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FOSTER PARENTS' PERSPECTIVES ON FOSTER CHILDREN WITH
AUTISTIC SPECTRUM DISORDER IN THE CHILD WELFARE
SYSTEM AND HOW THEY IMPACT THE LIVES OF
THE FOSTER PARENTS

A Project
Presented to the
Faculty of
California State University,
San Bernardino

In Partial Fulfillment
of the Requirements for the Degree
Master of Social Work

by
Uchechukwu Adaure Alozie
September 2011


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Approved by:



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ABSTRACT

Foster parents are vital advocates and protectors of their foster children, especially to foster children with special needs. Foster parents of foster children with Autistic Spectrum Disorder are instrumental in making sure that child receives adequate services and that the child is being provided with a safe environment that can promote permanency. The purpose of this study is to look at foster parents' perception on services that are provided to foster children with autism and how these services affect the children's safety and quality of life. The study used a qualitative design, with in-depth face to face and telephone interviews with nine foster parents of children diagnosed with ASD in Children and Family Services, CFS, of San Bernardino. This study found that the caregivers were not being sufficiently prepared to aid in the development of a child with ASD. A major recommendation of this study is for CFS to make policies that will require the preparation for these caregivers to be: in-depth, professionally handled, and universal to all agencies within the county. The results of this study hopes to help increase education and awareness about the disorder and how to aid these children within the CFS agency.

ACKNOWLEDGMENTS

I would like to use this section to thank those who have given me words of encouragements, guided me in the right direction, and have motivated me to do my best. I would like to thank Dr. Janet Chang, Sally Richter LCSW, fellow students of California State University, San Bernardino's School of Social Work, and some very good, edifying, and uplifting friends.

I would not have excelled in this program without the love, support, and honesty from my family. Thank you dad, Oguchi, mom, Chidinma, brothers, Ifeanyi and Nnaememka, sisters, Chikaodi and Chiamaka!!

Thank you to all of the participants of the research that took the time to share their insights and being candid; more importantly thank you for all of the hard work and love that you provide to these children who must overcome adversity and challenges in life that many of us take for granted.

I would like to thank God because He continues to open doors no man can open and close doors that no man can close.

DEDICATION

This study is dedicated to those that are not afraid to stand up for what is right, especially when it is on the behalf on someone else.

Hebrews 6:10 "For God is not unjust so as to overlook your work and the love that you have shown for his name in serving the saints, as you still do."

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CHAPTER ONE

INTRODUCTION

The introduction will begin with a problem statement that describes the population that will be the concentration of this research, the practice framework that affects this population's needs is focused on. The second part of this introduction will explain the purpose of the study and its implications for the social work practice in the child welfare system.

Problem Statement

Autism Spectrum Disorder, ASD, is a chronic condition that is complex to define because it contains an array of behavioral, social, and cognitive hindrances for individuals that all stem from neurological ailments. These disorders can affect communication, interpersonal relationships, and obsessive repeating behaviors; all of these areas are affected in different degrees for individuals. Individuals can range from low functioning, at one end of the spectrum, to high functioning individuals labeled as Asperger Syndrome (Child Trends, 2010). The levels range from mild to severe in: language development, short attention span, unresponsiveness to

verbal cues, and difficulty in expressing needs- as a result communicates is done through gestures rather than words (Lesser & Pope, 2007). These individuals prefer to spend their time alone; they have little interest in making friends, inappropriate laughing or giggling, little or no eye contact, difficulty interrelating with other children, and can be less responsive to social cues like smiles. There are degrees of over-activity and under activity in behavior; some individuals can be overly defiant while another could be overly passive and submissive. The behaviors of individuals who have ASD vary; some have no fear of danger, some have frequent tantrums for no apparent reasons, some seem to have an apparent lack of common sense, some have self injurious aggression or aggression towards others that many times are unprovoked (Blackwell & Niederhauser, 2003).

ASD is more prevalent in males than in females but there are no patterns of significance in race or socioeconomic status to indicate occurrence of this disease. Boys are four times more likely than girls to have ASD. In 2009, there were 423,773 children in foster care nationwide in the United States (Children's Bureau, 2009). Currently there are about 673,000 children with

ASD in the US (Child Trends, 2010). There are no data to show many children with ASD are in the foster care system.

All of these issues that the child undergoes directly affect their families. Parents are an important aspect in the development and safety of children with ASD. Parents advocate for the rights of their child. Parents closely watch the progress of their child in school and in social situation. Parents are also responsible for learning the intervention techniques needed for an autistic child's development. What happens to a child when their advocate, social support, and all around primary caregiver are gone? It is important to know that foster parents of children with ASD have an increased role in making sure the services that are provide for their autistic foster child are tailored to that child's needs and are promoting their safety and well-being.

