Combination</td>
<td>9 years</td>
</tr>
<tr>
<td>P9</td>
<td>F</td>
<td>55</td>
<td>Mental/emotional</td>
<td>14 years</td>
</tr>
</tbody>
</table>

The Interview Participants

Interview P1

Participant 1 is 60 year old female whom I met with to discuss her experiences in adopting and raising children with special needs. She resides in small rural community in North-Central Florida with her family, and has past work experience as Certified Nursing Assistant (CNA). The participant describes herself as a good mother who is actively involved in all of her children’s lives. This participant has a total of five children, four girls and one boy, who range in age from forty to thirteen years old. The three oldest children, two girls and one boy, are biological children, while the two youngest, two girls, where adopted fourteen and nine years ago respectively.

The participant had three biological children which she and her husband were raising. As the children got older she still had the desire to continue caring for young kids. Therefore she sat down with her family and discussed the options of bringing foster children into their lives. For her being a mother was extremely important and she
knew that there were a large number of children who could use her help. Her heart’s
desire was to help as many children as possible. This desire led her and her husband
to take the training course to become a certified special needs foster home. Fostering
children was the families’ initial experience with the public social service system.

The family fostered a number of children with special needs, each described as a
special gift to the family in which she learned something from. The family would have
children in the home for one day up to years, with a number of them moving to other
homes or being returned to their biological parents. This mother felt that it was
essential that no matter how long the family had the child they should help them feel
loved and important to the world. After doing this for years, the family was given the
option to adopt one of the children who was in their care. The social service agency
had searched for viable family members to adopt and care for the child; however when
there was no one available the mother was approached with the option of adopting. For
her there was no question on adopting the child, because she was already the child’s
mother in her mind.

Fifteen years ago a 6-month-old child was placed with the family, due to the
biological mother’s drug abuse and neglect. The child had been diagnosed with failure
to thrive and was exposed to drugs prenatally. The mother notes that they took the
child in and starting caring for her in the same way they would any other child that came
to their home. Ultimately, there was no viable home for the child within her family of
origin so as the foster family, they chose to adopt. This was the first time she had
considered crossing the line between a foster and adoptive family. She had learned in
the training courses that you can either choose to foster or adopt children, but often not
both. The bond as a mother was already there for her and she knew that the child was a part of her family and would be happy with them. Fourteen years have passed since the decision to adopt the child. Currently the child is 15 years old and freshman in high school. While she does have number of both medical and psychological challenges she is thriving within her family.

The second child whom the family chose to adopt was an African American female who was initially placed with the family as a foster child at 5 days old. She was born addicted to drugs; therefore was removed from the biological mothers care at the time of birth. As with any other child she was readily received by the family. She remained a foster child in the home while social services searched for suitable placement. In the end the biological mother was unable to provide a safe living environment for the child; therefore her parental rights were terminated. At this point the child had been in the home for a couple of years and the participant was the only mother the child had really ever known. So when the participant was presented with the option of adoption, she eagerly accepted the opportunity.

This adoption did not go as smoothly as the adoption of their first child. When the child was freed for adoption the family was approached in regards to adopting the child by the case manager. Again the mother felt that this was not a question and that she had sincerely been the only mother this child had known. The family started the adoption process and got excited about adding to their family. That is when the adoption case manager informed the family that would not be eligible for consideration when adoption placement was determined. The adoption agency had a policy regarding multicultural families. This policy prevented Caucasian families from adopting
an African American child. In this instance the family had to go to court and convince the judge that they would be prepared to provide the child with an appropriate cultural background. This step was necessary before the participant’s family would be considered a viable placement for the child. In order to convince the judge, the entire family wrote letters regarding the importance of the child to the family. Furthermore, the participant and her husband had to go before the judge to answer more in depth and specific questions regarding their plans of how to raise the child. This process was described by the mother as very emotional and trying because they were afraid of losing their daughter. In the end the judge approved the adoption and at the age of four she legally became a part of the family. The child is currently 13 years old and enjoys playing sports, being active, and hanging out with her friends. The placement is successful and the difference in race between the participant and her daughter has never proven to be a barrier. She is in the seventh grade and receives the full support of family in all her endeavors.

**Interview P2**

Participant number two (P2), is a 58-year-old female who lives in North Central Florida. She currently is a stay at home mother for her step-son, however previously held various service related jobs. While married to her previous husband, they adopted two children from the public adoption facility. She had no prior experience to illness, disabilities, or emotional issues prior to choosing to adopt. They adopted the first child, a two year old girl, 26 years ago. Three years later, the participant and her husband chose to adopt a 3-year-old male.

Participant number two’s adoption story is somewhat different. For her the experience began when she met what would be future husband. They discussed
having children prior to getting married and both knew that it was something that they had a strong desire for, however there were fertility issues. This was back in the early eighties where the primary choice to overcome infertility was adoption. So a couple years into their marriage, they decided it was time to start their family. They were unsure of the exact process, however chose to contact a local adoption agency and inquire regarding the process to adopt a child. This set into motion the adoption of their first child. The couple initially had to start with the application for adoption and complete the home study as well as backgrounds checks. After these steps were finished they met with the adoption case worker to discuss their desires in a child. Eventually they received the phone call that a child had been matched with them. The child was a two year girl who been foster her entire life. At the time of placement all they knew was that the child was born to an IV drug user and tested positive cocaine at the time of her birth. She had been abandoned at the hospital so there was little information on the mother or family of origin. While in foster care she had moved through numerous homes and it was reported that she was some behavioral issues and hyperactivity. From the start the child showed signs of attention deficit hyperactivity disorder and was ultimately diagnosed and treated for it. The other thing the family noticed was how the child appeared to get sick more frequently than most children. The family dealt with multiple illness, trips to the doctor, and stays in the hospital. The child was 15 years old and she spent a couple months sick with one illness after the other, and ended up in the hospital. The participant demanded that there was something more going on and at this time the child was tested for HIV/AIDS. To the family’s surprise the HIV test was positive. The child was exposed to HIV by her biological mother who was an IV drug
user. While the family had the answers to all of the child’s illnesses they were then faced with a whole new challenge. The child started treatment for HIV and she is now 28 years old and has a family of her own.

Three years after adopting their first child, the participant and her husband decided to expand their family. They again contacted the local adoption agency and started the process to be matched with another child. This time they were contacted with a three year old male child who was relinquished to the adoption agency by his biological parents. At the time of placement it was clear to the family that the child had been neglected and had some emotional issues. For the first week he was withdrawn and did not smile, but eventually acclimated to the family. Their son continued to have behavioral issues which escalated as he started school. The participant’s husband did not want to accept that his son had emotional issues and refused to recognize the need for services. As the behavioral issues escalated so did the tension between her and husband. Their son was eight years when the tension, stress, and uncertainty regarding the child’s health overwhelmed them and they divorced. At this point the participant attempted to locate services for her child, however was unsure of where or what types of help he needed. The family struggled with the child’s mental illness as he aged. He was diagnosed with Bipolar Disorder and Reactive Attachment Disorder, which he was hospitalized on multiple occasions for. While there have been challenges the participant described her son as overall a joy to have and that she would not change anything.

**Interview P3**

Participant three’s adoption experience was extremely unique. She is currently 59 years old and resides in North-Central Florida. She has worked within the child welfare
system for the past 25 years, and reports enjoying her work. She has a total of two children, one biological (boys), as well as one adopted male child. Her biological child is 35 years old and has a family of his own, while the adopted child is currently 16 years old.

For this participant adoption, foster care, and finding placement for children was something that she was extremely familiar with. She was a single mother raising her biological son when she decided to become a foster home for some of the children that she came into contact with. At the time she just wanted to foster children in order to be resource for the department. As a foster mother she primarily received adolescent children that would be in the home for a short period time, in order to give the case worker the ability to locate a more permanent placement. The mother enjoyed being a foster parent with no intentions of adoption; however everything changed the weekend a two year child was placed in her care.

As an employee with the social service agency, she was well aware of the children who were in the state's custody. There was one child in particular that had been extremely difficult to place in a foster home. She notes that at the time he was two years and would not spend more than a night in a foster home. The child would spend the days with the case worker at the local office, who would diligently work to find a placement for the evening so the child would have a place to sleep. This process occurred for a couple weeks, until Memorial Day weekend came around. At that time the case worker for the child, a friend of the participants, contacted her to see if she would be willing to take the child for the long weekend. The mother was initially unsure of caring for this child, she knew his background and the behavioral issues in which had
been displaying, plus she had only taken in teenagers up to this point. In the end she
decided to take the child for what initially was just going to be the weekend.

At the time of placement the child was two years old. He was removed from his
biological parents due to neglect, physical abuse, as well as the parents’ substance
abuse issues. He was one of a sibling group that was removed and placed into foster
care, however due to all of the children’s behavioral issues they were placed in separate
homes. The child was classified as a sexual predator at the time due to sexually acting
out in some of the homes he had been in. The participant notes that he had major
temper tantrums, mood swings, and anger outbursts.

The child came to her with nothing but the clothes on his back as well as a broken
pale and shovel for toys. She knew from the start that this child literally had nothing. At
the end of the weekend she chose to continue fostering the child while the case worker
continued to reunification process with the family of origin. So for the next two years the
child maintained scheduled contact with the parents until reunification was deemed an
unviable option. At this time the child’s biological parents rights’ were terminated and
he was available for adoption. The participant felt that even though she had been
caring for the child for two years she was unsure if adopting the child was the best thing.
For her it was when the child called her mom that she realized that she was the only
thing that he had and that he really needed her. Being called mother was a powerful
and important thing for her.

The child was five years old when he and the participant went in front of the judge
to finalize the adoption. Currently the child is 16 years old has made progress since first
being placed with the participant. He has been diagnosed with bipolar disorder,
attachment disorder, as well attention deficit hyperactivity disorder. The participant is
diligent in monitoring his medication as well as attending doctors and therapy
appointment which are helping him learn to manage the symptoms.

**Interview P4**

Participant 4 is a forty-five year old female who is married and currently resides in
North-Central Florida. She is actually the youngest participant in the study and has had
the child for the fewest number of years; however this has not impacted some of the
experiences that she has had with him. She is the mother of four children and also
currently has two other foster children in the home with her as well. Three of the
children are her biological kids and they range in age from eighteen to thirteen years
old. At this time all three children reside in the home with her and her husband. Then
there is the youngest child which is her adopted son. This child is currently eight years
old and was adopted five years ago when he was three. The family maintains their
license as a medically certified foster home, and continues to take children in. Currently
there is a sibling group of two children in the home with the family. The participants
noted that there is the possibility of these two kids coming up for adoption and the family
is considering adopting them as well.

This participant currently works as an occupational therapist in local rehabilitation
facility. She has practiced in the field for twenty years and notes that she has a lot of
experience in disability and illness. For this participant managing disability related
needs and understanding their impact on a person is part of her daily life. Therefore,
when presented with the option of caring for children with medical needs it was not even
a question to her. The participant noted that her professional knowledge has helped
while raising her child. Moreover, she noted that her husband is a preacher and has the
same desires as she does in caring for children who others deem as to difficult. This desire is what drove them to becoming foster parents and ultimately adoptive parents.

The families experience in getting to know the boy they chose to adopt was a little bit different than the other participants. For this family it all started once her youngest child got a little older. She noted that her and her husband both came from large families and knew even before getting married that they wanted to raise a large family. So as their youngest child got a little older the family started to venture into the idea of adoption. She notes that initially they were informed that the process of adoption would take an extended period of time and that there were no children at that time ready to be placed with them. At this news the family decided that the best way to assist some of these children was to become a certified foster family. Therefore, the participant and her husband went through all of the training courses and paperwork to be established as a medically certified foster home.

After becoming a certified foster home, they started taking in children who had a variety of medical issues. For most of these children they were with the family for a short period of time before being moved to another foster home or reunified with their parents. As a medical foster home the family would also serve as a respite location for foster families who needed a break. It was a respite location that the family first met the child that would later become their adoptive son.

One day the family was contacted to serve as a short term respite location for a three year old boy who had multiple medical issues. The family agreed to take the child for the respite period and after a couple of days he was returned to the original foster family. The participant noted that they served as a respite location for the child over the
next few months. That is when the original foster family decided that they could no longer care for the child’s needs. So the participant and her family chose to take the child in and ultimately adopt him. Through adoption the family is able to continue adding to their family and serve children who need their help.

**Interview P5**

The researcher met with participant five to explore some of her experiences when choosing and adopting a child who has special needs. This participant is a 58-year-old female who also resides in a rural community in North Central Florida with her family. She is currently married and is a stay at home mother. Her husband is preacher and has a church which he runs. For her, like many of the other participants, she had three biological children before entering into adoption. Her biological children were all grown and out of the house when she adopted her first child ten years ago.

This family came together under different types of circumstance than the other participants. For her and her husband they decided to adopt after their children were out of the home. She notes that the desire to adopt was driven by their passion to help kids and to continue building their family. The first child whom the family adopted 10 years ago was a male child who had been placed in foster care due to neglect by his biological parents. This child did not have any major medical or emotional issues at the time of adoption. For this family it was never their intent to specifically seek out a child who had special needs. However, two years later they were presented with that specific dilemma.

The mother talked about how a couple of years after adopting their first son, they were approached by an adoption case worker who was searching to place a 5-year-old child. It became evident that the case managers presented this child to them because
he was the biological sibling of their first adopted son. However, the situation with this child was a little different because he had been diagnosed with Autism as well as other medical issues. The family never sought out adopting a child who had special needs, but upon reflection regarding the situation did not hesitate to start the adoption process for this child as well.

Neither parent had any experience in raising a child with special needs; however the participant described her and her husband as not being daunted by the task ahead of them. The mother described how her cousin had adopted a child with Autism prior to them getting their son. She notes that this has been a huge help in understanding where to get help for the child as well as support services that are available to the family. Furthermore, she notes that one of her biological daughters is an occupational therapist and that she has a son-in-law who is an audiologist. The contact with family members who had medical experience was described as guiding post for the participant and helped her and her husband manage issues as they arose.

The oldest adopted son is now currently 16 years old and by the mothers’ report is doing well in school and adjusting social. The younger adopted son is 13 years old and still presents with major social and emotional issues in relationship to the autism. Regardless of the daily challenges and continual treatment that the child receives, she is grateful to have him as a part of their family.

**Interview P6**

This participant is a 65-year-old female who resides with her family in a rural community in North Central Florida. She is currently employed as a nurse and has been for the past 30 years. The participant and her husband have raised three adoptive children, which they adopted 28, 26, and 24 years ago respectively. This participant
was the only one who adopted her children from a private adoption facility; therefore she was provided the opportunity to adopt younger children. All three children were under six months old at the time of placement, and only one of the three children was classified as having special needs at that time.

For this participant her primary reason for choosing to adopt was similar to the second participant, which was due to issues of infertility. Starting a family was extremely important to the participant, so after being married to her husband for a couple of years they decided to start the adoption process. She was a member of the Lutheran Church, so she chose to use a private Lutheran based adoption facility.

To start the process she and her husband contacted the adoption facility and inquired on the steps necessary for adoption. They met with a counselor to discuss their desires regarding the type of child they were interested in adopting. After waiting for a couple of months the adoption agency contact the participant to inform them that they had a 3-month-old male child available for adoption. The participant and her husband were excited to receive the child and complete the legal steps in order to finalize the adoption. This child did not have any special needs and was perfectly healthy at the time of placement. This was not the case for the second child with which the family was presented.

The mother notes that two years after adopting their first son they were once again ready to add to their family. Again they approached the Lutheran based adoption facility, and requested to adopt another child. The circumstances of this adoption were a lot different than with the first child the participant chose to adopt. The participant notes that she was contacted by the agency who informed her that a baby boy was
available for adoption. She notes that the adoption counselor specifically chose her and her husband for this child, because it was apparent the child was going to face a number of medical issues throughout his life. The participant notes they were identified as a good fit because she was practicing nurse and had been for years. All they knew at the time was the boy was born prematurely with multiple birth defects. The most life threatening, which required immediate surgery, was his bowels formed outside of the body. So shortly after birth the child was rushed into emergency surgery to start the process of reinserting his bowels. The participant consulted with her husband on what they wanted to do. Ultimately, they decided to adopt the child.

The third child the family adopted was similar to the process with their first adoption. She did not have any medical or psychological needs, but her arrival completed the family and left the participant feeling happy and satisfied with her choices. Currently the oldest adoptive son and their daughter are out of house and leading very successful lives. For the second child adopted, he did face a number of medical complications and procedures over his childhood. He is currently 26 years old and lives at home with his parents. All of the family members are satisfied with outcomes of their choices.

**Interview P7**

The seventh participant was unique in the fact that he was the only male who was interviewed for the study. He is 63 years old and currently resides in small rural community in North Central Florida. He is retired, however, he spent 30 years working as an engineer. The participant is married and together he and his wife adopted two children. He also has two biological children from a previous marriage which he also raised.
The conversation of adoption started after his second wife was unable to get pregnant and they both knew they wanted a family together. Even though the participant had two biological children from a previous marriage, he knew that starting a family with his second wife was important. Furthermore, the participant notes that based on their religious beliefs children were a special gift from God. This desire led the couple to seek out an adoption agency that would assist them in adopting a child. Therefore, 26 years ago the participant and his wife were matched with their first child. He notes that they informed the case manager that they wanted a little girl; however at time of placement received a boy. The participant reports being overjoyed by the gift of a child and states that if the child had been their biological baby they would not have been able to choose the sex. Prior to choosing to accept placement of the child, the family was informed that the child had special needs and was born prematurely. The little boy was fighting for life at the time and had multiple medical issues along with a diagnosis of cerebral palsy. The participant talked about how he and his wife were given the choice to accept this child or not. For them it was not a choice, God was giving them this child to care for and it was something that he and his wife were willing to accept. Furthermore, the father also talked about how they would not have been guaranteed a healthy child even if he had been their biological son. For the participant and his wife, choosing to adopt this child was just natural for them.

The child was three months old at the time he was placed with the family, and the adoption was finalized a couple of months later. The little boy required multiple surgeries, medical procedures, and hospitalizations throughout his life to treat various medical issues in relationship to prematurity, drug exposure, and cerebral palsy. As the
child started school he was also diagnosed as having mild mental retardation and was placed in a self-contained school. The child is currently 26 years old and maintains a level of independence while living with his parents. The participant states that adopting him was one of the best decisions that he has ever made.

While the participant did not have any medical experience he described being grateful that his wife did. She is a nurse and has worked in the field for many years. The participant notes that she was a huge asset in managing the care of their child and especially the medical procedures. He feels that without her he does not know how he would have handled raising a child like his son.

**Interview P8**

The researcher sat down with participant number eight to gather insight on her experiences in adopting and raising a child with special needs. P8 is a 50-year-old female, who also lives in the North Central Florida. She has past experience as a CNA and worked in a local nursing home. She lives with her husband and two adopted children; however she also has two grown biological children.

They adopted the first child, a 2-year-old female, nine years ago after she was removed from her biological parents due drug use and neglect. At the time of the adoption the child had emotional issues related to the prenatal exposure to drugs. A couple of years later the family was approached by the social service agency with another child, a 16-month-old male, by the same mother. Once again the child was born with prenatal exposure to drugs as well as neglect and physical abuse. Their adopted son has been diagnosed with Attention Deficit Hyperactivity disorder, Asperger’s disorder, as well as a couple of other medical issues which have required multiple surgeries and medical procedures. For this participant, her professional
experience has helped her prepare for raising two children with medical and emotional
diagnosis.

The decision to adopt was a little different for this family. First of all the two kids they adopted were the biological children of a distance cousin who has was addicted to drugs and unable to care for them. The participant was approached by the adoption case worker to consider adoption rather than she and her husband taking the first step. While they may not have previously considered adoption, they were open regarding the options of adding to their family. Actually adding kids to their family was something that was important to both of them. The participant reports that the opportunity to take the first child in came at a very critical part of her and her husband’s life. This was important because she had lost a child at birth a couple months prior to the adoption agency contacting her. For the participant she felt that it was important for them to take the child in regardless of what issues they may face in the future.

Currently the female child is eleven years old and attends elementary school. She has since been diagnosed with both ADHD as well a suspected bipolar disorder. The family has to maintain a close watch on the child and monitor the medications and therapies which she receives. The families’ adoptive son is seven years old and presents with a number of social, emotional, and medical issues. As with his sister he receives a number of medications and therapies in order to treat the symptoms present. The participant is currently a stay-at-home mother in order to help organize, manage, and attend all of the appointments that her kids have. Regardless of the amount of additional stress in managing the kids’ special needs, she still describes them as a joy to have and enjoys watching them grow.
Interview P9

The last participant was also female and currently resides in rural North Central Florida. She and her husband chose to adopt a child 14 years ago. The child was seven years old at the time of adoption. She had spent three years in foster care as result of abuse and neglect by her biological father. The child witnessed her father shoot her mother and as a result has been diagnosed with post-traumatic stress disorder and depression. At the time of placement it was reported that the child was experiencing nightmares, anxiety, and difficulties adjusting to adoption. The participant describes a couple of really difficult years with the child. She notes that it took a large amount of effort to locate the necessary treatments and services the child needed. However, with therapy and medications the child was eventually able to adjust to being a part of their family.

The participant notes that she and her husband were raising one biological son when the thought of adoption was brought up. For them it seemed like a logical method of adding to the family, which they wanted to do. Furthermore, they described wanting to help kids who otherwise would not receive help from others. The family first became a foster home for children in the state’s custody. The participant notes that this provided them with the opportunity to care for and show love to a larger number of children. Being a foster family is how they first met their adoptive daughter, and when she entered the home they knew she had been through a number of different placements. The child presented with behavioral issues that made it difficult for other foster families to maintain the child’s needs, which is ultimately how she ended up being placed with the participant’s family. In the end the child’s biological father’s rights were terminated and she became available for adoption. The decision to pursue adoption
came after the participant and her husband discussed the option between themselves as well as with their two kids. So at the age of nine, two years after placement, the adoption was finalized.

Currently the participant’s adoptive daughter is 23 years old and is lives on her own. With medication and regular treatment she is able to manage her symptoms and lead a fully productive life. She is about to get married and is talking about starting a family of her own. The participant described feeling joy and pride in her daughter and notes that all of the challenges faced while she was growing up were well worth the payoff in the end.

Comparison of Participants

Similarities

As stated earlier, eight of the nine participants had some knowledge regarding people with disabilities prior to choosing adoption. The first participant had prior experience as a Certified Nursing Assistant (CNA). She worked at a nursing home for ten years prior to becoming a special needs foster home. While she cared for the elderly during her professional experience, the participant felt that the knowledge gained assisted her in feeling prepared for what to expect as a medically certified foster home and ultimately adopting two children with special needs.

The third participant was the only parent who had professional experience within the social service agency. This parent worked within agency which was responsible for finding placement for children who were taken into the state’s custody. She had personal knowledge of the adoption process, as well as the common issues children who are adopted face. This unique experience is what initiated her desire to become a foster parent, however on the other hand this experience is also what led to her being
apprehensive in adopting the child. Ultimately her professional experience has provided her with perspective and assistance on raising the child.

P4 works as an occupational therapist and has for the past fifteen years. For her disability and illness is a part of her daily life, so adopting a child with a disability just seemed natural to her. As with the other participants she felt that her professional experience has proven valuable regarding management of her child’s medical care. She notes that her professional knowledge has aided her in locating services, understanding insurance limitations and issues, as well as maintaining an awareness of the magnitude of care the child would require. The participant feels that she entered into the adoption of her child with a unique awareness of what caring for this child would mean for her and her family.

Participant number five is a stay at home mother who chose to adopt two children both with special needs. The participant did not have any direct experience with disability; however she gained disability knowledge indirectly. For this participant her daughter is an occupational therapist and her son-in-law is an audiologist. She felt that having resources and support from people with medical experience assists her in raising the two children she has adopted. Her daughter has guided her through the Medicaid process and is able to assist her in understanding some of the services as well as limitations regarding insurance. Furthermore, her indirect knowledge helps her know what type and where to locate the necessary services that her adopted children require.

Participant six works as a nurse in her local hospital for the past thirty years. She chose to adopt a child who was born prematurely with multiple medical issues.
Throughout his life he has required multiple surgeries, medical procedures, and advocacy for necessary services. Her knowledge and preparation to handle medical issues aided her in managing the child’s multiple procedures and needs. For her medical issues was also a normal part of her everyday life so she felt well equipped to handle any emergency that arose with the child.

Participant number seven is the only male who was interviewed and similar to P5 he did not have any direct knowledge of disabilities prior to adopting. He worked as a computer engineer consulting in a local business. He and his wife discussed adopting children and for him it was a strong desire towards family that led them down the path of adoption. Ultimately, they were given the opportunity to adopt a male child who had a number of medical issues. While this participant did not have any direct experience with medical conditions, his wife was a trained nurse who worked in the medical field.

P8 is a 50-year-old female, who also lives in the North Central Florida area. She has past experience as a CNA and worked in a local nursing home. She lives with her husband and two adopted children; however she also has two grown biological children. They adopted the first child, a two year old female, nine years ago after she was removed from her biological parents due drug use and neglect. At the time of the adoption the child had emotional issues related to the prenatal exposure to drugs. A couple of years later the family was approached by the social service agency with another child, sixteen month old male, by the same mother. Once again the child was born with prenatal exposure to drugs as well as neglect and physical abuse. Their adopted son has been diagnosed with Attention Deficit Hyperactivity disorder, Asperger’s disorder, as a well as a couple of medical issues which have required
multiple surgeries and medical procedures. For this participant, her professional experience has helped her prepare for raising two children with medical and emotional diagnosis.

The final participant, P9, is a 55-year-old female who adopted her daughter 14 years ago. At the time of adoption the child was seven years old and had been diagnosed with major depressive disorder along with post-traumatic stress disorder in relationship to the abuse she had experienced. The participant worked as a physical therapist and had professional experience in working with people who had mental illness. For this mother her professional experience was of assistance in navigating insurance issues as well as locating necessary services. The participant felt that this knowledge was paramount in her ability assist the child as various crises arose.

Another commonality amongst some of the participants was their choice to be foster families. Five of the nine participants, P1, P3, P4, P5, and P9, were certified foster homes prior to choosing to adopt. For these families the first meeting with the adoptive child occurred through foster placement. All of the participants noted that fostering allowed them the opportunity to assist a larger number of children. Furthermore, by fostering a child the family was aware of the challenges the child faced prior to adoption.

Differences

There were some differences amongst the participants that warrant highlighting. The method in which P8 entered into adoption was different than all of the participants. She was approached by the adoption agency rather than considering adoption and making first contact. Furthermore, this was case for P8 because she adopted children who had a distant biological connection to her and her husband.
Another interesting difference amongst the participants was that only two of the nine people interviewed considered adoption out of need due to fertility issues, rather than desire. This was the case for P2 and P6, and highlights an interesting characteristic regarding the study’s sample. Only one participant, P3, chose to adopt the child without having a partner involved to help. Furthermore, there was only one male, P7, who participated in the interview.

There was only one participant who did not have any medical experience or knowledge regarding disabilities prior to adopting. For P2, this lack of knowledge and understanding was a source of major stress for her and her family. This source of stress was ultimately overwhelming and is one of the major reasons that the participant and her husband chose to get a divorce. For this mother she described feeling helpless and overwhelmed, because she did not know how to help her child. Furthermore, these feelings were exacerbated by the adoptive father’s unwillingness to recognize the need for additional help.
CHAPTER 5
INTERPRETATION OF INDIVIDUAL INTERVIEWS

Research Overview

The researcher transcribed the individual interviews in preparation for data analysis. Data analysis and interpretation was completed using constant comparative methods in accordance with grounded theory (Glaser & Strauss, 1967). Development of theory from the data is the primary emphasis of grounded theory; therefore the researcher examined the emerging relationships among the themes to develop the theoretical framework presented in Figure 5-1. An ecological model was utilized to develop the theoretical framework to explain the parents’ adoption experience.

The ecological model is a general systems theory that focuses on relationships between a living entity and the aspects of his or her environment. As discussed in Chapter 2 the environment of a developing person is perceived as “nested structures, each inside the next.” (Bronfenbrenner, 1979, pg. 3). At the core of the theoretical model is the developing person. The ecological perspective of adoptive parents’ experiences places the parent at the center of the theoretical model. Spanning outward from the developing person (adoptive parents) is the micro, meso, exo, and macro systems of the environment. Furthermore, the developing persons’ behaviors affect and are affected by the environment (Bronfenbrenner, 1979). Therefore, this interaction is depicted by the bi-directional arrows between each level of the environment.

Ecological Perspective of the Adoption Experience

Microsystem

When analyzing the interviews it became evident that the parents were describing characteristics which defined their microsystem. Based on the ecological model the
microsystem is the developing persons' immediate environment (Bronfenbrenner, 1979). The immediate environment may be home, school, or work, but also includes the persons' behaviors, beliefs, and thoughts. For this study, the microsystem is defined as the personal constructs which emerged from the data.

Figure 5-1. Ecological perspective of the adoption experience

Personal constructs describe the individuals' experience throughout the adoption process as well as while raising the child. These experiences are based on the immediate environment, which include the adoptive parents as well as any biological or previously adopted children. Therefore, the parents' experiences include variables of decision making, emotions, and coping. Examples of these variables were evident throughout the interview and analysis process. For example, the decision making process for the parents was a prominent part of their experiences. Deciding to adopt a
child was the first step in the adoption process and each family considered different characteristics as import aspects of their decisions. These different characteristics will be discussed further later in this chapter.

The second personal construct variable evident during analysis was the adoptive parents’ perceptions throughout the process. Parents’ perception of the process was expressed in their emotions they experienced while interacting with the social service microsystem. For example, parents expressed emotions ranging from anticipation, to frustration, and joy. The final variable within the personal construct is coping. The parents’ methods of coping with the adoption as well as challenges that arose while raising a child with special needs was another important variable which helped define the parent’s microsystem. Throughout the interview process it became evident that the ability to cope was a necessary aspect for the adoptive parents and was important in determining satisfaction as well as success of the adoptive placement. Parents’ coping includes a variety of methods dependent upon the adoptive parents’ environment (microsystem). The combination of these variables defines the adoptive parents’ microsystem of the adoption experience and will be discussed further later.

**Mesosystem**

According to Bronfenbrenner the mesosystem of the model describes the interactions between the microsystems that the developing person comes into contact with (Bronfenbrenner, 1979). Bronfenbrenner proposes that the interactions between theses microsystems will create modifications in the developing person’s (adoptive parent) behaviors and thoughts, which ultimately modify the microsystem (Bronfenbrenner & Morris, 1998). Therefore, analysis of the mesosystem is an integral
aspect of the ecological model, because it aids in the understanding of the microsystem and how changes may occur.

Throughout the interviews, the parents described variables that define the mesosystem of the adoption experience. First it is important to consider the different microsystems an adoptive parent will come into contact with. Once a potential parent chooses to go through the adoption they invite a number of different microsystem into their environment. There is of course the direct microsystem which contains the potential parents and immediate family. Second is the microsystem of the social service agency which will be interacting with the family while matching the child and monitoring the adoptive placement. The final microsystem to consider is the legal system. The legal system is necessary to complete and finalize the adoption of the child. As the parents discussed their experiences in adopting a child with special needs, interactional constructs that define the mesosystem became evident.

The interactional construct relates to the parents’ experiences while working with the social service agency as well as the legal system. For this study, the variables of emotions and process were best defined under the interactional construct. These variables were evident throughout interview data. All of the parents interviewed described the emotions they experienced during the adoption process. The parents’ emotions which were directly related to the interactions with the social service and legal system help defined the mesosystem. For example, one of the most prominent comments by all of the parents was the frustration they experienced while interacting with the social service agency. The frustration was directly related to their microsystem (the potential family) interacting with the established guidelines and social workers.
within the social service microsystem. Each microsystem enters the adoption process with a unique set of expectations and standards. The emotion of frustration was commonly the result of conflict in views between the two microsystems. This conflict is clearly witnessed as parents’ describe the frustration they felt when attempting to obtain information from their adoption case manager. The parents’ discussed the assumption that the adoption case manager should be able to answer all of their questions, but failed to recognize that due to standards within the adoption system the case manager may not know or be able to access the requested information. Ultimately, the difficulties in obtaining information led the parent to feeling frustrated, which modifies their microsystem. Other interactional experiences and emotions are evident in the descriptions of the parents’ experience and will be discussed further.

The second variable describing the interactional construct is the process. The parents described their experiences, feelings, and thoughts as they progressed through the adoption process. As with the emotions variable, the process variable also describes the interactions between the multiple microsystems that the parents’ came into contact with. For example, parents discussed the impact that completing the adoption process had on them and their family.

**Exosystem**

The exosystem is the third environment expanding outward from the developing person, and as such the person may not directly interact within this system. Regardless of the lack of direct interactions, the components of this environment still influence the person. Therefore, recognizing the components of this environment is an important aspect of understanding the persons’ behaviors (Bronfenbrenner, 1979). According to Bronfenbrenner the exosystem commonly contains components such as extended
family, work environment, or school. For this study, the exosystem of the adoption experience is defined as the system construct.

The system construct emerged from experiences identified as important to the participants while interacting with the adoption system. The variables that compose this construct are foster care, adoption, and legal systems. These components are integral parts of the adoption process and therefore influence the adoptive parents’ experience. However, the adoptive parents do not function within each of these systems. These systems are classified as components of the exosystem because they influence adoptive parents’ experiences without direct interactions.

This study focused on the adoption of children with special needs from the child welfare system. As such these children have often been through specific steps to reach adoptive placement which is described in Chapter 1. This process starts with the child being removed from the biological parents and placed into the foster care system. Therefore, the foster care system plays a key role and decisions made at this time will ultimately impact the adoptive parent. When analyzing the data, some themes emerged regarding the decisions at the foster care level. These themes include the decisions regarding moving the child’s placement, how long to allow for reunification steps to continue, and determining adoptive placement. The impact of these themes will be described later.

The next step for the child is to be cleared for adoption and once this occurs the adoption case manager assumes responsibility for the child. Responsibility for the child’s case includes making decisions regarding the child’s placement and continued care. At this time the variable of the adoption system becomes a component of the
exosystem. As with the foster care system, decisions made at this time will influence the adoptive parents' experience. While analyzing the data, parents experiences related to the adoption system became evident. Themes related to the adoption system include the steps of the adoption process as well as decisions made regarding adoption placement.

First, is the theme of the steps necessary to complete the adoption process. The adoption system has standard guidelines that all potential parents must complete in order for a placement of the child to occur, which is discussed in Chapter 1. These steps emerged from the data as all the participants described what was necessary for them to complete in order to finalize the adoption of the child. According to the ecological theory the decisions by the adoption system to establish guidelines regarding the adoption process impact the adoptive parents' experience. The data collected from this study supports the influences of these decisions as the participants also described how the steps of the adoption process impacted them as well as their family. The impact of the adoption process will be discussed further.

The second theme related to the adoption system was the decisions made regarding the placement of the child. The adoption case manager as well as the participants within the adoption system make decisions which they feel best promote successful placement for the child. These decisions often include separating sibling groups, placing a child in an open versus closed adoption, or who to approach when adoption becomes the goal. All of these decisions as well as their impact on the adoption experience emerged during data analysis. This again supports the assumptions that events occurring at the exosystem impact the developing person.
The legal system is the final component of the exosystem. Adoption is the completion of a legal process in which the adoptive parents assume all rights and responsibilities for the child, thus requiring the court system (Adamac, 2008). This variable was evident throughout the analysis of the data as parents described the process in which they went through in order to finalize the adoption of the child. The legal system was described simply as a necessary aspect of the process; however some parents expressed the desire to understand the legal system in order to feel comfortable with the process. This variable will be described further in the data analysis.

**Macrosystem**

The outermost environment which impacts the developing person is the macrosystem. As discussed in Chapter 2 the macrosystem encompasses all the other systems, and is composed of laws and regulations as well as cultural attitudes that impact the shaping of the microsystem (Schweiger & O’Brien, 2005; Bronfenbrenner, 1979; Bronfenbrenner, 1998; Palacios, 2009). First it is important to establish the integral role that legislation plays in the adoption process. Both federal and state legislation establish the foster care and adoption systems as well as the procedure in which they follow. All of the different legislation regarding adoption is described in Chapter 2. While this aspect of the macrosystem was not evident in the data collected from this study, its impact on the microsystem is still an integral part and will be discussed further in Chapter 7. The other component of the macrosystem is cultural attitudes and for the purpose of this study is defined as the social construct.

The macrosystem encompasses society’s views of adoption which is defined as the social construct. The social construct illustrates the societal views that arose from
the participants’ discussions on the adoption experience. This construct contains the variables of social views, social pressures, as well as peer pressure. The variable of social views describes the parents’ experiences outside of their family. This experience was evident in the descriptions the parents’ provided while interacting in society and define others views of adoption. The second variable, social pressures, describes the impact the parents felt in regards to the way others viewed the adoption. For example, some parents described how their extended family does not treat the adopted child the same as biological children because of the social concepts of adoptions. These variables will be discussed further in the data analysis section.

The last component of the model is the arrow running from the macrosystem towards the developing person. This arrow models the top down effect, which according to ecological theory establishes that each system impacts the person’s behaviors. So characteristics within each system will shape or change the person’s behaviors. Therefore, based on this concept a change at any systems level will alter the person’s behaviors.

**Microsystem: Personal Construct**

At the microsystem level the participants identified personal constructs which shaped their immediate environment. The personal construct includes decision making, and emotions.

**Decision Making**

First, is the variable of decision making where participants identified a number of characteristics which aided in their decision to adopt a child who had special needs. One of the prominent characteristics was knowledge of the healthcare field. A commonality among all of the participants was their experience in the medical field. The
parents discussed how their experience in the medical field along with the accompanying knowledge of disability was a huge factor in helping them feel comfortable in caring for a child with additional needs. The parents often stated that this experience allowed them to be prepared not only for what to expect, but how to handle emergencies as they arose. Feeling prepared to handle the additional issues meant that the parents were not uncomfortable when being presented with a child who had special needs. In the following statement from P4, she discusses her career and how it shaped her views on choosing to adopt a child with special needs.

P4: Well, I'm an occupational therapist and have worked with kids with ..... So as an OT, it doesn't bother us at all to have a child with special needs.

P3 discusses her experience in the foster care field and how her work knowledge assisted her in the decision to adopt the child.

P3: I worked actually placing children in foster homes at the time the child was placed with me. I knew what issues the child had and I knew that he had been extremely hard to place. .... at first I was not sure if I wanted to adopt him. Then I realized that I had taught the MAPP classes and I knew that I had the skills and training to be able to take care of this child and to understand as well as deal with the issues that he has.

P6 also describes how her role as a nurse made her a suitable choice for adopting a child born prematurely with a number of medical issues.

P6: I mean I had years of experience in working with illnesses and medical problems and had an understanding of what this child would face in the future. I felt that my knowledge plus the fact that we would not have been guaranteed a child with no issues if we had a biological child played a huge role in us deciding to adopt the child.

Another characteristic described by participants as important in making the decision to adopt was the desire to be a mother and have a family. The parents who chose to adopt described a strong feeling towards having a large family. This desire was a driving force behind parents choosing to adopt, because most of the participants
in the study had biological children prior to choosing to adopt. The consensus among most of the participants was that being a mother and surrounding themselves with family was a unique and special role that they had the desire to establish. The feelings of family are evident in the statement by P4 on how powerful the desire of being a mother was to her and how it helped her make the decision.

P4: From the moment I picked the child out of the car seat and he looked at me and he called me mama and that just—ah, that was amazing for me. I had fostered teenage children for years and nothing compared. ......I just knew that he needed someone and he was calling me mama so I knew what I needed to do.

P1 describes the bond a mother has with a child and expresses how powerful of an experience it is to her.

P1: I just wanted them, it was the mother in me and I have always been that way. My husband and I continually talked about this, ... we knew that we wanted to help as many children as we could. And every time from the second they were in my arms there is a bond. I don’t know to me there is no building a bond. It is there. That mother in me was automatic, even having my own children. We just loved her like any other baby we had.

The majority of participants identified the exploration process they went through when coming to the decision to adopt a child with special needs. This process was individualized for each participant but included several aspects such as discussing special needs adoption with his or her partner, referring to educational sources, as well as relying on religious guidance. Discussion between partners was an important aspect in coming to the decision to adopt a child. The participants described having lengthy conversations regarding if they should adopt as well as the characteristics of the child in which they could manage. For a number of participants, the decision to adopt was not made quickly, instead they explained how there had many conversations over a period time regarding their desires both as a couple and family. The participants even
explained how it was important for them to include their biological children in these
discussions in order to assure they were comfortable with the family's decision. This
statement by P5 displays how discussing things with their partner was an important part
of the decision making process for them.

P5: My husband and I sat down together and discussed what it was that we
both wanted. We talked about adding children to our family and both felt
that we wanted to do that, but was not sure of adopting a child with special
needs. It was a hard thing for us to determine but we really felt that it was
the right thing for us. It was important to us that we were on the same
page in our decision prior to entering the process.