It is important to study the level of participation of foster parents with autistic foster children because parents with a child who has special needs require additional monetary, social, educational, and psychological resources to be able to adequately care for

that child. Caregivers of children with ASD are more likely to feel isolated, more likely to have difficulties coping with life stressors, and many need additional information on how to deal with their autistic child (Ruffalo, Kuhn, & Evans, 2006). These parents require help in getting resources and maintaining support and stability for themselves as well as for their child. Individuals who parent children with ASD need to have skills in advocacy, knowledge in treatments for ASD, social support, social network systems, and training on how to handle their autistic child, and knowledge about the disorder. Many of the therapies and interventions that autistic children require, incorporates the use of caregivers and their families (Shannon, 2004). This research topic is important because there is a great deal of stress that comes with parenting a child with ASD. The challenges of getting services that the child is suppose to have; the need for reliable and competent service providers is important for these caregivers (Siklos & Kerns, 2006). The health needs of these caregivers are also affected when parenting a child with ASD (Benjak, Mavrincac, & Simetin, 2009). There is also familial stress that comes with caring for an autistic child; the family

dynamic is alter when additional attention is placed on a child who requires trips to therapy, extra attention for maladaptive and disruptive behavior (Finn, 1999; Ruffalo, Kuhn, & Evans, 2006).

The amount of resources to be able to take care of a child with ASD is not equal to what it takes to care for a typically functioning child. Currently in county social work practice, there are no explicit steps or regulations for county social workers to follow when placing a child with ASD into a foster home. There are no guidelines for the social worker to follow in training and equipping a foster parent to adequately care for a child with ASD while maintaining their own well-being.

Purpose of the Study

The purpose of this study was to examine how foster parents contributed to the wellness and permanency of an autistic foster child, to know if foster caregivers were adequately equipped to care for a child with ASD, and interviewed foster parents of children with ASD to get their opinions and perceptions about whether their autistic foster children were receiving adequate services and if these services increased the child's safety and

quality of life. The study tried to find out how foster parents participated in the development and treatment of an autistic foster child. The study found the roles that foster parents play in the development of a foster child with ASD. The study intended to know if foster caregivers were having their own needs met so that they can meet the needs of their autistic foster child. The study focused on knowing what kind of stressors foster parents dealt with having autistic foster child is in their care. This study then evaluated if autistic foster children were being given appropriate placement in the foster care system. The study aimed to find the current practices that are in place for social workers to aid foster caregivers with autistic foster children. Mainly focusing on the Department of Children and Family Services in San Bernardino, CA this research conducted a qualitative study.

The study employed a qualitative study to collect data. The data is collected is in the form of words, descriptions, narratives, and perspective opinions. The concept of quality and efficacy are not complex but they are subjective to the person that answered questions. This study hoped to have an inclusive view of how

autistic foster children and their foster parent gain a sense of normalcy and adjustability in life, so input from the respondents would lead to new topics and new ground to cover.

This study was both exploratory and descriptive. The purpose of the exploratory process was to explore the topic of ASD in the child welfare system and be familiar with the practice of how autistic children are managed in social services. The descriptive research aspect of this study described the situation and gave an accurate account of the role foster parents take caring for a child with ASD and how the county equips them to parent that child. This research gave a picture of how the child welfare system in San Bernardino handled ASD individuals through the eyes of foster parents.

The type of sampling that occurred was a non-probability sampling in a targeted population that is minute, limited, and highly specific. The sample criteria will be limited only to foster parents of foster children from age three to twenty-one, to show efficacy of the current practice and treatment of autistic foster children and its impact on the foster caregiver. No ethnicity was excluded to expectantly show that there

could be culturally or even racial biases on quality of services received, that same concept went to gender. The target pole was be limited to CFS San Bernardino and Riverside offices.

Significance of the Project for Social Work

In the field of social work, especially working with the foster children population, there are consequences and implications that arise when following the increasing diagnosis of children with ASD. The safety and quality of life for children with ASD in the foster system are a significant reason why this study is important. If children go without proper intervention and support; social skills and speech skills will not develop effectively or not develop at all. It should be the concern of society, the child welfare agency, the foster children, foster families, all social workers, and a personal responsibility to understand how foster children with ASD are coping with the services given to them and how foster parents are contributing to their well being. The danger of not properly giving services to foster children and youth with ASD can be damaging and life long; that not only affects the individual suffering from

ASD but the society. There are societal costs for caring for individuals with ASD that taxpayers are responsible for, through the regional centers of the communities and the foster care system; in addition to behavioral therapies in upbringing, extensive adult care, and the indirect cost to the public due to those individuals not being in the productive workforce (Child Trends, 2010).

This study aimed to contribute to the social work practice by assessing if appropriate training is needed for foster parents who will have an autistic child in their care. This study hoped to show that it would be beneficial to implement specialized social workers and foster parents unit who will be prepared to handle this special population. This study aimed to establish policy requiring that a foster parent be properly trained and educated on ASD to foster that targeted population. This study showed whether autistic foster children were getting their needs met and how CFS, and foster parent involvement aided to the wellness and safety of autistic foster children. It was also the hope of this study that its results could help social workers make knowledgeable placement decisions and make compatible placements for autistic children.