These results demonstrate how a necessary part of the exploration process for this
participant, was to assure that she and her partner were making the right decision and
were “on the same page”, prior to entering the adoption process. Moreover, some
participants felt that it was important to gain information and education regarding the
process as well as what to expect when adopting a child who has special needs. The
participants expressed that seeking educational resources helped eliminate some of the
fears and made them feel more prepared. Furthermore, for some of the participants the
education allowed them to gain a sense of control over a situation that was described as
foreign and often frustrating to them. This part of the exploration process is evident in
the statement made by P8.

P8: When we were thinking about adoption and the child was cleared for
adoption we starting thinking back on our training courses over the years
and how they discussed the fact that you have a choice, you can be a
foster parent or adopt and what do you want. Thinking back on the things
that we learned helped us feel prepared to adopt a child with special
needs and really seemed to give us the confidence and desire to proceed
forth.

Another characteristic identified by the parents as important when considering
adoption was faith. The use of faith is a common method of seeking assurance
regarding a variety of decisions. Depending upon the person’s microsystem and established beliefs, religious guidance played an integral role in the adoption process. A couple of participants explained their faith and how it was important in helping them make the decision regarding adoption.

P7: Probably my faith was one of the most integral things in choosing to adopt. My wife and I chose to consult with friends of the church, our spiritual guidance, and turn over the decision to our faith. And the decision was conferred to me in the temple in Atlanta.

The final decision making characteristic identified was the lack of assurance that a biological child would not have any issues. P6 expresses her opinions on being presented the option of adopting a child with medical issues. This statement shows how being presented with a child who had a disability did not appear to be any different than if she had a biological child. A number of times during adoption the potential parents feel they are getting to pick and choose the characteristics of the child, but fail to keep in mind that nature does not work that way. In this next statement P3 describes her feelings on adoptions and how there are no guarantees that this child will be any different than a biological child.

P3: Our mindset all along …., we could have refused to take our first child because we wanted a girl but our mindset was that if I had been able to get pregnant, I wouldn’t have not taken a girl if I had been pregnant with a girl and the same thing with a disability. Right, and we would not have said, you know, too bad let the State take it if we had had a child born with medical problems. So to us it was the same, because there are no guarantees with biological children either.

**Emotions**

Throughout the interviews, all of the participants noted a number of different emotions in relation to the adoption process as well as raising a child with a disability. The first emotion noted in the participants’ experiences was anticipation. The
participants’ described experiencing anticipation prior to the child being placed. The parents had progressed through the stress associated with deciding to adopt a child, which left the parents full of anticipation for the adoption match to occur. The parents stated that waiting to be matched with a child took a couple of months. This emotion was described by P9 when she talked about completing the background process of adoption.

P9: Once you are given the okay then you have to wait and wait, wait, wait, wait, until they find the right child for you. The process takes a long time and a lot of patience. You just want that child in your care and I was really unsure of when it was going to happen. It seems like it took forever.

Another emotion in which parents related to their experiences with the child was joy. Joy was actually represented in two different periods of the adoption experience. First, the parents felt joy when the child was placed with them, and second was the joy they felt when reflecting on their experience of parenting the child. The participants explained that once the waiting was over and a child was placed with them that they felt extreme joy. This first statement by P6 shows her joy when the adoption process was finalized and she was considered the legal guardian.

P6: You know I really just expected it would just be like the same as if I had had the child. Just expecting to be to be a happy little family (increase tone of voice and intonation) you know just the joy of having children and my children were a joy from the moment that they were placed with us. …But when we did finally get a child wow what joy that was to me and my husband, it is like nothing I can explain. It was just the joy of finally getting to be family and to have the child in our care. It really made all of the waiting seem worthwhile.

The parents also expressed joy they experienced while raising the child and being able to witness them develop into a person.

Along with the positive emotions of raising a child, parents also commonly expressed negative emotions including frustration and fear. The feelings of frustration
were related to a number of aspects in both adopting and raising the child. One of the primary areas of frustrations was the confusions regarding what type and where to locate medical and psychological services necessary to address the symptoms which their child was displaying. These difficulties were reported by a couple of the parents who knew some type of services were necessary, however did not know where to start. These parents even discussed contacting the adoption agency for guidance but not finding any assistance, which only escalated their level of frustrations. This lack of understanding is evident in the discussion by P8.

P8: It really wasn’t easy in the beginning; I knew there were issues that needed treatment. The kids were having behavioral problems and the boy I adopted was unable to hear. Finding the right people to get to was a major challenge and was extremely frustrating. I tried contacting the adoption agency for assistance, and questioned them on their recommendation on where to take the kids for service. They told me that “we don’t know where to tell you take them.” It was extremely frustrating.

P2 expresses a similar situation with her son and how the adoption agency was of no assistant in helping her understand where to get help.

P2: The major problems started going on in elementary school and I called CHS to receive help regarding the issues and found out I was on my own. I did not have any knowledge regarding these types of issues, and I had no clue where to take the child to get help.

The second negative emotion suggested by the participants was fear. One parent specifically talked about his fears for the child’s future and interacting in regular school. Here he describes how he was sure the child was going to have problems in mainstream school with teasing and social skills.

P7: I was scared to death for him to be in a regular school system because I know there’s some bad dudes there and I always had a vision – I always had a vision of him being trapped in the bathroom. Oh, my gosh it just – just that picture just – just keeps coming to my mind and so I really didn’t want him there. And – but I guess, what, the last two years, I guess, he went part-time to the high school and he’d go down the hall and call his
name and say how ya doing? I mean, just – he did so much better than I expected and it turned out that my fears for him were not justified.

While this participant went into the experience of sending his child to school with fears, he was able to quickly realize that the child was capable of handling the social environment. Another participant expressed similar fears regarding the child's future. For her these fears are compounded by the fact that she is an older parent. The participant explains that when initially considering adoption, her age was not a factor, however she realized later that it impacts the adoption experience. She discuss the realization that she is not as physically able to care for the kids and fearful for what this means as they emerge into adulthood. This is evident in the following comment by P1.

P1: When you are young, I mean when you have these children in your possessions, you loving them your bonding with them you really cannot think -20 years down the road that you are going to be tired, and gray haired and that you are going to be like me. And there is always the fear now with them being bipolar of what is going to happen to them. (Crying) Can they take care of themselves mentally; are they going to be able to hold down a job. Are they going to end up, with rage and violence is she going to be up in prison one day for hurting someone. I mean I think of the future and I cannot say to my child you need to take these drugs because mommy don’t want you to ever be in jail. It really just makes me very fearful for what the future might hold.

Mesosystem: Interactional Construct

For this study the mesosystem level is defined by the interactional construct. The interactional construct contains variables of perceptions and process. The variables of perception and process describe the experience of the parent’s microsystem interacting with the microsystem of the social service agency.

Perceptions

Throughout the interviews the parents discussed their perceptions of the experience directly related to their interactions with the microsystem of social service.
agency. These perceptions were expressed in the feelings of frustration directly related to the parents’ interactions with adoption case manager. The parents described being frustrated with a couple of characteristics related to the adoption system including: lack of information, and the lack of post adoption support. A number of the participants felt that the case managers were not providing all of the information regarding the potential adoptive child. It was expressed by some participants that they felt the case manager withheld the child’s physical, emotional, and psychological history from fear that they would no longer be interested in adopting the child. Furthermore, parents expressed frustrations at the lack of information which was provided about medical/psychiatric history regarding the family of origin. P3 points out how the lack of background information often leads to feelings of frustrations.

P3: My child has two other siblings and it’s like with his middle sibling. That adoption failed and I think it is because the frustrations built up regarding the lack of information and understanding on the magnitude of issues that all these kids had. This led to that adoption failing.

Feelings of frustration were also related to the lack of support parents felt they received following the adoption. A common theme among the participants was lack of post adoption support. A number of the participants described contacting the adoption agency seeking guidance on how to locate the necessary services once the child’s issues increased. The participants describe a lack of guidance from the adoption agency. One participant states that it was like being “abandoned with this child.” The feelings of abandonment left the participant extremely vulnerable and overwhelmed. Furthermore, the participants note that the lack of assistance from the adoption agency created a delay in the child receiving essential services. These feelings and experiences are evident in the following statements by P8 and P2.
P8: I tried contacting the adoption agency for assistance, and questioned them on their recommendation on where to take the kids for service. They told me that “we don’t know where to tell you take them.” It was extremely frustrating ....

P2 expresses a similar situation with her son and how the adoption agency was of no assistant in helping her understand where to get help.

P2: I started telling his dad when he was in preschool that he needed some type of help and that there just was not something right..... This started going on in elementary school and I called CHS (Children’s Home Society) to receive help regarding the issues and found out I was on my own. It was all up to me. You would think that there would be something more. Even a support group but there was nothing. So we went on like that for a long time without my son receiving any services. It was just really overwhelming and frustrating.

Process

The second variable within the interactional construct is the process. The process describes the participants’ experiences while completing the steps involved during the adoption. The decision to adopt requires the potential parents’ microsystem to interact with another microsystem. This interaction can create tension within each system. For the participants the areas of tensions identified were directly related the lack of communication between the foster and adoption system, lack of guidance by adoption case managers, and the pace of the adoption process.

The participants discussed the process they went through in order to finalize the adoption of the child. Each participant described the process as extensive and invasive for the family. The participants expressed this experience as stressful especially when having to repeat steps multiple times due to a lack of communication between the foster and adoption system. One area which commonly was referred to as repetitive and time consuming was the finger printing and background check process. The participants described how they were required to be finger printed multiple times especially if they
fostered the child. The parents often described this as confusing because they had already gone through the finger printing/background process with the foster care system. Regardless of being cleared for fostering these records where not transferred to the adoption agency, therefore requiring the parents to complete this process again. The participants felt that this was an extremely time consuming process and required them to arrange their schedules in order to complete. This experience is discussed in the statement by P4.

P4: We have been fingerprinted three different times. I mean our fingerprints have run to the same organization doing FBI background checks on us. I don't understand why they can't use the same fingerprints and call up and say, “You have this person's fingerprints on file. We just need an update.” Doesn't make any sense to me.

The next area of tension related to the theme of process was the lack of communication or missing information between the foster and adoption agency. The parents described facing major barriers when seeking information regarding the child's past medical care. The participants noted that they often had questions which they posed to the adoption case worker, but these questions went unanswered because of separate foster care and adoption system documentation. Furthermore, the participants noted that the adoption case manager stated that the records from the foster care system do not transfer to the adoption agency. The lack of continuity between the two agencies was described as a major point of contention for the parents. The lack of communication was not only related to information regarding the child, but also forms related to the family. A number of the participants fostered the child prior to choosing to adopt and expressed that the adoption agency required them to redo a number of the same forms. This was described time consuming and it only extended the timeframe required for finalization of the adoption.
P9: I guess for me the biggest challenge is that the foster and adoptive organizations don’t keep the same data. They don’t communicate as well. They’d make you do it all again and it’s the same paperwork. This was really frustrating to us because it slowed down the process and required us to do the same things over again.

The next area of tension related to the process was the lack of guidance regarding what to expect throughout the adoption process. Specifically, one participant discussed the uncertainty related to the steps in which she was expected to complete for finalization to occur. She noted that it would have been helpful if the adoption case manager would have been able to provide her stepwise layout of the process. The participant expressed feelings of being lost, overwhelmed, and frustrated without knowing what was supposed to happen next in the process. Furthermore, she notes that case manager was unable to provide a timeframe in which she could expect the necessary paperwork and legal process to be completed. This again left her feeling tense regarding the process, as well as uncertain on how to proceed in order to expedite finalization.

P4: We couldn’t really get anybody to really give us this happens and then this happens and then this happens. She kinda gave us some global steps, but we wanted like some tangibles. So when will the home study be finished and when do we talk to the attorney? You know what I mean? So we didn’t have a timeframe. She wouldn’t give us like, “I’ll be done with this in two weeks and then after that you’re gonna do this in a week and then…”

A final area of tension related to the theme of process was the frustration the participants expressed in relationship to the pace which finalization occurred. The consensus among the participants was that the adoption process was slow and took a couple of years before finalization was achieved. For the participants this was an extended period of time in which they and their family were in limbo. Therefore, participants described feeling frustrated due to extended period in which they were
unable to be a legal family. P4 talks about some of the things that her and husband experienced while navigating the adoption process.

P4: It was so frustrating for us to go through the process….. Then time just kept dragging on and nothing was being accomplished it’s like they want us to jump through hoops and submit to all sorts of things but then once it is their (adoption agency) responsibility then things change. It was hard for a family because we didn’t know what to expect and just felt like we were in limbo. A lot stress and frustration could have been avoided by just communicating the process to us better.

P8 also commented on the pace of the process by saying:

P8: The state moves real slow. That’s one problem. It took two years to complete the process and go before the judge in order to finalize. That was a long amount of time where I was caring for the child, but yet legally he was not technically my child.

Exosystem: System Construct

System construct describes the exosystem level of the environment and includes themes related to the foster care, adoption, and legal systems. Potential parents are required to interact with these three environments while navigating the adoption process. While the participants are not directly a part of these environments, they still influence the adoption experience. This influence was evident in the parent’s discussion regarding adopting a child with special needs.

Foster care

Throughout the data analysis process aspects of the foster care system and its impact on the adoption experience were discovered. The first theme in relation to foster care was the advantages of fostering the child prior to adopting. Five of the nine parents fostered the child prior to choosing adoption, and this was described as an important aspect in their experience. The participants expressed that fostering the child provided them with the opportunity to grasp the concept of the child’s needs.
Furthermore, the participants felt that since they had been caring for the child and managing the needs for a period of time that continuing that role would not be burdensome.

P9: The most helpful thing during the adoption process was getting to know him as his foster care mother, honestly, ‘cause I think it’s a lot easier to adopt someone you know better, than having somebody come in your home and you don’t know them. It’s easier, I think, to go from foster to adopt ‘cause you have had the opportunity to see what they’re like, to hear what they’re like, to see their needs and, you know, live with them.

While fostering the child is described as a good way to understand the child needs, some participants had different views on the challenges posed by the foster system. The first challenge in relationship to the foster care system is the duration of the reunification process. The participant expressed this as challenging due to the fact that reunification process continues even while the biological parents progressively fail the child. The participants then have to witness the disappointment in the child and feel very helpless throughout the process. Furthermore, the participants expressed the impact that the disappointment had on the child’s behaviors and their ability to form attachments with the adoptive family.

P3: Yeah, well, he was in foster care until he was four, so for two years we went through the foster care process where they – the state tried to reunify him with his parents. This was challenging because I was able to witness the disappointment in him every time his parents didn’t keep visits or would not uphold promises. His negative behaviors were always worse when he returned from a visit and it made things difficult.

Similar to the challenges expressed regarding the reunification process is the instability a child experiences while in the foster care system. Specifically, one mother described how the child she adopted had been transferred through ten different homes during his six months of foster placement. The child had major emotional and behavioral issues which created difficulties when attempting to locate a suitable foster
home. The participant believe that this instability contributed to the formation of attachment disorder that child has.

P3: He was in foster care. He was one of the children that were very, very hard to place in foster care. He was so hard to handle that they would then have to pick him up, keep him in the office, drag him around. The continual movement in the foster care system only exacerbated some of behavioral issues and attachment problems. I believe that it really made him feel like he was not wanted by anyone.

**Adoption system**

The adoption system and its role in the process became evident as the participants described the steps necessary for finalization. The participants identified nine broad areas in which completion of tasks were necessary for finalization. These areas are discussed in table 4 which shows each step of the process as well as a discussion from participants on their personal experiences. Eight of the participants seeking to adopt, went through the public foster care system and one participant went through a private religious entity. The two agencies followed similar processes and the steps described where the same. Furthermore, all of the participants described working through an adoption case manager to navigate the steps and complete the process. These steps are explained in Table 4 with excerpts from the interviews which highlight the themes.

Another concern regarding the adoption agency brought up by a number of the participants was some of the decisions made by the case managers. One of the primary challenges discussed was the agencies decision to separate siblings in order to make adoption easier. Two participants adopted a child that was a part of a larger sibling group and feels that this decision has negatively impacted the child. Both participants express that their child has a desire to maintain a connection with their
biological sibling, however due to the decision and general practice of the adoption agency this has been impossible. The participants note that the inability to maintain contact with their siblings has had a negative impact on the child’s emotional wellbeing and created tension for the child. These challenges have also impacted the child’s ability to form attachments with their adoptive family.

**Macrosystem: Social Construct**

The final level of the environment is the macrosystem, which is defined by the social construct. The social construct encompasses themes regarding societal views of adoptions. The participants do not directly interact within this environment; however it also influences the participants’ overall experience and decisions. The influences were evident in throughout the data analysis.

**Social pressures**

While discussing the adoption experience the theme of social pressures arose as an important aspect to a number of the participants. The parents discussed society’s views of children with special needs and the impact this has had on their experiences of raising the child. For instance, P5 talks about consulting with their bishop regarding the decision to adopt a child with special needs, and how his strong views on the issues affected the guidance he provided them.

P5: We had a really good friend, actually our bishop here in town and – and we went to him and told him the situation because they had told us a week-and-a-half or two weeks before we actually went down and got the child. We explained that he was premature and that he had some medical issues. And this guy, our spiritual leader and typically the person whose advice which we would follow, because we valued his opinion, told us that he would not touch the situation with a ten foot pole. I think his words were I’d let that one alone. And I mean he would have been wrong because we would have missed out.
This parent also discussed thoughts on raising a child with special needs has been reflected in the comments and statements made to her including this one.

P5: And subsequently (to adopting the child) many people have said, oh, my gosh you're just so – so wonderful and everything but to us it's like, we just wanted children.

Another participant, P8, expresses similar experiences with things people say to her about her choices to adopt a child with special needs.

P8: I was talking with a friend one time and they said to me “Wow those kids are really lucky that you decided to adopt them and take them in, you are pretty amazing for choosing to do that”. I was just shocked by the statement, because these kids have given me so much. They are the reason I get up in the morning, they keep me going, and keep me feeling young.

Here P1 discusses something she experienced while at the store with one of the children she chose to adopt.

P1: At one point I went off the deep end at. I was hugging and kissing on her, just the natural baby you know. This couple walked beside me and the lady said that is disgusting that white woman kissing on that black baby. And the mother in me come unglued, I just stopped and turned around and said excused me. I said ma do you know what the word love means, and she said yes I do. I said well if you do then you will know that there are people who adopt children and take care of children just because they love children and I am sorry that you judge me because I love this baby.

This interaction really sheds light on society’s view of the diversity adoption creates, as well as some the challenges adoptive family face.

   Another social aspect is the extended family’s views on the decision to adopt a child who has special needs. The family may choose to support the family decision and help with process. This is evident in the following part of the conversation with P2.

P2: My own biological children had to write letter about why they wanted a baby sister a black baby sister. My grandchildren wrote letter, because they just did, they didn’t see color. You know, and umm and in our eyes it was just a baby. Know my older children look out for the girls and say hey
mom guess what is out and they will send her stuff. Furthermore, the girls our willed to my oldest daughter if something were to happen to me and my husband. The family support has helped throughout the process.

In contrast the extended families views of the adoption may be of disapproval and lack of acceptance of the adopted child. This was the situation for P3.

P3: My parents were against me adopting the child, they felt he had too many issues and the fact that I was a single parent would cause issues. When I have struggles with the child’s emotional issues my parents are of no assistant. They just tell me that I knew what I was getting myself into and that they told me it would be this way. Basically it is I made my choice and I have to deal with in on my own. You know even today they do not treat him the same as they do my biological children and it is evident to the child

Emerging Themes Regarding Life Care Plans

During the interviews, each participant was given an example of a life care plan and questioned on their opinion of the use during the adoption process. When reviewing the data it is evident that the themes fell into two categories. The first category is the thoughts regarding life care plans applicability and the second category is recommendations for the life care plan. Themes regarding the guidance, and knowledge were apparent in the first category. The second category includes broad themes of availability of services, as well as transportation.

Applicability

When presented with a life care plan some of the participants expressed how having this tool would have provided some much needed guidance regarding their child’s care. Parents often talked about the frustrations they experienced when locating or knowing what types of services to arrange for their child, and felt that this resource would have altered that experience. These comments by P2 show how she feels a life care plan would provide potential parents with guidance.
P2: Personally, I think it’s a wonderful – you know, something like that would have been so helpful. Because, I mean, we were just no guidance whatsoever, no help, whatsoever. With the first child and all his emotional problems, you know, that would have, I think, curtailed a lot of it, you know, just having these steps to be followed because things got so out of control with him.

P1 talks about how she has been feeling isolated regarding her child’s issues without any assistant on what to do. This participant expresses thoughts on how the life care plan could provide some clarity regarding the situation.

P1: You know when she got diagnosed, ADHD? I’m like how do you get any hope for this child? I kept saying, Something’s not right. Finding out this was going on was only the first step. Then we had to find services and no one was there to help us know what we could do or what she would need. So yes, definitely. This would be awesome, it would really help guide someone to the types of services the child would need.

Knowledge

The second area in which parents felt life care plans could assist is in providing knowledge. One area of knowledge that the life care provides is the time frame which services would be necessary for the child as well as a holistic view of the disability needs. The participants felt that providing guidelines on when services would be necessary would be of great help. One participant discussed how having something like a life care plan would have prevented the delay in diagnosing their child. She noted that if her and her husband knew to have their child evaluated by a psychiatrist for behavioral issues then the family may not have gone so long trying to figure out where to get services. Furthermore, the parents note that this information would also allow them to monitor the services provided to the child. It was expressed that having a life care plan would provide the parents with more autonomy and control over their child’s care.
Some of the participants discussed how the knowledge gained from the life care plan will help parents understand the magnitude of the child’s needs. Participants felt that this knowledge would help in a couple of ways. First it would allow for the potential parents to gain insight on the magnitude of care regarding the child’s special need. This knowledge will then allow for the potential parents to make a more informed choice regarding their ability to care for that child. The second area discussed by the participants was the ability to provide potential parents with the understanding that adopting a child with special needs will require a long term commitment, which is discussed by P3.

P3: I think this (life care plan) would help because you would see that it was lifelong, that this therapy isn’t going to take two years and it’s gonna be over with. It’s ending at the end of that child’s life. And then for parents who don’t have Medicaid, the financial end of it they really need to look at also. I just feel that parents really need to know.

P5 talks about how the life care plan will aid people without any medical background gain knowledge on the disability as well as the related needs.

P5: I think it is wonderful idea, because some people don’t have any idea. Not everybody that adopts a child is that aware of medical aspects. I have a daughter who is an occupational therapist and a son-in-law who is a speech therapist. From them I knew about Medicaid and I was well aware that all of those things are covered you know things like that. So I knew a lot of the stuff because I was exposed to it and a lot of people aren’t and they have no clue what to expect. So for somebody who do not know, obviously this would give them some piece of mind regarding some of the things that they would worry about when adopting that child.

Similar to P5’s comment, P4 also notes that the life care plan will help parents with no medical experience gain knowledge regarding the types of services necessary.

Furthermore, she notes that this type of knowledge will have the potential to empower parents in controlling their child’s medical care especially regarding the type and amount of services that are recommended.
P4: Well, I think it’s good for people that are not familiar with the system because you kinda know when the evaluations are supposed to happen, so if they were happening more frequently you could say, “What’s going on?” You know when it ends, 21, what to expect as far as frequency of services. I believe that this could really help parents who don’t understand disability gain some of that knowledge.

Here P2 looks back on her experiences of raising a child with special needs and how the knowledge gained from a life care plan may have improved the outcome of her situation.

P2: But with the boy…. his needs were so great … the counseling and then all the expense there was, of course, way more than we had ever expected. And if we had really realized it…. we could have had him maybe on Medicaid and…under programs where the government would have helped us. But we had no idea and so we were grasping for straws, if we had a life care plan then, we might not have gone through so much with him.

The final area of knowledge which participants felt the life care plan provided regarded available resources. P7 talked about how even educated people do not always know what resources are available for people with disabilities and how this plan will assist parents in identify the types of resources obtain for their child.

P7: People even people who are resourced and maybe even, still don’t know about these kinds of things and in some cases may know about them, but are not sure what help they can provide their child. For us it was the Medicaid Waiver program, we did not really know about this service and even when it was brought to our attention we stated that are child did not need it. Eventually is brought to our attention that we were being selfish by not helping our son get on the waiver program, because as it was explained to us these services will help after we are no longer to care for him. So I can see where this plan will help people understand what services are out there, as well as how that can aid in the child’s care.

Recommendations

While reviewing the life care plans participants were questioned on what modification to the model would improve its applicability to the adoption system. One of the recommendations was to consider the area and availability of services for that area.
Specifically P3 talks about how living in a small town means that she has to go out of town to find the necessary treatment for her child. She notes that traveling to receive the necessary services has been a major challenge for her and was not something that entered her mind prior to adopting the child. For this participant she felt the service recommendations are great, however it is important to understand that they might not always be readily available to the adoptive family. Therefore, she feels the life care plan should include awareness that services might not always be available or will require traveling in order to locate the necessary treatment.

In relationship to the availability of services in the local area, is the transportation for treatment that might be necessary. This participant notes that amount of money and time that goes into traveling to receive services is not something that she considered while preparing to adopt the child. P3 also talked about she has had to travel to receive the necessary treatments for her child and how including transportation considerations in the plan might be important.
Table 5-1. Themes regarding the steps in the adoption process

<table>
<thead>
<tr>
<th>Theme</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>TPR hearing and transfer to adoption</td>
<td>P3: And so it came up to the time where the TPR hearing was there. Parents didn’t show for the TPR hearing, so it was TPR by default, he had called me Mama for 2½ years.</td>
</tr>
<tr>
<td>Meeting with Adoption case manage</td>
<td>P2: We started out with just a contacting adoption agency at that time there was nothing in our town and we told them our desire to adopt a child. An adoption case manager contacted and we initiated the process.</td>
</tr>
<tr>
<td>Adoption Application</td>
<td>P9: After contacting the adoption agency they sent us just a huge application. They had a required time that they want you to have been married and wanted to know why I wanted to adopt and in our case it was I could not have children.</td>
</tr>
<tr>
<td>Collecting reference letters</td>
<td>P1: They wanted letters, we had to have 25 to 30 letters from anybody who know as at a certain amount of time. Coworkers, friends, family, neighbors, you know a variety. I have a stack of those letters giving why it was okay for us to adopt</td>
</tr>
<tr>
<td>Submitting to a home study</td>
<td>P4: Completing a new home study because we did the foster care home study and then – actually not a new one. I guess they had to update it. But they came to our home and looked sleeping arrangement and the suitability of the home for a child.</td>
</tr>
<tr>
<td>Finger printing for background checks</td>
<td>P4: And we had to get our 18-year-old fingerprinted ’cause he had just turned 18. He previously wasn’t fingerprinted ’cause he was under 18 and had to get our 13-year-old fingerprinted for adoption</td>
</tr>
<tr>
<td>Taking MAPP classes</td>
<td>P5: We had to attend specialized parenting classes that were designed to prepare us somewhat for what to expect.</td>
</tr>
<tr>
<td>Regular visits by the case worker</td>
<td>P8: After the child is placed with you, you have to go through a supervisory period. During this 90 day period the case worked comes out at least once a month to check on the status of things</td>
</tr>
<tr>
<td>Meeting with judge/finalization</td>
<td>P3: We went to the hearing. He was being adopted, and so we went in front of the judge and the judge talked to him and said, “This is your forever mama” and said, “This is your forever child,” and we agreed and signed the papers and the attorney filed them.</td>
</tr>
</tbody>
</table>
CHAPTER 6
FOCUS GROUP RESULTS

Focus Group Demographics

The researcher facilitated two focus groups, each comprised of six case managers. The first focus group included case managers who worked at a local public adoption facility. The years of experience in the field ranged from three to five years with all of the case managers having personal experience in placing children with special needs. All of the participants had educational background, bachelor degrees, within social service or education fields.

Table 6-1. Participant demographics for focus group 1

<table>
<thead>
<tr>
<th>Participant</th>
<th>Gender</th>
<th>Age</th>
<th>Years in adoption</th>
<th># of SN adoptions</th>
</tr>
</thead>
<tbody>
<tr>
<td>CM 1.1</td>
<td>F</td>
<td>35</td>
<td>5 years</td>
<td>12</td>
</tr>
<tr>
<td>CM 1.2</td>
<td>F</td>
<td>24</td>
<td>3 years</td>
<td>5</td>
</tr>
<tr>
<td>CM 1.3</td>
<td>F</td>
<td>27</td>
<td>4 years</td>
<td>8</td>
</tr>
<tr>
<td>CM 1.4</td>
<td>F</td>
<td>32</td>
<td>5 years</td>
<td>9</td>
</tr>
<tr>
<td>CM 1.5</td>
<td>F</td>
<td>30</td>
<td>4 years</td>
<td>10</td>
</tr>
<tr>
<td>CM 1.6</td>
<td>F</td>
<td>29</td>
<td>3 years</td>
<td>6</td>
</tr>
</tbody>
</table>

The second focus group was comprised of six adoption case managers who worked at a public adoption facility. The participants within this group also had personal experience in placing children with special needs and the years of experience in the social service field ranged from four to seven years. As with the first focus group all the participants had similar educational background with bachelor degrees in social service or education field.

Table 6-2. Participant demographics for focus group 2

<table>
<thead>
<tr>
<th>Participant</th>
<th>Gender</th>
<th>Age</th>
<th>Years in adoption</th>
<th># of SN adoptions</th>
</tr>
</thead>
<tbody>
<tr>
<td>CM 2.1</td>
<td>F</td>
<td>27</td>
<td>4 years</td>
<td>11</td>
</tr>
<tr>
<td>CM 2.2</td>
<td>F</td>
<td>38</td>
<td>7 years</td>
<td>20</td>
</tr>
<tr>
<td>CM 2.3</td>
<td>F</td>
<td>26</td>
<td>4 years</td>
<td>15</td>
</tr>
<tr>
<td>CM 2.4</td>
<td>F</td>
<td>33</td>
<td>5 years</td>
<td>14</td>
</tr>
<tr>
<td>CM 2.5</td>
<td>F</td>
<td>35</td>
<td>6 years</td>
<td>18</td>
</tr>
<tr>
<td>CM 2.6</td>
<td>F</td>
<td>34</td>
<td>5 years</td>
<td>9</td>
</tr>
</tbody>
</table>
Overview of Significant Findings from Focus Group

Two focus groups with adoption case managers were conducted. The researcher utilized both the audio and video recordings to prepare transcriptions for analysis. The transcripts were reviewed and coded using conventional content analysis. The primary goal of conventional content analysis is to describe a phenomenon, particularly when there is limited research or existing theory available. Data analysis includes first reading through the transcripts in order to achieve immersion. Next, the researcher identified key concepts or codes. The codes are then grouped into categories, subcategories, and the themes within each area (Hseih & Shannon, 2005). The analysis process results in an organized structure that explains the key concepts of the phenomenon being studied (Figure 6-1) for the organizational structure on special needs adoptions.

The analysis of the focus groups revealed three broad categories including perceptions, overview of adoption, and life care plans. The different categories are represented in three different boxes and are the top layer of the organizational structure. The first category represented in the organizational structure is perceptions. For this study, the category of perceptions is defined as the case managers’ overall views of adoption of children with special needs. Their views encompass the findings from the case managers’ discussions regarding their personal experience in placing children with special needs.

Under each category are the different subcategories, which further defines the phenomena. The subcategories within perceptions are barriers, characteristics of those who adopt children with special needs, and needs of the adoptions system. The subcategory of barriers describes the case managers’ experiences in placing children with
special needs and the challenges they have faced in doing so. The second sub-category includes themes related to the case managers’ opinions on those who choose to adopt children with special needs. The final sub-category, needs of the adoption system, highlights the case managers’ perceptions of steps that may help increase in the rate of adoption for children with special needs. All of these themes are discussed in more detail within this chapter.

Figure 6-1. Organizational layout of categories.

The second category is overview of adoption system and is defined as the characteristics of the social service agency which impact everyday adoption practices. Subcategories of types of adoptions and methods of preparing the child and potential
parent for adoption are within this category. The first subcategory of types of adoptions encompasses three different options that the case managers consider when attempting to place a child with special needs. The second subcategory is defined by the techniques and procedures which the case managers complete in order to prepare both the child and potential parent for finalization.

The third and final category of the organizational structure is life care plans. This category encompasses the case managers’ discussion regarding the potential uses of life care plans during the adoption process. There were three subcategories including, applicability, recommendations, and concerns. The subcategory of applicability is defined by themes regarding the ways in which a life care plan may potentially benefit the process. The second subcategory includes recommendations on how to modify the life care plan to increase its applicability to the adoption process. Then the final subcategory includes the discussions regarding some of the concerns the case managers expressed. All of these are discussed in further detail below.

The final component of the organizational structure is the two arrows pointing from the category of life care planning towards the categories of perceptions and overview of adoption. These arrows depict the influence in which life care plans have on the themes within each category. The influences of life care plans are discussed in further detail later in this chapter.

**Perceptions: Barriers**

The adoption case managers identified a number of issues that in their experience has negatively impacted the placement of a child with special needs. The issues identified as barriers were based both on the characteristics of the potential parent as well as the case managers role in placement. One of the primary issues which case
managers cited as a barrier was potential parents’ concept of desired characteristics they were willing to consider when adopting a child. The first characteristic that the case managers noted was the age of the child. The overall consensus among the case managers was that parents are more willing to adopt a younger child, and often specifically request a baby. This was one of the concepts discussed by the case managers in the second focus group.

CM 2.5: In my experience I have always found it a lot easier to place a young child, because everyone wants a baby. It is the most common request that we get at the agency when a family puts in an adoption application.

CM 2.2: I agree with that. I think that parents come in wanting to adopt a child that appears to be from their family. So the first they tend to be interested in is the age of child. Parents tend to state that they don’t want a child that is over a year or two old.

CM 2.4: Yeah that has been my experience in most situations as well, however what I think is funny is that by adopting a younger child the family has no clue what types of issues the child might display in the future.

The case managers in the first focus group also discussed similar issues with the age of the child. This participant also points out how as a case manager find it easier to locate placement when the child is younger.

CM1.4: Umm it is a lot easier to place a young child. Everyone wants a baby, and they generally do not have the issues that an older child would have because they have not been in the system as long. There is a big difference; it is a lot harder to place an older child for adoption. It takes a special set of parents to be able to do it.

The second characteristic which the case managers identified was specific issues or needs that the child might have. The case manager all agreed that parents commonly express the desire to adopt a child with mildest issues possible. The case managers discussed how this is extremely difficult to accommodate because the
children awaiting adoption tend have at least some level of emotional trauma in their past. The parents’ desire was to be able to have a child that they felt would make them proud and fit into their family. This is evident in the following discussion from the first focus group.

CM1.6: In general most of the parents want mild behaviors. They want as normal of a kid as they can get.

CM1.2: I agree and in my experience the type of characteristics parents consider they want. Umm, but in general most of the parents want mild behaviors. They want as normal of a kid as they can get. We don’t have, I don’t think I have ever seen anyone come in and say I want the hardest to place kid. But generally the less problems there are with the child the easier they are to place. There are more parents that are available and want those kinds of children.

The attitude regarding minimal issues in the child was described by case managers as another reason in which potential parents are not willing to even consider adopting a child with special needs, thus placing a huge barrier to finding permanency. This barrier was also discussed in second focus group as well.

CM2.5: Most people when they think about adopting they want the child that has no needs, no problems, they just want the perfect little child that would have been born into their family if they had had the child. The first barrier that I see is getting adoptive parents to think about adopting a special needs child.

CM2.2: Ahh so I find that one of the barriers with placement is giving them the information that the child has special needs they immediately opt out. You miss out on being able to give them some more insight into how the child would enhance their life and those kinds of things because they immediately turn off any idea of adopting that child with certain needs.

In relationship to the child having minimal issues is the parent’s concern regarding the financial strain that will accompany adopting a child who has a disability. The case managers discussed their experiences in presenting a child with special needs to a family and one of the first things they bring up is the amount of cost they will incur due
to treatments, medical expenses, as well as what types of medication and supplies the child might need. The case managers note that the parents often see a child who has a disability as requiring more time, attention, and money to care for. One case manager discussed how she had a family tell her that they did not have the money or ability to raise a child who had special needs and they were not interested in going into debt in order to adopt a child. This highlights parents’ lack of education regarding children with disabilities and how their assumptions often prevent them from grasping the reality of the child.

The final characteristic that case managers witness in people seeking adoption is the potential parents desire to adopt a child who has similar looks, abilities, and interests as them. The case managers note that in their experience parents want a child that matches their hair, eye, and skin color in order to maintain similarities. In this discussion the case managers talk about how they have witnessed these desires.

CM2.6: They (potential parents) want a child like them and so I think that is another barrier when you’re talking about a child with a disability because if a parent is looking to adopt a child like them they don’t want to face up to that child having a disability and then not being able to reach the potential level that they think they are capable of. They view it may be as a failure. Other than the child being like them, you get all kinds of requests. You get some and not to say that every adoptive parent out there looking to adopt a child without any special needs because we do have family that are geared for that. I have had all sorts of requests from down to the color of eyes the color of hair, the height, the weight, the age.

This comment highlights how parents feel similarities are not just the physical characteristics of the child, but include functional aspect of the child as well.

Another barrier described by case managers was potential parents’ lack of education regarding special needs. The case managers discussed about how potential parents who come to the agency seeking to adopt a child often do not have any
understanding regarding children with special needs. They note that the potential parents do not have any experience in children with special needs. This lack of experience often leads to ignorance and stereotypes on the potential parents’ part, thus making them less willing to even consider a child with special needs. One case manager discussed how a common stereotype she witness is how parents feel that the child will not have a future because of they have special needs. The case manager notes that in her experience parents believe that a child with special needs will not be able to succeed at school, and will ultimately be dependent up on them. Another example was with children who have behavioral issues and noting that the parents are worried about how the child’s behaviors will reflect on them. The experience of this barrier is displayed in the following comments by the participants.

CM1.3: Umm lack of education of the parents, the adoptive parents. But then prior to adoption it can be just regular behaviors of the children related to being in foster care or related to any kind of trauma they may have experienced and umm getting services for those specific behaviors. It just seems that parents’ lack of understanding regarding children with special needs leads them to over exaggerate the implications of the child’s needs.

Case managers also talked about how the lack of knowledge regarding special needs left the parents feeling uncertain regarding the child’s future. They note that the uncertainty of the child’s future often leaves parents feeling unprepared to handle the child’s needs.

CM 1.5: I agree that lack of knowledge is a major issue and creates obstacles. Parents often want to know what is going to happen in the future with this child. They want to have knowledge of if this child is going to have this illness or this problem and if they had a child of their own they would not have known that. So that they are asking questions that we cannot answer and they want some sort of guarantee that with the disability or the issues that the child has that they are not going to get any worse. They want to know, we would except this child today the way it is the way the child is but if
the child is going to get worse or problems happen then we are not sure we are going to be interested.

The case managers also described personal characteristics that potentially impact the adoption process. The case managers point out that potential parents often have very specific questions regarding the child’s needs and future. Furthermore, the case managers note that they often do not have the background or knowledge to answer the questions potential parents have regarding what to expect. Therefore, the case manager is not able to provide essential insight in the child’s needs leaving the parents feeling very uninformed and insecure regarding the responsibility of caring for a child with special needs. This issue is present in the following discussion from the first focus group.

CM1.6: Potential parents coming in wanting to know a lot of information about the child and what needs they have. Parents always want to know how the child’s needs will change over time and what caring for the child will look like ten years down the road. This is not information that we have and I often find it difficult to provide answers to the parents when I myself do not know them. It is often frustrating because we do not always have the knowledge of what the child will need.

CM1.1: That is good point, because we generally do not have any specific training or education in the disabilities that child’s have. The only knowledge that we have is commonly from the personal hands on experience that we have obtained from working with kids. This experiences does not provide us with answers to a lot of the parents are asking. And I know my education background is in social services and that is common for people in this field, so we just don’t know and do not have the information about the child’s needs.

Perceptions: parents who adopt children with special needs

In contrast to the barriers that case managers identified in the adoption process, is the description of parents who they feel are more likely to consider adopting a child with special needs. The overall consensus among case managers were people with medical
backgrounds are more likely to adopt a child who has special needs. They noted that in their experiences those who had knowledge of disability and the disability related needs appear more accepting when a child with special needs was presented to them. The case managers discuss how the medical experience appears to help the parents feel more confident and capable of handling the emergencies that may arise. Furthermore, the case manager notes that since these parents have training with disabilities and illness they tend to not over exaggerate the child’s needs. Plus these parents will have a realistic understand of what services and care the child will require over time. The discussion of case managers’ experience is evident in the following discussion.

CM1.3: Umm there is always one foster home or one adoptive home who is geared to handle any emergency. And I have a person whose house is set up almost like a mini clinic where she can deal with that. I placed children in adoptive homes who have medical backgrounds like a RN a medical doctor and those kinds of things. They are the ones that are not afraid, they have some training.

CM1.2: Yeah I have seen that as well. People with medical backgrounds are more willing they don’t have that sense of fear that others have. They feel like they have a little bit of knowledge in dealing with medical emergencies. Some parents can go totally bazooka when their child gets injured and I think sometimes just having that knowledge give them a more calming effect as to how they can deal with a emergency and they are not so frightened.

The case manager’s noted that they often feel more comfortable in presenting a child with special needs to people who have foster children, parenting experience, or medical background. The participants explain that first they know a parent who has a medical background or parenting experience will tend to be more open minded regarding the potential of adopting a child with special needs. The second reason was that they believe it does take some medical or parenting experience in order to know how to
handle issues that may arise with a child who has special needs. This concept is evident in the following statement.

CM2.6: When we are trying to place a child, like maybe an older child who has some kind of special needs some kind of issues or diagnosis, we usually look at experienced parents. Either people who have been foster parents for a long time, or have raised their own children successfully, either that or parents who have umm some kind of experience with children whether they maybe are a therapist themselves, or they work intensively with children a lot. We would look for someone who has more experience to handle those kinds of kids. Putting a special needs child in a home where they don’t have any experience is just asking for problems and so in those cases we give them as many services as we can and hope that it works out.

Perception: needs

While the case managers’ discussed the challenges they have faced when placing children with special needs, they also identified what they felt would help improve placement. First, case managers talked about the need for additional education. Specifically, the case managers’ felt educations should address general information on what a special needs child is and some of the common types of disabilities. The following discussion between case managers highlights their opinions on the need for additional education.

CM 2.3 I think one of the biggest things is education of the parents. Parents often misunderstand the needs of the child and automatically assume it will be additional work, therefore preventing adoption of a child with special needs

CM 2.1 Umm we just need to keep educating people. We need to let them know that the issues that are there.

The second area identified as a need by the case managers for parents to more open minded regarding the children available for adoption from the foster care system. They explained at how parents come into their office with a rigid and set notion of what
type of child is available for adoption as well as what they are looking for. One case manager noted that it was almost like the parents where shopping for a child and wanted to pick out the best one. This experience with parents left the case managers feeling extremely frustrated. For this reason they feel that parents should enter into adoption with an open mind and no preconceived assumptions regarding what type of child they are interested in adoption. Furthermore, the case managers note that part of their frustration is related to the fact that parents often overlook really great children because of their close minded approach to adoption. This theme is evident in the following discussion from focus group 1.

CM 1.6: I really feel that parents come into the agency with unreal expectations of what we have to offer them. They are often so stuck on what they want and not what is in the best interest of some of the kids. It really frustrates me to see this happening time and time again.

Overview of adoption: types of placements

When the case manager talked about the adoption process a couple of different methods of adoptions were identified. The first method discussed is to have a family member of the child to adopt them. According to the case managers this form of adoption is called kinship adoption. All of the participants agreed that kinship adoption is their first avenue when possible. The case managers described searching for family members who are available and willing to adopt the child once their biological parents' rights have been terminated. The consensus among the case managers is that this is often the best route for the child and results in the easiest, most successful placement for the child. The case managers felt that relatives are often willing and better suited to take the child because they have an understanding of the child's needs and will be more prepared to handle whatever issues might.
The case managers went on to describe that when a family member is not available to adopt the child they go to the second option. For most of the case managers the second option is approaching the foster parent and discussing whether they would be interested in adopting the child. If the parent is interest then the process for a foster adoption is initiated. According to the case managers a foster adoption is where the certified foster parents, which are sheltering the child, choose to legally adopt that child. Similar to the case managers’ discussion regarding relative adoption, they also feel that foster adoption is a good choice for the child. The case managers noted that in their experience those who have fostered the child and then choose to adopt are more likely to have already bonded with the child, which results in fewer issues of attachment disorder and behavioral discord. Furthermore, the case managers note that the foster parent has been caring for the child and therefore understands the child personality as well as the magnitude of their needs. The case managers felt that this unique understanding of the child aided in the adoption process. This theme is evident in the following discussion from focus group two.

CM 2.4: I always think that an important step in choosing where to place the child for adoption is to approach the foster parents who have the child. Depending upon the amount of time they may be willing and want to adopt the child. I have even had foster parents who were waiting and following the TPR hearing just so they could adopt the child.

CM2.6: Yeah the foster parents are often a good ally for us to turn to when considering adoptive placement. It seems that they already have an understanding of the child and that would help them in incorporating the child into their family.

The final method of adoptive placement for the child which the case managers discussed was a search through the adoption agency. The case managers notes that in their experience that children with special needs often end up being placed in
nonrelative adoption if placed at all. The case managers described how this form of adoption places the responsibility of matching the child’s needs with a potential family on case worker. Furthermore, they note that this form of adoption takes the longest for finalization to occur due to the difficulties of locating a family that is willing to adopt the child. The case managers expressed frustration in relationship to locating families that want to adopt special needs children. They also note that in their experience these children often go through numerous attempts to be placed with a family, however they often fail. Failure of the adoption placement only increases the issues they witness in the children.

**Overview of adoption: preparation for adoption**

The case managers describe the services that are provided to potential parents as well as the child in order to prepare for adoption. First, they describe the education that potential parents receive from the adoption agency. Each parent must successfully complete an extensive parenting class to learn what to expect when caring for the child. Moreover, the parent will be provided with any special training that will better prepare them to care for the child’s special needs. The example of a child with diabetes was provided. One case manager reports that in the past she has had nurses meet with the parents in order to provide training on how to handle their medical issues. The final thing that the case managers described was providing information about the child. This information includes past medical history, any behavioral issues that the child has shown, and ways to help the potential parents prepare for the child.

The child also receives information and support during the preparation phase. The case managers express that it is very important to encourage the child to express their feelings regarding adoption. One case manager described having the child keep a
journal of their thoughts and feelings. Moreover, the case managers note that it is important to sit down with the child and listen to their concerns. They feel it is necessary to ask open ended question that allow the child to think about situation and then respond in their own words. The final thing discussed in preparing the child is giving them information on the adoption process and dynamics. This is often done by giving the child information on characteristics of the potential family, as well as books on what adoption is like.

Life care plans

The last category identified from the focus groups was perceptions on the use of life care plans during the adoption process. Each participant of the focus group was provided a copy of the sample life care plan and asked to discuss their opinions on its use with special needs adoptions. The sub categories to emerge were applicability, recommendations, and concerns. The themes within each subcategory are explored below.

Life care plans: applicability

The focus group leader discussed what the life care plan was and then questioned the case managers regarding their opinions on its use in the adoption system. The overall response to this was positive and case managers identified how they felt it would aid the adoption process. The first area where case managers described the use of life care plans is in providing parents with a more realistic understanding of the child’s needs. The case manager expressed that one of the things that they often witness is parents being fearful of the child’s future and what it may look like. They felt that the life care plan would show parents that the child does have a future and eliminate some of
those unnecessary fears. The following statement describes this opinion on the life care plan.

**CM 2.1:** I think this great, you know so many parents think of all the things that could go wrong in the child’s future and I often think they over exaggerate this situation. This would provide the parents with something to look at, take home with them, and think on.

Next the case managers felt a life care plan would assist the process in helping parents understand the realistic financial ramifications of raising the child. The case managers expressed that the plan being based on what Medicaid would pay for will help the parents gain an understanding of how the child’s insurance will absorb and offset most of the financial strain. This would eliminate parents for over estimating the amount of financial burden they will assume if they were to adopt this child.

The final area in which the case managers felt that life care plans would be beneficial is aiding them in answering parents’ questions. The case managers reiterated that they do not have experience, training, or knowledge of disabilities, which led them to being unable to provide the parents with a lot of information on what to expect in the child’s future. As one of the case managers pointed out, the parents had questions that she was just unable to provide answer to.

**CM1.2:** I feel that the use of a life care plan would help me out a lot. I was trained in social work, but nowhere in that did we learn about disability or developmental issues in children. Parents want answers to their questions and some guarantee that we know what the child’s future will look like. A life care plan will provide us with the opportunity to give parents these questions and in doing do they may be more willing to adopt a child with special needs.

**Life care plan: recommendations**

During the discussion of the use of life care plans, the case managers identified a couple of areas which they felt would be important to include in a life care plan. The
first thing brought up by the case managers was to have the plan include adoption specific issues. A couple of the case managers pointed out that one of these issues would be the treatment for attachment disorder. The case managers explained that in their experience a large number of the children experience attachment difficulties which ultimately requires counseling. The case managers discussed how they have attempted to locate appropriate counseling services, but have confronted difficulties in doing so.

The second recommendation discussed by the case managers was the inclusion of the adoption stipend within the life care plan. Case managers felt this would help in a couple of ways. First it would again display how to offset some of the financial strain associated with a special needs child. This would help the parents understand not only is there insurance to pay for the medical needs (Medicaid), but an additional stipend that can be used to purchase supplies and equipment. The second reason the case managers felt this was important, was to educate parents on the fact that an adoption stipend is available. The case managers stated that in their experience parents who enter the adoption agency looking for a child are often unaware of the financial incentives involved in the process. This would help them understand the impact that the stipend money would make on their ability to raise a child.
CHAPTER 7
DISCUSSION

Chapter Preface

The purpose of this study was to identify the current challenges associated with special needs adoptions and the applicability of life care plans to address these issues. The study involved acquiring and analyzing qualitative feedback from adoption case managers and adoptive parents regarding their perceptions of the adoption process as well as understanding and applicability of life care planning. This chapter is separated into four sections, discussing the findings from the previous chapter. The first section includes an interpretation of the findings from the individual interviews and focus groups. The second section depicts a discussion regarding the limitations of these studies. The third section illustrates the implications of the findings for clinical practice, theory, and future research. The final section concludes the findings of the current study.

Overview of Significant Findings

Qualitative Interviews

Qualitative interviews were conducted to obtain the perspective from adoptive parents on the experience during the adoption process as well as the use life care plans in adoption. Utilizing the constant comparative method described by Corbin and Strauss (1990), the researcher coded a number themes related to the adoption experience. The themes were utilized to develop the theoretical framework, ecological perspective of adoption experience. The ecological perspective organizes themes within four system levels of the environment. At the center of the model is the adoptive parent with the
micro, meso, exo, and macro system expanding outward. The discussion of each system and the impact it has on the developing person is included in this chapter.

**Microsystem: Personal Construct**

The microsystem describes the individuals' immediate environment in which they interact with. The characteristics most important to the developing person (adoptive parent) are located within this system. Furthermore, this system is closest to the developing person because it has the greatest impact on the person's behaviors. For this study the personal construct described the parents’ microsystem and includes themes of decision making and emotions.

**Decision making**

The first theme is the description of the decision making process for the parents. This description revealed two characteristics, which impacted a person's decision to adopt a child with special needs. These characteristics are knowledge of disability and desire to have a large family. Participants described knowledge of disability as an extremely important factor in their decisions to adopt a child with special needs. The parents expressed that they had experience in working with disability and that this knowledge led to them to feel more comfortable in their abilities to appropriately handle the child's needs. There is limited literature regarding the specific impact of medical/social service experience on person's readiness to adopt. However, there is literature regarding the impact of being prepared for what to expect when adopting a child with special needs.

Several studies have found a correlation between parents’ perceived level of preparation and successful outcomes of adoptive placement (Unger, Deiner, & Wilson, 1988; Berry, 1990; Sturgess, Selwyn, 2007). Specifically, one of the studies examines
factors which aided in parents feeling prepared when considering adopting a child with special needs. This study revealed that parents who reported feeling very prepared had adequate training and information regarding what to expect with the child (Egbert & Lamont, 2004). The literature supports the positive impact of preparation when entering into special needs adoptions. Parents with professional experience have a unique understanding of the child’s needs as well as the long term impact on the family, therefore making them more likely to successfully adopt a child with special needs.

While research supports preparation in special needs adoptions, there is no research specifically focusing on the impact of professional experience in the medical/social services field on the decision to adopt a child with special needs. Therefore, further research needs to be conducted in order to further understand the characteristics of parents who decide to adopt a child with special needs. Specifically, research should examine the impact of professional experience. The characteristics identified by the research will then encourage recruitment of parents who are open to special needs adoptions as well as shed light on methods to mitigate the concerns other potential parents may have.

While there is no published work on the topic, the characteristic of medical/social service experience positively impacting decision to adopt has been replicated in the pilot research as well as focus groups with case managers in this study. As discussed in Chapter 2, research with adoption case managers was performed. The case managers in this study discussed that in their experience people with medical experience tend to be more willing to adopt a child with special needs. Furthermore, the results from the focus groups with case managers in this study also revealed similar findings with the
case managers noting that medical experience alleviates some of the common barriers they have witnessed. These findings support the need for further research into the impact that medical experience has on willingness to adopt a child with special needs. If further research supports this finding, then adoption case managers should develop strategies to recruit people with medical and social services experience to consider adopting children with special needs.

Another factor that parents felt impacted their decision to adopt a child was the participants desire to have a large family. A consensus among the participants was the importance of family and how they enjoyed having children around them. The statistics on who chooses to adopt support a shift in families who consider adoption from primarily infertile couples to now including larger families. Approximately thirty years ago those who sought adoption were couples who were unable to have biological children and were forced to turn to adoption as a method of creating their family (Gilman, 2001). The shift in the characteristics of adoptions reveals that both couples and single parents now utilize adoption as method of adding to their biological family (Child Welfare Gateway, 2010). The statistics support the findings from this study, because seven of the nine participants interviewed had biological children prior to choosing adoption.

Another strong factor which impacted the participants desire to adopt, was their perceived ability to mother these kids and ultimately help the child achieve permanency. Some research regarding children with special needs does show that people sometimes choose to adopt in order to prevent the child from languishing in foster care (Schwartz, 2008). This article examines some of the factors associated with people who chose to
adopt children. One of the primary factors was parents choosing to adopt in order “rescue” the child from long term foster care. This finding supports the participants’ desire to help as many children as possible and shows an altruistic aspect in special needs adoptions.

The final aspect regarding the desire for family is the social concept of motherhood and family. The participants all described parenting as an important role which they felt they must fulfill. This desire was one of the important factors in the participants' decision to adopt. The literature on adoption does reference the social roles of parenting as important motivators in people’s decision to form a family through adoption (Adamec & Miller, 2007). The social concept of family and the pressure in which people feel to have a family or be good parents does influence a person’s decisions (Schwartz, 2008). While the research population this information is based on does not match the current sample, it does highlight how the role of parenthood is an important aspect of decision-making process. The understanding of the social desires and pressures will help adoption case managers assist parents in navigating through the adoption process and determining if adopt a child with special needs is truly right for them.

A valuable finding from the study was the decision-making steps that were important to each family in reaching the decision to adopt the child. This process was individualized for each family but included communication with partner, gathering educational information, and turning to religious faith for guidance. First of all, communication and agreement between the couple was an essential aspect when deciding to adopt a child. The consensus of the literature supports that communication
regarding desires was an important predictor on the success of an adoption placement (Schwartz, 2008; Egbert & Lamont, 2004). The article by Schwartz highlights the importance of communication among partners on their desires regarding adoption. The author reported that if partners fail to communicate or are unable to reach an agreement then the success of the adoption will be in jeopardy (Schwartz, 2008). Furthermore, Egbert and colleagues examined factors that predicted a family’s preparedness when entering adoption. They found that communication was an important factor in determining how prepared the family was (Egbert & Lamont, 2004). With research supporting the importance of communication amongst partners, it will be imperative for the adoption case manager to assess the family’s level commitment, the couple’s level of agreement, as well as provide opportunity for open communication during the pre-adoptive phase.

An important aspect of the decision making process for parents was their faith. The parents discussed turning decisions regarding what was best for the family over to their faith system. Furthermore when making a decision regarding to adopt, parents would consult religious leaders for guidance. Research shows that faith plays an integral role in numerous life decisions and the choice to adopt is no different (Patel, Williams, & Marsh 2004; Egbert & Lamont, 2004). The literature shows the parents will commonly resort to religious guidance when traversing the adoption landscape. This is especially true as they face challenges or are forced to make difficult decisions. According to Patel and colleagues (2004), the successfully incorporation of religious beliefs during the adoption process was an important predictor in the overall success of the placement. Based on the literature the use of faith is an important aspect of the
adoption process (Patel, Williams, & Marsh, 2004; Egbert & Lamont; Adamec, 2005). These findings highlight the need for adoption case managers to be sensitive to peoples’ faith and provide an opportunity for continued exploration.

**Mesosystem: Interactional construct**

The mesosystem is the second level of the environment expanded outward from the developing person. This environment describes the interactions of multiple microsystems. The applicable microsystems when examining adoption are the adoptive family, social service agency, and the legal system. The two themes prominent as parents described their interactions with these microsystems are perceptions and process.

**Perceptions**

The theme of perceptions encompasses the parents’ description of their feelings throughout the adoption process. One of the prominent feelings was frustration. The parents expressed frustration in relationship to the lack of information provided at the time of adoption as well as lack of post adoption services. A consensus among the participants was that there was a lack of information provided at the time considering adoption. The parents expressed that case managers were often unable to answer their questions or provide background information on the child. The consensus among the research reveals that limited information is a common and major problem within the adoption system (Barth, Berry, Goodfield, & Carson, 1986; Groze, Young & Corcran-Rumppe, 1991). Specifically, one study found that 58% of their sample reported not receiving enough information regarding the child’s need. This study cited the lack of information as a major barrier to the adoption process (Reilly & Platz, 2003). The
findings along with the literature support the need for better methods of transmitting information to the potential parents.

**Process**

The second prominent theme within the mesosystem is the process. The theme of process describes the participants’ experiences while completing the steps required in finalizing adoption. Two areas were prominent in the participants’ interactions and these were lack of interagency communication and lack of post adoption support.

The lack of interagency communication was also cited as source of frustration with the foster care system. The parents discussed how there is a major disconnect when a child’s case is transferred from the foster care worker to the adoption case manager. Multiple parents experienced frustration with missing information or having to redo paperwork, due to the changes in case plan goals. For example, as one participant pointed out, the entire family had to arrange taking more time out of their schedules to go through the frustrations of getting finger printed and submitting to yet another home study. The parents expressed that these things had already been completed for a foster care file and felt it was unnecessary to have to wait for them to be resubmitted with adoption in the title rather than fostering. Furthermore, the parents noted that this was one of the factors that held up the adoption process and forced them to wait longer for the finalization. The issue of communication between agencies was identified as an obstacle in youth finding adoptive placement after termination of parental rights (TPR). The researchers of this study stressed the need for continuity in care between foster care worker and the adoption case management (Cushing & Greenblatt, 2009). Further research is necessary to examine the impact of interagency communication on the
adoption experience. If research continues to support the negative impact of communication, than clinical practice needs to explore options to alleviate this barrier.

**Exosystem: System Construct**

The exosystem encompasses themes related the parents experiences with the social service system. The parents described themes specifically related the foster care and adoptions systems. These descriptions were evident in the data analysis as well as how they shaped the participants adoption experience.

**Foster Care System**

The parents commonly discussed the role the foster care system played in their adoption experience. Foster care was described as both a challenging as well as a positive experience that impacted the decision to adopt. First of all, the parents expressed their foster care experience was often challenging and led to tension within the family as well as tension directed towards the system itself. The tension was related to the amount of time the system would attempt to reunify the child. The parents who adopted their child from the foster care system explained how the biological parents were allowed to remain in the child’s life for an extended period of time, while attempts to reunify the child were continually made by the caseworkers and judge. Limited research has been conducted on the impact of biological parents lingering in the child’s life for an extended period of time. Regardless of the limited research, it is clear that uncertainty and instability in a child’s life negatively impacts his or her emotional wellbeing (Bruhn, 2003; Rubin, O’Reilly, Luan, & Lacalio, 2007).

The participants expressed that the attempts to reunify the child with their biological parents went on for upwards to two and half years and became extremely frustrating as they watched the child continue to be let down and hurt emotionally.
throughout this process. Furthermore, these actions by the foster care system delayed the families’ ability to legally adopt the child and “officially” become a family. The impact of delaying permanency has been cited frequently in the literature as a major challenge within the foster care system (Bruhn, 2003; Rubin, O’Reilly, Luan, & Lacalio, 2007; Lawence, Carlson, & Egeland, 2006; Vinnerljung, Hjern, & Lindblad, 2006). When permanency is delayed the child is more likely to be diagnosed with attachment disorder, psychological disorders, as well as health related problems due to the amount of stress and tension within their life (Bruhn, 2003; Rubin, O’Reilly, Luan, & Lacalio, 2007; Lawence, Carlson, & Egeland, 2006; Vinnerljung, Hjern, & Lindblad, 2006).

In response to the negative impact of delaying permanency the federal government enacted the Adoption and Safe Families Act in order to promote a more rapid placement of the child. As discussed in Chapter 2, the primary goal of ASFA was to accelerate the permanent placement of children through implementation of shorter time limits for making permanency decisions. The provision to accelerate permanent placement means that states must initiate court proceeding to free a child for adoption no later than fifteen months after the removal from their parents (Moe, 2005). To date there is little data available on the impact of ASFA; however the information that is available displays little change in the timeframe that children are freed for adoption (Rockhill, Green, & Furrer, 2007; Humphry, Turnbull, & Turnbull, 2006). This evidence is consistent with the findings from this study and supports the parent’s claims of frustrations regarding the length of the reunification process.

On the other hand fostering a child was viewed as a positive experience that impacted the parents’ perceptions of the child. A total of five of the nine parents
interviewed had fostered the child prior to choosing to adopt. These parents felt that the foster experience allowed them to gain invaluable insight into the child’s needs and daily routine. It was this hands on experience that assisted the parents in feeling confident regarding their ability to handle the child’s needs appropriately and therefore adopt the child. Literature regarding adoption shows that foster parent adoptions is good method of achieving permanency for hard to place children (Frey, Cushing, Freundlich, & Brenner, 2007). Furthermore, research highlights the fact that foster parents and the child form attachments during foster care. The attachment of the child to the foster parent increases the ease of the adoption process and reduces the likelihood of disruption (Ponciano, 2010; Reilly & Platz, 2003). Moreover, the ease of foster care placement is consistent with the findings from the case managers who participated in both this study and the pilot research. The case managers felt that in their experience creating an adoptive placement with the foster parents was one the most successful permanency options.

**Adoption System**

Another finding of the study is the steps which parents went through to complete the adoption of the child. Table 5-1 provides an overview of the nine different steps. Parents identified various emotions throughout the process, which were discussed earlier within the category of personal construct. However, the overall consensus about the adoption system was not usually positive. The parents felt that the process was long and drawn out, furthermore it was noted that the adoption case managers were unable to provide them with any guidance regarding the timeframe of the adoption process.
A major difficulty expressed by a number of the participants was changes in caseworkers throughout the process as another source of frustration. The high turnover of caseworkers is a known fact in the adoption system and its impact has been examined in the literature (Cushing & Greenblatt, 2009). Like this study the literature shows a negative impact on the adoption process in association with high case manager turnover, therefore clinical practice needs to examine ways to reduce case manager turnover rates.

**Macrosystem: Social Construct**

An interesting finding that emerged from this study was the impact that others’ social views had on the parents’ adoption experience.

**Social views**

The parents talked about how their friends, religious leaders, and families’ viewed their decision to adopt the child. The perception of parents’ choice to adopt was often negative. Some of the parents discussed how their families did not accept the adopted child as part of the family and would treat them differently than the biological children. Socially adoption is often viewed as a last resort for parents who cannot have children and according to the literature is not the preferred method of forming a family (Schwartz, 2008). This social belief was apparent in the some of the parents’ experience in how the adopted child was viewed as different.

Another impact of the social view was how parents were viewed as “saints” by others. The parents described how people would often come up to them and express how grateful the children should be for them deciding to adopt. Furthermore, the parents talked about how others told them they were “wonderful” for choosing to adopt a
child that had special needs. This view is ingrained in both societies’ perception of adoption as well as people with disability.

**Life Care Plans: Applicability**

The participants were shown an example of a life care plan then asked to respond regarding their opinions of its use during the adoption process. The overall consensus of the plan was extremely positive. Parents felt that it provided large amount information regarding the child’s potential needs. This information was reported as helpful in regards to parents gaining a realistic perspective of caring for the child. Furthermore, parents felt that having a life care plan would provide them with guidance on what types of evaluations, supplies, and services that their child may need. Parents noted that having this information would provide them with the ability to take charge of their child’s care, which is something that a couple of parents felt were missing from their parenting experience.

Parents were asked to comment on the amount of information provided by a life care plan. Overall parents felt that there was a lot of information provided by the plan, however the information was adequate to address the necessary perspective that parents will face. The parents expressed that it was important for people to gain a realistic understanding of what caring for the child will look like. Furthermore, the parents felt that having this amount of information would allow parents to prepare for upcoming needs that may not be covered by Medicaid or other insurance policies. The ability to understand and prepare for future needs will alleviate one the identified barriers of case managers which was perceived financial strain of adopting a child with special needs vs. adopting a child without special needs.
Another interesting finding when discussing the life care plan was how it would encourage parents to recognize the needs for services sooner. Specifically, one mother discussed how it was difficult for her and her husband to recognize and accept the fact that their adopted son was displaying mental health symptoms. She felt that being provided a life care plan could have made a huge impact on timeliness of acquiring services, and as such impacted the child’s overall functional ability.

The life care plan was identified by parents as a tool that would impact a number of the frustrations that they experienced throughout the process. Parents talked about how having a life care plan would have alleviated some of the frustrations in relation to being provided with little information regarding the child’s background as well as current and future needs. As discussed earlier, a lack of information has been identified as major barrier during the adoption process, especially when placing children with special needs. The life care plan will address this barrier and allow the parents to acquire a realistic perspective of the child’s current and future needs.

Parents knowing what types of services would be appropriate for the child’s need was another area of frustration. Again the parents felt that having a life care plan would eliminate these difficulties they experienced after the finalization. Furthermore, the life care plan will provide the parents with a post adoption roadmap that will reduce the frustrations related to the lack of responsiveness from the adoption agency after adoption.

As stated earlier one of the characteristics that impacted people’s decision to adopt a child with special needs was the knowledge in the medical field. Parents often reported that their professional knowledge of disease and disability meant they had a
better understanding of the child’s needs. Life care plans have the potential to provide prospective parents with some of the same understanding and knowledge of disability. The goal of life care plans is to educate its intended audience and as such when provided to potential parents will educate them regarding the child’s needs. This level of education will be essential in helping parents form an educated decision regarding adopting a child who has special needs.

Educating parents has the potential to impact adoption in both a positive and negative manner. First of all, information and education was identified as essential parts of the decision making process. Therefore by providing parents with this knowledge they may realize that they are able to care for the child and the child’s needs are manageable. This would lead to a potential increase in the number of special needs adoptions. In contrast, the parents may view being provided with a life care plan as overwhelming and as such decrease the number of adoptions. The potential of life care plans to negatively impact the number of special needs adoptions is not necessarily bad. As discussed in the Chapter 2, the dissolution rate of special needs adoptions is significantly higher than that of children without special needs.

Research regarding the use of life care plans during the adoption process is extremely limited and to date there is only one study that has explored its feasibility (Buckles, Pomeranz, & Young, 2009). This study found that basing a life care plan on Medicaid was a viable option and could be applied to adoption process. Further research is necessary to continue exploring the applicability of life care plans. If there continues to be positive responses to its uses in adoption than clinical practice should make efforts to implement this model.
Life Care Plans: Recommendations

Based on their experience of raising a child with special needs the parents were asked to make any recommendations that would make the life care plan more applicable to adoption system. A couple of themes were identified as important. First of all, the parents recommended that the plan take into account the area in which the parents lived. Some of the parents note that one of difficulties they have faced is locating the necessary services. This was of particular concern to parents who lived a small community and would have to travel for an hour or greater to receive appropriate treatment. This recommendation is extremely important thing to consider in the development of a life care plan.

In association to availability of services, is the amount of time and money necessary to travel to medical appointments. A couple of parents pointed out that it takes both time and money to travel the necessary distance to keep regular medical and mental health appointments. One parent’s recommendation was to include travel expenses in the life care plan as way of preparing parents for the out of pocket expenses that would be required. Including travel expenses is a recommendation that could be easily included in the plan, furthermore Medicaid actually reimburses parents thirty-five cents a mile for travel (Florida Medicaid Handbook, 2009).

Focus Groups

This researcher conducted two focus groups consisting of adoption case managers to gain insight into their perspective of the issues present when attempting to place a child with special needs. Utilizing the conventional approach of content analysis the researcher coded a number of themes in relationship to the case manager’s experiences (Moen, et al., 2009). As presented in Chapter 6 the themes emerged into
three broad categories: perception of special needs adoption, system construct, and assessment of life care plans.

**Perceptions: Barriers**

Based on their experience, the adoption case managers identified a number of characteristics they perceived as barriers for potential parents considering adopting a child with special needs. One of the primary barriers described by the case managers is how parents approach adoption with very specific desires regarding what type of child they are willing to adopt. In their experiences the case managers felt that the most common request from potential parents was to adopt a younger child, as close to infancy as possible. This desire is supported by the adoption literature (Cushing, & Greenblatt, 2009; Reilly & Platz, 2003; Westhues & Cohen, 1990; U.S. Department of Health and Human Services, 2008).

Moreover, case managers talked about how matching a family with a younger child is difficult, because the foster care population on average is comprised of older children. Specifically, the most recent statistics from the Adoption and Foster Care Analysis and Reporting System (AFCARS) reveals that the average age of children in foster care awaiting adoption is eight (AFCARS, 2009). Furthermore, the average age of a child with special needs awaiting adoption is ten (AFCARS, 2009). These findings highlight how the age of a child impacts placement, thus making it more difficult to locate families that are willing to adopt children with special needs. As such the adoption agencies should explore methods of recruiting families that might be interested in adopting an older child.

In addition to adopting a younger child, the case managers reported that parents have a tendency to pursue children with similar qualities as the family, such as looks
and abilities. Based on the case managers’ experience they believe that parents are attempting to create an illusion of a biological family even when the child is adopted. The concept of seeking children who are similar to the family is discussed in the adoption literature. Specifically, multiple studies have found that when parents consider adoption as a method of forming a family, they often look for a child that will appear as a natural member of the family. This concept impacts parent’s abilities to consider a child with special needs, especially since disability is not a common characteristic among families considering adoption.

According to the case managers, families are just not really interested in dealing with special needs. They discussed how families immediately opt out of adoption when finding out that the child has special needs. The case managers report that this is often frustrating because they are not given the opportunity to explain to the family how much that the child has to offer them. Based on the discussion with the case managers it really seems as though potential parents go into the adoption process seeking a child who has as few issues as possible. It supports the theory that parents whose choose to adopt are seeking a child that will require the littlest amount of effort and stress on their part. The fact that a child has special needs is a well-documented deterrent to choosing to adopt. Multiple studies have shown that the documentations of behavioral, emotional, and physical problems in a child decrease the likelihood of the child being adopted (Reilly, & Platz, 2003; U.S. Department of Health and Human Services, 2008, Macomber, et al., 2005; Dave Thomas Foundation, 2007). Furthermore, findings from one study reveal that adoption case managers viewed the limited pool of interested families as a major barrier to placement (U.S. Department of Health and Human
Another similar finding is how parents are less likely to consider even attempting to adopt a child from the foster care system based on the assumption that all these children have additional behavioral, emotional, and physical problems (Dave Thomas Foundation, 2007). Knowing that adoption of children with special needs is not a desirable goal; the foster care system should explore potential methods of addressing this barrier in order to increase the number of special needs adoptions.

Another barrier associated with special needs adoption as identified by case managers relates to financial concerns. The case managers report that parents assume that adopting a child with special needs is automatically accompanied with a greater financial burden. First parents assume that it will be difficult to provide the child with health insurance, and that even with health coverage treatment would require additional out of pocket expenses. Furthermore, the parents believe that there is a financial discrepancy in raising a child with and without special needs. This discrepancy is based on parents’ assumptions of greater expenses related to supplies, medications, and other necessary equipment. While there is evidence to support that a child with a disability will require more financial strain, there are also techniques to reduce this burden. The first technique is through state funded health insurance programs, and the second method of offsetting additional cost incurred is through an adoption subsidy.

As discussed in Chapter 2 each child that is adopted from foster care system maintains Medicaid insurance coverage. A provision of the federal legislation, Adoption Safe Families Act of 1997 (ASFA), established state funding healthcare (Medicaid) for children with special needs. ASAFA states that the child will maintain Medicaid eligibility regardless of the adoptive parents’ income or geographical location. (Adamec
& Miller 2007). The case managers noted that potential parents are concerned about affording health coverage for the child. Since the child maintains Medicaid the parents will not accrue any additional expense in relation to the child obtaining health care coverage.

The case managers also expressed that another financial concern of potential parents is the amount of out of pocket medical expenses necessary when raising a child with special needs. The child will have Medicaid health coverage and as such the majority of the child’s physical and mental health related needs are fully reimbursed by the insurance plan. One study has examined the extent to which Medicaid and supplementary health care programs adequately meet a child with special needs’ care. This study examined the recommended needs of a child with cerebral palsy through life expectancy, as stated on a life care plan, with a comparison of type and frequency of services Medicaid covers. It was discovered that Medicaid adequately addressed the child’s physical and mental needs in relationship to both the type and frequency of services. There were only two sections of the life care plan where none of the recommendations were covered by Medicaid programs including: leisure time and aids for independent functioning. Under each of these section recommendations for adaptive toys, assistive computers, and summer camp were included (Buckles, Pomeranz, & Young, 2009). Based on the findings of this study, potential parents will incur little to no out of pocket medical experiences.

The second method of addressing the financial strain of raising a child with special needs is through a federal adoption subsidy program. Title IV-E establishes an adoption assistance program that provides adoptive families with a monthly subsidy.
The primary goal of the monthly subsidy is to assist parents with expenses acquired in relation to caring for a child with special needs. To be eligible for the subsidy the child must have a documented special need, and be available for adoption (Child Welfare Information Gateway, 2004). The monthly amount varies for each child and is based on age, level of need, and race/ethnicity of the child (Gibbs, Dalberth, Berkman, & Weitzenkamp, 2006). The average amount of monthly subsidy is 675 dollars; however this amount can range from 350 to 1000 dollars per month. Parents are able to use the money for any needs related to the child. Child related needs may include adoptive toys, summer camps, supplies, and medicine. The subsidy will help alleviate the parents concern of additional financial burden acquired from the needs of the child. Furthermore, this money has to potential to cover any expenses that are not paid for under Medicaid. The literature has examined the economic impact of the adoption subsidy on out of pocket expenses. The findings from several studies demonstrate that the adoption subsidy helps offset the additional expenses related to caring for a child with special needs (Gibbs, Dalberth, Berkman, & Weitzenkamp, 2006; Hansen & Hansen, 2005; Child Welfare Information Gateway, 2004). This evidence supports the concept that the adoption subsidy will aid parents with any expenses incurred, however potential parents are often not aware of availability of the adoption subsidy. Therefore, it is important for the adoption case managers to make parents aware of the availability of assistance and how it will benefit them while raising a child with special needs.

Another interesting barrier identified by the case managers was the impact that lack of education regarding special needs has on the adoption process. The case managers explained that the parents do not understand the implications of the child’s
needs and therefore often over exaggerate their impact on the child. The parents’ over exaggerations of the needs generated feelings of uncertainty regarding the child’s future. The case managers described how parents had concerns regarding the child’s future and their ability to successfully manage these issues. These concerns often led to parents feeling uneasy regarding adopting the child and therefore choosing to decline adoption. Limited research is available on the impact that lack of parental education has on the adoption process. However, there is one study that explored the barriers to placing children with special needs (Puddy & Jackson, 2003). The findings from this study revealed that lack of experience/education with special needs children was a significant barrier. The study findings note that the lack of experience reinforced the unrealistic expectation regarding the child’s behavior and abilities as well as their impact on the child’s future. These findings are similar to impact that the adoption case managers described in this study. Further research regarding the impact of lack parental education is warranted since to date limited research is available. If further research substantiates lack of parental education as a barrier, then it will be important for adoption agencies to provide more intensive education for potential parents prior to matching.

In addition to the potential parents’ lack of education, is the impact of case managers’ misunderstandings regarding disability. The case managers talked about how their educational backgrounds are often in social services, which means they really do not have any educational training on disability. Furthermore, the case managers also discussed a lack of any specialized training regarding the demands of children with special needs. The case managers point out that they really do not have any more
information regarding special needs than the potential parents. Therefore, the case managers display an inability to adequately address parents’ questions and concerns. Researchers have examined the influence that lack of specialized information regarding the child’s needs has on the adoption experience. Several studies have identified that lack of information has a negative impact on the adoption (U.S. Department of Health and Human Service, 2008; OPPAGA, 2008; Barth, Berry, Goodfield, & Carson, 1986; Groze, Young, & Corcran-Rumppe, 1991). Specifically, one study reported that 80% of the study population felt that lack of information was a major barrier during the adoption process (U.S. Department of Health and Human Services, 2008). While these studies explored the impact regarding lack of information, none have identified the rationale as to why this occurs. The findings of the current study uncover case managers’ lack of knowledge as one of the primary barriers to providing adequate information to potential parents. As such it is important for the adoption system to explore methods of training the adoption case managers in the area of special needs adoptions.

**Perceptions: Needs**

Along with the discussion of the barriers present when placing a child with special needs, the case managers identified needs that they felt would help eliminate some of issues present. First of all, case managers felt that there is a need for additional education of potential parents. Currently the only educational course provided for potential parents is the Model Approach to Partnership in Parenting (MAPP). This course is a ten week long intensive parenting class coordinated by two certified trainers, generally a social worker and an experienced parent (Puddy & Jackson, 2003). The class provides potential parents with information on the adoption process, as well as an intensive introduction to parenting skills. However, the course curriculum does not
include any aspects specific to raising a child with special needs (Adamec & Miller, 2007). Therefore, case managers’ note that MAPP classes are effective in helping parents make decisions regarding adoption, however fall short on educating parents regarding special needs children. Very little research has examined the effectiveness of MAPP classes in preparing parents for the problems confronted when raising a child with special needs. To date there is only one study examining the current MAPP curriculum and how well it prepares parents. The study found that the MAPP training course is more of a decision making tool to assist parents in choosing to adopt, rather than a program that prepares parents to manage behavioral problems (Puddy & Jackson, 2003). The findings from this study are consistent with the reports from the adoption case managers. The consistency among these findings supports the need for additional research to explore the effectiveness of current educational methods on preparing potential parents for adoption. If further research confirms this broad gap in training then a review of the current MAPP curriculum is warranted.

While the effectiveness of the current MAPP classes is in question, the evidence still shows that this training curriculum fails to provide parents with education on special needs. Therefore, the tasks of providing disability related information will fall back on the adoption case managers. The current study highlights the importance of case managers providing adequate information to potential parents, therefore requiring adoption agencies to explore methods of disseminating disability related information to the potential parents.

The other characteristic that the case managers felt would help the adoption process was for parents to be more open to the idea of adopting a child with special
needs. As stated earlier one of the primary barriers is the specific desires of potential parents when approaching adoption. Furthermore, the findings of one study regarding the barriers present in the adoption system highlighted the challenges presented by a limited pool of parents open to special needs adoptions. The literature supports the lack of willingness on the part of potential parents in considering adopting a child who has special needs, however does not offer any suggestions regarding methods of addressing these concerns. The case managers in the current study felt that if parents would be more open minded when coming to the adoption agency, then they would have the ability to help them understand what a child with special needs has to offer their family. There is no research available on how to help parents enter adoption with an open mind, just information on how close minded parents are regarding adoption. Therefore, methods of confronting this barrier need to be explored with further research.

**Perceptions: Those Who Adopt Special Needs Children**

An interesting finding of the study is what the case managers identified as characteristics of parents who choose to adopt children with special needs. The case managers noted that people who have medical backgrounds appear to be more willing to consider adopting a child with special needs. The case managers felt that the medical knowledge helped the parents have a more realistic understanding of the child. Furthermore, the case managers talked about how the medical knowledge appeared to help the parents feel more competent in caring for the child. The findings regarding the impact of medical background on the adoption process has been replicated from the pilot study with case managers, as well as evident in the interviews with parents who have adopted child with special needs. As such it is important aspect for adoption case managers’ to incorporate when recruiting adoptive parents.
While the findings from this researcher’s pilot study as well as this study reveal medical background as a common characteristic of those who adopt children with special needs, there is limited evidence in the literature to support these findings. A couple of studies have been conducted to identify some of the characteristics which impact a potential parents’ ability to adopt a child with special needs. The first study reviewed fifty-six families who had adopted children with special needs to develop a profile of the parents. The findings of the study show that 71% of the parents had known or lived with someone who had a disability prior to choosing to adopt (Unger, Deiner, & Wilson, 1988). This study highlights that fact that some experience or knowledge of disability is important factor that contributes to a person’s decision to adopt a child with special needs.

The second study explored parent’s level of preparedness to raise a child with special needs. This study interviewed families as a method of identifying how prepared a family felt as well as what characteristics aided them feeling prepared. The article identifies that the families who felt very prepared report having adequate training and information, adopted previously, or had previous experience with children (Egbert & Lamont, 2004). While this study did not report how the parents obtain the training/information, prior experience in the medical/social service field would result in adequate training/information. Therefore, this study supports the concept that those with professional or personal experience in the medical/social service field would be more likely to handle raising a child with special needs.

A couple of studies have identified some characteristics of parents who choose to adopt children with special needs, however none of these studies specifically focused
on the impact that professional experience in the medical/social services field have on adoption. Therefore, further research needs to be conducted in order to further understand the characteristics of parents who decide to adopt a child with special needs. Specifically, research should examine the impact of professional experience. The characteristics identified by the research will then encourage recruitment of parents who are open to special needs adoptions as well as shed light on methods to mitigate the concerns other potential parents may have.

**Overview of Adoption: Types of Adoptions**

According to the case managers there are three different types of placement options they consider once a child is freed for adoption including: kinship adoption, foster adoption, or non-relative adoption. The first option is kinship adoption, which is defined as a biological family member choosing to adopt the child. Based on discussions with the case managers this is viable option for permanency when a family member is available and willing to take the child. The primary challenges noted by the case manager are that kinship adoption is often not a viable option for the children which are foster care. This is evident in the statics regarding adoption from the foster care system. In 2009 a total of 57,466 children were adopted from the public adoption system, and only 32% or 17,300 of them were kinship adoptions (AFCARS, 2010).

Regardless of the availability of relatives in the position to adopt, the case managers still report that kinship placement is one of the easier placement options. The case manager states that it is often an easier placement because the family members tend to have some understanding of what the child’s needs are like. Furthermore, kinship placement is often preferred for the child because they are able to maintain a relationship with a portion of the family of origin. This connection often helps children
establish bonds with the adoptive family especially since the child may have had contact with the relative prior to being placed for adoption. Literature on the topic regarding kinship adoption supports more positive attachments between the child and family (Lorkovich, Piccola, Croza, Brindo, & Marks, 2004; Nickman, et al., 2005; Ryan, Hinterlong, Hegar, & Johnson, 2010). Research also reveals that children adopted by relatives experience fewer numbers of disruptions in their placement (Magruder, 1994). A huge factor contributing to the development of attachment disorders in adopted children is the number of foster placements the child experiences (Bruhn, 2003; Lawence, Carlson, & Egeland, 2006; Bada et al., 2008). Since children adopted through kinship experience fewer disruptions in overall placement, they are less likely to develop an attachment disorder. The lower likelihood of attachment disorder is related to more overall positive outcomes from the adoption (Ryan, Hinterlong, Hegar, & Johnson, 2010). The study conducted by Ryan and colleagues (2010), specifically focused on the overall outcomes of children placed in kinship versus those in non-relative adoptions. The findings of the study reveal that families formed through kinship adoption where more likely to report satisfaction with the adoption, a willingness to adopt again, as well as a positive relationship with the adopted child. This supports the case manager’s perceptions and experiences when attempting to place a child with special needs.

While relative placement is a good option for some children, it is frequently not available for children who are in the foster care system awaiting adoption. This leads to the second and most common type placement in which case managers consider, adoption by the foster parents. According to the adoption data in the fiscal year of
2009, 57,466 children were adopted from the public foster care system. The majority of the finalized adoptions were by foster parents with a total of 29,417 or 54% (AFCARS, 2010). This data supports foster adoption is an extremely viable option in order to obtain permanency for children with special needs.

The case managers identified discussing the option to adopt the child with the foster parents is one of the first steps they take in exploring placement options. Furthermore, it is reported that in the case managers’ opinions adoption by the foster parents is one of the best options for the child. The child has already formed a bond with the foster parent which aids in the child’s transition. Moreover, case managers note that the foster parents already have an idea of the demands required by the child’s needs. This finding is consistent with the interviews of parents who had adopted children with special needs. A total of five of the nine parents had fostered the child prior to choosing to adopt and felt that the foster experience provided them a greater sense of understanding. Furthermore, foster parent adoption is associated with lower disruptions rates, higher satisfaction outcomes, and fewer adjustment issues. As discussed earlier, the literature regarding foster parent adoption supports these findings.

The final type of adoption is to recruit potential parents and then match the child’s needs according to what people are looking for. This actually is the least common method of finding permanency for a child with special needs. Of the 57,466 finalized adoptions in 2009 only 14% of those were from non-relatives (AFCARS, 2010). In accordance with the statistics the case managers note that this is the most difficult type of placement to seek for a child. Again they referred back to the barriers they have witnessed from potential parents. In their experience, the case managers described
that children who are waiting to be matched with a parent tend to linger in the system for an extended period of time. Furthermore, it is noted that the longer the child is in the system along with the greater number of placements, the more behavioral and psychological issues they see developing in the child. The negative impact of the length of stay on a child’s psychological wellbeing is well documented in the literature (Bruhn, 2003; Lawence, Carlson, & Egeland, 2006; Bada et al., 2008). Based on this knowledge it is important for the adoption system to explore methods that could increase parents willingness to adopt a child who has special needs.

**Overview of Adoption: Preparation for Adoption**

While discussing the adoption process the case managers identified steps they normally take in preparing both the potential parents and the child for the finalization. Currently, the case mangers note that the people who are interested in adopting a child start by attending MAPP training classes. These classes are designed to educate the person on the adoption process, provide parenting skills, and prepare them for things to expect. The current training has major issues as identified by the case managers. The case managers note that at this point there is no specialized training for parents on what to expect when adopting children with special needs. As discussed earlier, the MAPP training classes fall short when it comes to preparing potential parents for the adoption of children with special needs. Furthermore, the research supports the class as more of a decision making tool rather than a program that prepares parents to manage behavioral problems (Puddy & Jackson, 2003). This leaves the parents feeling unprepared and full of unrealistic expectations regarding the child.

The case managers discuss how there are limited opportunities during the adoption process for the potential parents to gain information on raising a child with
special needs. These comments by the case managers is consistent with the experiences of parents who noted that very little information was provided to them at the time of adoption. The lack of information often led to undue frustrations regarding their adoption experience and is an important aspect the process that needs to be examined. As such the researcher looked at the literature regarding the impact that lack of information has on the adoption experience. The literature shows that one of the primary reasons for dissolution of an adoption is the lack of information and preparation provided by the adoption agency (Schwartz, 2008). Since the parents were not adequately informed at the time of adoption they were ill prepared to handle issues as they arose. Moreover, parents in the current study also recognized knowledge as important fact in the decision making process. Further research is necessary to examine the impact that lack of information has on the adoption process and how this issues can be modified.

**Life Care Plan: Applicability**

The adoption case managers viewed an example life care plan and discussed their thoughts regarding its use during the adoption process. The overall consensus was that life care plans would be beneficial. Specifically case managers recognized issues they felt the life care plan would address. The case managers talked about the implications of life care plans for both the potential parents as well as the case manager. The case managers talked about how a life care plan would provide potential parents with additional information regarding the child’s needs. This information would help the potential parents’ gain a realistic understanding of special needs, therefore mitigating the issues this creates during the adoption process. The case managers’ note that having a plan that looks towards the future of the child may help parents grasp
the concept that the child does have a future. Furthermore, the case managers talked about how a future perspective will eliminate parents’ fears regarding the uncertainty of how disability related needs may change over time. This uncertainty was one of major barriers which the case managers have witnessed.

Another interesting finding is how the case managers perceived the possibilities of a life care plan to aid potential parents in understanding the financial aspect related to the child’s needs. The case manager explained that the potential parents often express fears that caring for the child would create a major financial burden compared to raising a child without special needs. Since the life care plan establishes a concrete method of viewing the child’s disability related needs and the finances necessary to meet them, it will help parents comprehend the financial aspect of the child. Furthermore, the case managers note that establishing the plan on what Medicaid will pay for helps parents understand that the child’s insurance will cover the medical needs. Therefore the plan will illustrate that caring for a child’s medical needs is similar to caring for a child without special needs. Case managers also talked about how providing this plan to potential parents will allow them to prepare for any of the child’s needs that will not be covered by insurance, thus mitigating some of the financial concerns. Overall, the case managers felt that having this financial information regarding the child’s needs will be very helpful when parents are exploring adoption.

The next theme identified by the case managers was how the life care plan will help answer potential parents’ questions. The case managers note that when people come in seeking adoption they tend to have a large amount questions regarding the children available. Furthermore, the case managers note that when parents hear about
children who have special needs they tend to shy away from the idea of adopting a child with those characteristics. As discussed earlier, the literature regarding adoption shows that parents often report feeling uncomfortable in considering adopting a child who has special needs (Reilly & Platz, 2003). These feelings are related to the lack of knowledge, unanswered questions, and false assumptions regarding the child (Reilly & Platz, 2003; Ponciano, 2010). The use of a life care plan was identified by the case managers as a method of answering parents’ questions regarding the child’s current and future needs, as well as a realistic understanding of the financial aspect. The case managers believe that this tool will help them convey a realistic picture that will provide parents with a holistic and factual understanding of the child. As such it will address some of the common concerns they hear from parents when discussing a child with special needs.

The final theme regarding the application of life care plans was education/knowledge for potential parents. The case manager felt that people with medical backgrounds or a personal understanding of disability where more likely to consider adopting a child with special needs. The perception of the case managers was that a medical background meant that the parents have education on how to handle the special needs of the child. Therefore, the case managers believe that utilizing a life care plan during the pre-adoptive phase will give potential parents a similar understanding and confidence in handling the child’s needs.

The case managers also recognized the applicability of life care plans to aid them during the adoption placement. During the focus groups case managers described how it was frustrating for them because they did not have any medical background or
training regarding special needs. This lack of knowledge made it difficult for them to answer important questions which the potential parents where asking. Often the case managers felt that their lack of ability to appropriately answer questions hindered the adoption process. The case managers talked about how a life care plan would provide them essential knowledge regarding the needs of the child. This knowledge would allow them to provide potential parents with more adequate information and address the concerns that parents express to them. With the additional knowledge case manager felt that they would be more prepared to seek adoptive placement for a child with special needs.

In addition to answering parents’ questions, the case managers also identified the additional knowledge gained from a life care plan will aid them in establishing the appropriate post adoption services. Case managers felt that their lack of knowledge regarding a child’s current and future needs was a major barrier to knowing what type of care was necessary. This became extremely impactful when attempting to assist a family with what types of services the child will continue to need after leaving the foster care system. Furthermore, the case managers talked about how the adoption system has recognized the need for more accurate post adoption services. As such, the case managers are being assigned the additional role of establishing post adoption services for a family at the time of finalization. Therefore, a life care plan would be very impactful in knowing what types of services to establish.

The final impact of the additional knowledge case managers’ gain from a life care plan is assistance in matching a child with the potential parent. The case managers discussed how it is often difficult to know if a potential parent is going to have the ability
and knowledge to handle a child’s needs. The impact of predicting a parent’s ability to care for the child’s needs is extremely important, because if they are unable to then dissolution of adoption occurs. The literature has established both the higher rate of dissolution of adoption for children with special needs as well as the negative impact it has the child. The life care plan will provide the case managers with a better understanding of the child’s needs; therefore they will be more capable of assessing a parent’s readiness to adopt.

Life Care Plans: Recommendations

The case managers made recommendations when considering the life care plan model and its use during the adoption process. The case managers felt that it was important for the life care plan to not only focus on the issues related directly to the disability, but to also include treatment options to address some of the problems commonly associated with children who are adopted. The case managers noted that a number of the children with special needs have been in foster care for an extended period of time and in relation have emotional difficulties. Of specific concern, the case managers identified issues related to attachment and how this often creates difficulties as the family attempts to adjust to the adoption. Difficulties with attachment are commonly identified in the literature as a major issue in adoption of children with special needs (Bruhn, 2003; Lawence, Carlson, & Egeland, 2006; Bada et al., 2008). Furthermore, research also supports that increased amount of time and number of placement is associated with an increase in mental health symptoms (Lawence, Carlson, & Egeland, 2006; Bada et al., 2008). Based on the findings of this study as well as the supporting literature, it will be important to consider adoption specific issues when developing a life care plan.
Another interesting finding was the recommendations by the adoption case managers to include the monthly adoption stipend in the financial aspects of the life care plan. The case managers discussed how it was important that parents understand that Medicaid will cover the majority of the medical expenses, but that including the monetary stipend will highlight how families have the potential to meet the financial demands of raising the child. Furthermore, this stipend could be included in the plan as a way to cover the unmet expenses. Case managers felt that including this in plan would provide them with a tool to help parents understand the monthly stipend and highlight how it lessen the financial strain of raising a child.

Life Care Plans: Concerns

The case managers talked about some of the issues they felt might impact the implementation of life care plans within the adoption system. First, case managers talked about the issue of who would be developing the life care plans. They expressed concerns on how the life care plan would work within the system. Specifically, they noted that someone would need specialized training in life care planning in order to develop the plan and they are not sure how that would work. Furthermore, was the concern of how the plans take into consideration each child’s needs was also discussed. These are both very viable concerns regarding the implementation of life care plans. Future researcher needs to explore these issues and methods of addressing.

Another issue that case managers identified was the availability of appropriate services. The case managers felt that locating good treatment options for some of the issues present in children who are adopted is difficult. The example of reactive attachment disorder was brought up by the case managers. The case managers talked
about how in their experience locating a therapist that is competent in treating reactive attachment disorder has been almost impossible in their area. The availability of appropriate services is something important to consider in the development of a life care plan. Moreover, this issue experienced by adoption case managers highlights the need for specialized training of healthcare professional on adoption specific issues.

**Assuring Trustworthiness**

Trustworthiness refers to the significance of the study’s findings and is commonly achieved through credibility, transferability, dependability, and conformability (Lincoln, & Guba, 1985 p.290). The researcher chose to use data triangulation as a method to increase the trustworthiness of the current results (Johnson, 1997). Data triangulation is the use of multiple data sources to help understand a phenomenon and allows for “cross checking” of information and the conclusion drawn (Johnson, 1997). The researcher chose to gather information and code data from the interviews, focus group, as well as observational field notes. This allowed for multiple sources of data and the ability to gain congruence among themes identified.

Another challenge to trustworthiness of the study is the assumption that researcher’s biases will impact the data analysis and interpretation (Patton, 2002). To account for this limitation the researcher established steps to maintain reflexivity. As discussed in Chapter 3, “reflexivity” is assuring that the researcher attends systematically to the context of knowledge construction throughout the research process (Maltrud, 2001). This is especially important when examining the effects of the researcher and their biases at every step of the process (Maltrud, 2001). In order to maintain “reflexivity” throughout the research the following steps were performed:
The researcher completed necessary training in qualitative methods, which provided awareness on basic qualitative research methods, theoretical frameworks, developing discussion guides, and conducting interviews.

Following each interview or focus group the researcher recorded her opinions and reactions to the process in field notes.

The researcher utilized computer software that allowed for tracking changes and opinions during the coding process.

The researcher consulted with her committee chair regarding the themes that emerged from the data. Furthermore, consulted with a peer group regarding coding framework as well.

The researcher maintained a continuous awareness of personal biases that may influence the qualitative process. A personal bias statement was discussed in Chapter 3.

**Limitations**

This research study has a couple of limitations that are inherent with qualitative research methods. A primary limitation of the current study is the sampling technique utilized to recruit participants. As discussed in Chapter 3, the researcher chose to use purposeful sampling methods, because it best fit the research goals; however purposeful sampling has the potential to create a homogenous sample. A homogenous sample limits transferability of the results to the broader population. The sample of case managers was homogenous in gender, years of experiencing, and geographical area, furthermore, the sample of parents was also homogenous in gender, socioeconomic status, and geographical area. The homogeneity of both samples limits the transferability of the results; however this was not the goal of the current study.

Another major limitation to the study is the sample size. Both research methods involved the use of a small sample sizes, nine individual interviews and six members in each focus group. This creates limitations in the reliability of the studies finding,
however again the primary goal of this study was gain rich information regarding the phenomena. Additional research is warranted to gain further insight into the experiences of a more diverse group of parents and case managers.

**Study Implications**

**Clinical Practice**

The results of this study provide a greater understanding of the issues present during the special needs adoption process and areas where improvements are necessary. Furthermore, the knowledge gained regarding the use of life care plans sheds some light on the potential tool to address the present issues. This knowledge will aid adoption case managers when searching for adoptive placement of a child with special needs. Specifically, the findings of this study have the potential to impact the following areas of the adoption process: recruitment of potential parents, screening of potential parents, and education of potential parents, as well as post adoption placement, and the use of life care plans.

One of the major findings of the study is that people with medical or social service backgrounds tend to feel more comfortable in adopting children with special needs. As such adoption agencies should direct recruitment efforts towards this population. By increasing recruitment efforts of people with medical backgrounds this will aid the adoption case manager in identifying an appropriate adoptive placement. Another factor recognized in the results that impacts the recruitment process is how foster care parents seem to be more likely to adopt a child who has special needs. This again has huge implications for the recruitment process, because this study provides adoption case managers with information to encourage the transfer of foster placements into adoptive placements.
The knowledge acquired from the results of this study support the need for some method of assessing potential parents’ readiness to adopt a child with special needs. The findings regarding characteristics that impact parents’ decisions making can potentially aid the case managers in assessing readiness and understanding of the magnitude of parenting a child who has special needs. Furthermore, this will be an important addition to recruitment process that may impact the high dissolution rate of special needs adoptions.

The need for more education is extremely evident in the findings of this study. This includes education for the potential parents as well as education for adoption case managers. One of the primary factors discussed by the adoptive parents as essential to their comfort level of dealing with special needs was the knowledge they had from their professional experiences. Therefore, it is important for the adoption system to recognize the needs for more specialized training of potential parents regarding the dynamics of raising a child with special needs. Furthermore, another potential method in educating potential parents is to provide them with informational pamphlets, articles, or general information that will increase their health literacy. This study also displayed the importance that a life care plan will have on the potential parents’ awareness of the child’s needs, thus providing them with individualized educational tool that will also increase health literacy. The increased health literacy will allow parents to gain a holistic and realistic view of the disability that will aid their decisions to adopt a child.

Education of the adoption case managers is also a major implication of the findings from this study. The study revealed a lack of knowledge, on the part of the adoption case manager, regarding the implication of special needs on the child’s future.
This lack of knowledge greatly impacted their ability to answer potential parents' questions, which led to the parents' feelings uneasy regarding the child's future needs and their ability to manage them. Therefore, parents would be less likely to consider adopting that child. The evidence here supports the need for specialized training for adoption case managers who will handle special needs adoptions.

As stated earlier life care plans are dynamic documents that organize a concise plan for the current and future needs of individuals with disabilities (Weed, 2004). Furthermore, the primary goal of the life care plan is to educate its intended audience, as such the life care plan is well designed to address some of the issues identified by this study. First of all, knowledge was identified as important determining factor in choosing to adopt a child who has special needs. The life care plan will be a tool that adoption case managers can provide potential parents during the assessment process in order to provide them with an individualized knowledge of the child’s need. This knowledge will aid the parents in making an informed decision and provide them with the assurance that the disability is manageable.

Another issue identified in this study is the case managers’ lack of understanding regarding disability and how this impacts the adoption process. By implementing the use of life care plans, the adoption case managers will have a tool that will aid their understanding of the child’s needs. This is instrumental to assisting the case managers in adequately addressing potential parents’ concerns regarding adopting a child with special needs.

Finally, life care plans will aid the parents after the adoption has been finalized. A major finding of the study was the lack of support and direction provided to parents after
the adoption is finalized. Providing parents with life care plans at the time of adoption will address this concern. Furthermore, it will empower parents in understanding, directing, and being proactive with their child’s care.

Theory

In accordance with grounded theory, a theoretical framework regarding the adoption experience was established. The framework was discussed in Chapter 5, and developed using Bronfenbrenner’s ecological systems theory as a model to guide the emerging themes from the data. According to Bronfenbrenner’s theory, the developing person’s extended family is often placed within the micro or exosystem of their environment. This view treats the extended family as an entity in which the developing person comes into contact with. However this perspective fails to take into account the cultural attitudes of these members, which may also impact the developing person.

For the purpose of this study, the researcher felt that the extended family played a large role at the macrosystem level of the environment, because the impact of the extended family was directed by their cultural attitudes. So rather than viewing the extended family as part of the exosystem, an entity that interacts with developing person, the data suggests the impact of the extended family was derived from their cultural/societal beliefs. The participants did not discuss their extended family as part of the decision making or process of adoption, which are the variables within the micro and exosystems. Discussion regarding the impact of the extended family was not brought up by participants until describing their experiences while raising the child. The description regarding the impact that the extended family had on the adoption experiences appeared to be directly related to the extended family’s cultural views. If the extended family’s attitude was to be accepting of diversity, then the impact
appeared to be inclusive and positively shaped the participants adoption experience. On the other hand, if the participants’ extended family’s attitudes were biased then the impact appeared to be based on segregation in which the family treated the biological and adoptive children differently. The concept of taking into account the extended family’s cultural attitudes on the developing person would by definition place them within the macrosystem.

Considering the extended family as a component of the macrosystem is a unique finding based on the data collected from this study. This finding highlights the needs for a shift in perspective regarding ecological theory. The change in perspective will impact the conceptualization of data when using the ecological theory. Therefore when a researcher utilizes the ecological perspective as a framework for theoretical development, they must take into account the impact of extended family’s cultural attitudes on the experiences of the developing person. Overall, the extended family may fall both within the exo and macrosystems of the environment.

**Research**

The findings from the pilot work as well as this study highlight the fact that life care plans are both feasible and applicable within the adoption system. However, both of these studies were rudimentary and exploratory in nature with the goal of establishing precedence for the use of life care plans. The knowledge gained from these studies supports the need for further research to continue to explore the benefits and risks associated with life care plans during the adoption process.

First it is important for future research to explore the applicability of life care plans with a more diverse sample. As discussed earlier one of the primary limitations to this study was the sampling techniques used. Purposeful sampling creates a homogenous
sample, and for this study the participants were homogenous in gender, geographical location, socioeconomic status, and race. Replicating this study to include a demographically diverse sample would allow for a better representation of the general population, therefore increasing the generalizability of the findings.

Future research needs to focus on methods of implementing life care plans within the adoption system. The first step in doing this is to develop a study that will explore the actual impact that the life care plan has on adoption. The future research will create a framework for an adoption life care plan based on the recommendations from this study. The modified framework will then be given to parents who are considering adopting a child who has special needs. The opinions on the amount of information and the level of assistance provided could then be assessed.

Another method of exploring the impact of using life care plans during special needs adoptions would be to utilize a longitudinal research model. Gathering longitudinal data would allow for a better understanding of how a life care plan not only impacts the decision to adopt, but the overall success of the adoption. This will shed light on the use of life care plans and will help determine if utilizing a life care planning consultant during the adoption process would be beneficial.

A prominent finding emerging from the data was the case managers’ lack of health literacy and its negative impact on the adoption experience. Therefore, future research needs to explore potential methods of educating adoption case managers regarding children with special needs. Moreover, the findings also support the impact of low health literacy on the part of potential parents as well. Future researcher should also explore methods of increasing health literacy for parents who consider adoption.
Conclusion

This study sheds light on some of the issues present in adoption system. Furthermore, the findings support the use of life care plans with special needs adoptions. The case managers described some of the barriers that they had witnessed in their experiences of placing children with special needs. These barriers were based on potential parents’ opinion of adoption as well as what it means to raise a child with special needs. The identified barriers are some of the reasons for lower adoption rates of children with special needs.

A number of areas important to adoption decision making and frustrations related to adoption of children with special needs were identified from the interviews with the parents. This information sheds light on areas where are current adoption system is failing to provide the necessary information and support to those who choose to adopt. The combination of this information along with the reports from the case manager highlights the need for a comprehensive tool to educate both the parents and adoption case managers. One of the potential tools is life care plans. This preliminary study showed promise for the application of life care plans within the adoption system. Further research is necessary to continue development of an adoption life care planning model, as well as explore the method of implementing this model into practice.
APPENDIX A
DISCUSSION GUIDE FOR INDIVIDUAL INTERVIEWS

The goal of this interview is to gather information on your experience adopting a child who has special need and your opinions on the use of life care plans. You have received a consent form to sign, which indicates that you understand your rights as a participant and consent to this interview. The interview will be audio recorded. I am going to ask you question regarding the adoption process as well as the use of life care plans. There is no right or wrong answer to the questions, just answer the questions to the best of your abilities. Before we do you have any questions?

1. What process did you go through in order to adopt your child?
   a. What challenges did you face?

2. What made you decide to adopt a child who has additional needs?

3. What information was provided to you by adoption agency?
   a. Was this enough information to know what to expect?
   b. If not, what additional information would have been helpful?

4. What was the main thing you wanted to know about when going through the adoption process?

5. What types of questions were the case managers unable to answer for you?

6. What was most helpful thing when making the decision to adopt a child with special needs?

7. What is your opinion of the life care plan
   a. What are your thoughts on the amount of information included in the plan?

8. What do you think about using life care plans for parents who are considering adopting a child with special needs?

9. What changes if any would you make to the life care plan in order to make more suited to the adoption process?

10. Is there anything else you would like to add?
I greatly appreciate your time to participate in this interview. The responses you provided will give us valuable information regarding the adoption children with special needs and the potential use of life care plans.
This focus group is designed to help understand the challenges in placing children with special needs in adoptive homes as well as to gather your perceptions of the use of life care plans in the adoption process. You signed the consent form stating you understand the research process and your rights as a participant. The focus group will be both audio and video recorded. I will bring up topics for discussion and you are free to comment on them in any way you wish. Are there any questions?

1. What challenges have you faced when attempting to place children with special needs?

2. How is placing children with special needs different than placing children without special needs?

3. What impact does potential parents attitudes have on the adoption process?
   
   3a. In your opinion, what can be done to change parents perceptions or attitudes?

4. What information do you provide to potential parents?

5. In your opinion what is the most common thing parents want to know about when considering adoption?

6. What type of information seems most helpful for parents when they consider adopting a child with special needs?

7. What things do you normal do to prepare a family to adopt a child with special needs?

8. What is your opinion of the life care plan?
   
   8a. What is your perception on the amount of information included in the life care plan?

9. How do you see life care plans being used in adoption process?

10. What changes if any would you make to the life care plan in order to make more applicable to adoption process?

11. Is there anything that anyone would like to add?
I greatly appreciate you taking time out of your busy schedules to participate in this focus group. The information you have provided will help understand the challenges faced in the adoption process as well as the potential use of life care plans in the adoption system.
APPENDIX C
SCRIPT FOR INTRODUCING LIFE CARE PLANS

A life care plan is a comprehensive tool that organizes the disability related needs for an individual. This tool allows for a realistic understanding of the therapies, medical appointments, and supplies required to adequately meet the needs of an individual with a physical or emotional disability. By establishing future needs the life care plan will help families prepare for supplies or maintenance that is necessary. The life care plan is organized into 16 different sections that establish what the child currently needs now and is anticipated to need in the future.

You can look at the life care plan provided, which is an example of how the plans are normally organized. The child was a year old at the time the plan was developed and has Cerebral Palsy as a result fetal distress prior to delivery. Cerebral Palsy is a disorder that affects the body movement and posture of the individual. Commonly people with cerebral palsy experience uncontrollable reflex movements in their limbs as well as muscle tightness that may affect any part of the body. The sample plan explains the physical, medical, and psychological needs of the child. Are there any questions regarding the life care plan?
## Projected Evaluations

<table>
<thead>
<tr>
<th>Item/Service</th>
<th>Age Year</th>
<th>Frequency/Replacement</th>
<th>Purpose</th>
<th>Comment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Developmental Psychology</td>
<td>Beginning 5 6/9/04</td>
<td>1 X/ 2-3 years to age 21</td>
<td>Evaluate developmental levels and monitor for behavioral problems</td>
<td>• Covered under the Developmental Disability Waiver</td>
</tr>
<tr>
<td></td>
<td>Ending 21 2020</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Psychological Evaluation</td>
<td>Beginning 5 2004</td>
<td>1 X Only</td>
<td>Assess family's needs and formulate a counseling program to address them</td>
<td>• Covered by State Medicaid Plan</td>
</tr>
<tr>
<td></td>
<td>Ending 5 2004</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Physical Therapy ***</td>
<td>Beginning 5 2004</td>
<td>2X/Year through age 21; thereafter 1X/year</td>
<td>Assess physical therapy program</td>
<td>• Covered by State Medicaid Plan</td>
</tr>
<tr>
<td></td>
<td>Ending Life exp.</td>
<td></td>
<td></td>
<td>• IDEA will provide evaluation for school related tasks</td>
</tr>
<tr>
<td>Occupational Therapy ***</td>
<td>Beginning 5 2004</td>
<td>2X/Year through age 21; thereafter 1X/ 3 year</td>
<td>Assess occupational therapy program</td>
<td>• Covered by State Medicaid Plan</td>
</tr>
<tr>
<td></td>
<td>Ending Life exp.</td>
<td></td>
<td></td>
<td>• IDEA will provide evaluation for school related tasks</td>
</tr>
<tr>
<td>Speech Therapy ***</td>
<td>Beginning 5 2004</td>
<td>2X / Year</td>
<td>Assess speech therapy program</td>
<td>• Covered by State Medicaid Plan</td>
</tr>
<tr>
<td></td>
<td>Ending 21 2020</td>
<td></td>
<td></td>
<td>• IDEA will provide evaluation for school related tasks</td>
</tr>
<tr>
<td>Nutritional Evaluation</td>
<td>Beginning 5 2004</td>
<td>2 X/ Year through age 18; then 1 X / year thereafter</td>
<td>Monitor nutritional needs and make recommendations</td>
<td>• Covered under the Developmental Disability Waiver</td>
</tr>
<tr>
<td></td>
<td>Ending Life exp.</td>
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</tbody>
</table>

Services not covered under projected evaluations include vocational evaluation and disabled driver evaluation.
<table>
<thead>
<tr>
<th>Item/Service</th>
<th>Age Year</th>
<th>Frequency/Replacement</th>
<th>Purpose</th>
<th>Comment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Behavioral Analysis Services*</td>
<td>Beginning 5</td>
<td>1 X/ week for 3 months now, 2X / month for 3 months at ages 6, 8, 10, 12, 14, 16, 18, and 21</td>
<td>Implement a developmental stimulation and behavioral modification program for caregivers to follow.</td>
<td>• Covered under the Developmental Disability Waiver • Covered by CMS</td>
</tr>
<tr>
<td></td>
<td>Life Exp.</td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Family Counseling</td>
<td>Beginning 5 2004</td>
<td>1 X/ week for 3 months now, 2X / month for 3 months at ages 6, 8, 10, 12, 14, 16, 18, and 21</td>
<td>To help the family cope with the situation and becoming stronger advocates</td>
<td>• Covered by State Medicaid</td>
</tr>
<tr>
<td></td>
<td>Ending 21 2020</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Physical Therapy **</td>
<td>Beginning 5 2004</td>
<td>2X/week through age 21 (48 weeks / year); thereafter 4 - 6 X / year</td>
<td>Enhance muscular development and prevent contractures</td>
<td>• 1X / week limit under State covered Medicaid. CMS covers the overage on services.</td>
</tr>
<tr>
<td></td>
<td>Ending Life exp.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Occupational Therapy **</td>
<td>Beginning 5 2004</td>
<td>2X/week through age 21 (48 weeks / year); thereafter 4 - 6 X / year</td>
<td>Cognitive and visual stimulation and introduce adaptive technology to enhance functioning</td>
<td>• 1X / week limit under State covered Medicaid. CMS covers the overage on services.</td>
</tr>
<tr>
<td></td>
<td>Ending Life exp.</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Speech Therapy **</td>
<td>Beginning 5 2004</td>
<td>2X/week through age 21 (48 weeks / year); thereafter 4 - 6 X / year</td>
<td>Address speech, language, and cognitive deficits</td>
<td>• 1X / week limit under State covered Medicaid. CMS covers the overage on services.</td>
</tr>
<tr>
<td></td>
<td>Ending 21 2020</td>
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</table>

*Instead of Developmental Psychologist Medicaid covers Behavioral Analyst. Behavioral Analyst can address the same behavioral modification issues. Services not covered under therapeutic modalities would be disabled driver training.
<table>
<thead>
<tr>
<th>Item/Service</th>
<th>Age Year</th>
<th>Frequency/Replacement</th>
<th>Purpose</th>
<th>Comment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Educational Testing</td>
<td>Beginning 5</td>
<td>1 X / year</td>
<td>To assist supplemental therapist in coordinating with school sponsored program</td>
<td>• Covered by CMS • Some educational related testing is covered by IDEA</td>
</tr>
<tr>
<td></td>
<td>Ending 21 2020</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Special Education Program</td>
<td>Beginning 5</td>
<td>Weekly educational</td>
<td>Educational and therapeutic program</td>
<td>Special education programs provided at the cost of county, state, and federal government</td>
</tr>
<tr>
<td></td>
<td>2004</td>
<td>program</td>
<td></td>
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<tr>
<td></td>
<td>Ending 21 2020</td>
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</table>
### Home Furnishings and Accessories

<table>
<thead>
<tr>
<th>Item/Service</th>
<th>Age Year</th>
<th>Frequency/Replacement</th>
<th>Purpose</th>
<th>Comment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nebulizer</td>
<td>Beginning 5</td>
<td>1 X / 3-4 years</td>
<td>Treatment for Bronchial Pulmonary Dysplasia</td>
<td>• Covered by State Medicaid</td>
</tr>
<tr>
<td></td>
<td>Ending 21 2020</td>
<td></td>
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<td>• Covered by CMS</td>
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</table>

### Medication

<table>
<thead>
<tr>
<th>Item/Service</th>
<th>Age Year</th>
<th>Frequency/Replacement</th>
<th>Purpose</th>
<th>Comment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Prescription Medication</td>
<td>Beginning 5</td>
<td>Annual cost</td>
<td>As prescribed by physician</td>
<td>Current medications are: Albuterol and antibiotics needed prior to dental visits secondary to heart condition</td>
</tr>
<tr>
<td></td>
<td>Ending 21 2020</td>
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</table>

Generic prescription medication is covered under Medicaid insurance as needed.

### Home Care / Facility Care

<table>
<thead>
<tr>
<th>Item/Service</th>
<th>Age Year</th>
<th>Frequency/Replacement</th>
<th>Purpose</th>
<th>Comment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pre - Age 21 Respite Care (HHA) *</td>
<td>Beginning 5</td>
<td>1 night per week for 4 hours; 1 weekend / month for 36 hours (640 hours / year)</td>
<td>Prevent parental burnout</td>
<td>• Covered under the Developmental Disability Waiver • Covered by CMS</td>
</tr>
<tr>
<td></td>
<td>Ending 21 2020</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Pre - Age 21 Case Management **</td>
<td>Beginning 5</td>
<td>3 - 4 hours / month (36 - 48 hours / year)</td>
<td>Coordinate and oversee care</td>
<td>• Covered by CMS • Covered by State Medicaid Plan</td>
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<tr>
<td></td>
<td>Ending 21 2004</td>
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</table>

* Limited to 8 hours in one 24 hour period and a total of 720 hours per year
** Limited to 32 minutes per day
<table>
<thead>
<tr>
<th>Item/Service</th>
<th>Age Year</th>
<th>Frequency/ Replacement</th>
<th>Purpose</th>
<th>Comment</th>
</tr>
</thead>
</table>
| Pediatrician / Internist | Beginning 5 6/9/04 | 4 X / year for 15 years; 2 X / year thereafter | Care required in addition to the routine care all children required     | • Covered by State Medicaid Plan  
• Covered by CMS                                       |
|                      | Ending Life Exp. |                                            |                                                                         |                                                   |
| Neurologist          | Beginning 5 2004 | 1-2 X / year                              | Monitor for seizure disorder and other neurological problems            | • Covered by State Medicaid Plan  
• Covered by CMS                                       |
|                      | Ending Life Exp. |                                            |                                                                         |                                                   |
| Orthopedics          | Beginning 5 2004 | 2-4 X / Year through age 15; thereafter 1X/year | Monitor bone development and contractures                                | • Covered by State Medicaid Plan  
• Covered by CMS                                       |
|                      | Ending Life exp. |                                            |                                                                         |                                                   |
| Physiatrist          | Beginning 5 2004 | 1-2 X / year                              | Monitor habilitation plan, need for treatment of spasticity, orthotics | • Covered by State Medicaid Plan  
• Covered by CMS                                       |
|                      | Ending Life exp. |                                            |                                                                         |                                                   |
| Ophthalmologist *    | Beginning 5 2004 | 2-5 X / Year through age 10; thereafter 1X/year | Monitor eyes, vision, and strabismus                                    | • Covered by State Medicaid Plan  
• Covered by CMS                                       |
|                      | Ending Life exp. |                                            |                                                                         |                                                   |
| Cardiologist         | Beginning 5 2004 | 1-2 X / year                              | Monitor heart condition                                                | • Covered by State Medicaid Plan  
• Covered by CMS                                       |
|                      | Ending Life exp. |                                            |                                                                         |                                                   |
| Pulmonologist        | Beginning 5 6/9/04 | 2 X / year                               | Monitor bronchial pulmonary dysplasia and pulmonary insufficiency       | • Covered by State Medicaid Plan  
• Covered by CMS                                       |
<p>|                      | Ending Life Exp. |                                            |                                                                         |                                                   |</p>
<table>
<thead>
<tr>
<th>Item/Service</th>
<th>Age Year</th>
<th>Frequency/Replacement</th>
<th>Purpose</th>
<th>Comment</th>
</tr>
</thead>
</table>
| Otolaryngologist *     | Beginning 5 2004 | 2 X / year through age 14; then 1X / 2-3 year through age 21 | Monitor for seizure disorder and other neurological problems           | • Covered by State Medicaid Plan
|                        | Ending 21 2020   |                       |                                                                          | • Covered by CMS                              |
| Neurosurgeon           | Beginning 5 2004 | 2 X / year through age 20; thereafter 1X / year | Monitor VP shunt                                                       | • Covered by State Medicaid Plan
|                        | Ending Life exp. |                       |                                                                          | • Covered by CMS                              |
| Pathology lab work     | Beginning 5 2004 | 2-3 X / year          | Monitor functions with a CBC, Metabolic panel                           | • Covered by State Medicaid Plan
|                        | Ending Life exp. |                       |                                                                          | • Covered by CMS                              |
| Neurological diagnostics| Beginning 5 2004 | 1 X / Year            | Monitor Shunt with Shunt Series, EEG, CT of head, MRI of Brain          | • Covered by State Medicaid Plan
|                        | Ending Life exp. |                       |                                                                          | • Covered by CMS                              |
| Cardiac Diagnostics ** | Beginning 5 2004 | See individual test for frequency | Monitor heart functioning with Chest X-ray, EKG (1X / year), Echocardiogram (1x/year), stress tests | • Covered by State Medicaid Plan
|                        | Ending Life exp. |                       |                                                                          | • Covered by CMS                              |
| Pulmonary Function testing | Beginning 6 2005 | 1 X / Year            | Monitor pulmonary functions                                             | • Covered by State Medicaid Plan
|                        | Ending Life exp. |                       |                                                                          | • Covered by CMS                              |

* Hearing Exams are limited to 1 every 3 years; follow up visits to address tubes are covered at the same rate
** EKG was requested twice a year; however is only covered for one a year
LIST OF REFERENCES


BIOGRAPHICAL SKETCH

Vicky P. Buckles, PhD., CRC, CCT, RMHCI is a graduate of the rehabilitation science doctoral program at the University of Florida College of Public Health and Health Professions (Gainesville, Fl.). Dr. Buckles received her master’s degree in Rehabilitation Counseling from the University of Florida in 2004. Dr. Buckles also received her Bachelor of Science degree in health science from University of Florida in 2002. Accomplishments during Dr. Buckles’s career included her being a recipient of the 2009 John Muthard Award for excellence in research of the University of Florida College of Public Health and Health professions, Department of Rehabilitation Counseling, 2009 Life Care Planning student paper award winner. She also received a Graduate Teaching Assistant Award from University of Florida as well.

Over the past seven years Dr. Buckles has worked as mental health counselor with children. Dr. Buckles is a Certified Rehabilitation Counselor, Certified Clay Therapist, Certified Adoption Competent Therapist, and Registered Mental Health Counselor Intern. Her experience working with children is what helped shaped the current research interests. While in the doctoral program Dr. Buckles worked as a teaching assistant in multiple undergraduate courses in the Health Science Program. This experience allowed her to gain the skills and knowledge necessary to instruct college courses.