Research Question: From the perspective of foster caregivers, how do ASD centered services affect the quality of life for children with ASD, what roles do foster parents play in the permanency and well being of an autistic foster child, and how does having a foster child with ASD affect the life of a foster caregiver?

CHAPTER TWO

LITERATURE REVIEW

Introduction

Chapter Two contains literature that is pertinent to the research being conducted. This chapter is separated into literature about types of services that autistic children need, characteristics that make for an ideal foster parent to a child with special needs, assessing the needs of foster parents of foster children with autistic spectrum disorder, foster parents' roles and responsibilities in caring for an autistic child, challenges of receiving adequate services for foster children with special needs, and finally a section on theories that are guided the concepts of children with ASD and how the kind of services they are receiving promotes their wellness and safety.

Types of Services that Autistic Children Need

Blackwell and Niederhauser (2003) detailed the kinds of services and therapies that children with ASD need as intervention and coping instruments. They indicated that early diagnosis and intervention could make for a better outcome for children with ASD. According to Blackwell and

Niederhauser (2003), part of an adequate intervention should include parent education, parental support, structured social interaction play, school based education, behavior management, medical treatment, and respite. They emphasized the need of adequate resources and competent services. Blackwell and Niederhauser (2003) introduced the Individuals with Disabilities Act of 1990 that explained the right to services for school aged children and preschool aged children that include speech-language therapy, occupational therapy, and physical therapy. This study was dedicated to finding out whether these kinds of services are being practiced in the social work area, from the perspective of the foster parents.

A particular popular service for children with ASD receive is done by Board Certified Behavior Analysts (BCBAs) using scientifically validated Applied Behavior Analysis (ABA) treatment. Schreck and Mazur (2008) performed a quantitative study tried to find whether these BCBAs were using the scientifically validated research in ABA treatment for children with ASD, or if their interventions were based on unproven trends. The article helped guide this research project in finding out

if the foster parents are able to distinguish between the qualities of services the foster children are receiving or if they have a say in the type of treatments the children get.

McConachie and Robinson (2006) conducted an analytical study of a 2-year follow up of families in an evaluation group course for 56 children and their parents. The study attempted to understand the quality of specific services that are given to children with ASD in the general population. The researchers concluded that the current services and quality of care for children with ASD and their families have are no where close to meeting the standards set for Autistic Spectrum Disorders Good Practice Guidance (GPG) (2002) and the National Autism Plan for Children (NAP-C) (2003) (McConachie & Robinson, 2006). NAP-C (2003) recommended that the services provided to children with ASD be multi-disciplinary and involve different types of agencies consisted of professional with specialist skilled in ASD; which includes a key worker, speech therapist and language therapist, and a social worker to support the family. The last recommendation that the study examined was that preschool children have entry to

autism exclusive program for around 15 hours a week with purposely trained service providers (McConachie & Robinson, 2006). The researchers found that access to a skilled ASD-trained staff; regular visits from professional to ensure that the families used newly acquired skills are being implemented in the home to promote the child's development of skill in certain key areas. Granted the research study, NAP-C (2003) and the GPG (2002) were done in England, their content and concerns are universal when dealing with ASD children and the kind of challenges to services they receive.

Characteristics That Make for an Ideal Foster Parent to a Child with Special Needs

Rhodes, Cox, and Coakley (2006) conducted a quantitative study to find out why certain people become foster parents of children with special needs and how that reason related to foster home operations. They found that families that were more willing to foster children and teenagers with special needs have parented more kinds of children with special needs, have had more placements, are less likely to quit, and usually have been fostering children for a significant amount of time. According to Rhodes et al. (2006), there was a benefit to be willing

to foster children with special needs because the parents were able to have more placements at a faster rate. The findings concluded that foster parents who were more willing to deal with children with special needs get more placements, more placements equals more money.

The case study of a specialized foster home in Finland for individuals with developmental disabilities, conducted by Szymanski and Seppala (1995), showed two key aspects for successful placement and stability for foster children with developmental disabilities. These foster caregivers were treated like employees of the social service agency and that their care giving status was an occupation. These foster caregivers were paid salaries as well as given reimbursements for any expenses that they provided for their foster children. Szymanski & Seppala (1995) discovered that there was a selection process between foster parent and foster child to make sure both are compatible, ensuring stability of the placement. Part of this research project is to find out whether something like this is occurring, are children with ASD being specially placed in adequate placements? It raises aspects of how the child welfare system in California recruits foster parents and how they retain them to

ensure safety and quality of life for foster children with special needs.

Assessing the Needs of Foster Parents of Foster Children with Autistic Spectrum Disorder

According to Brown, Mayhew, and Moraes (2005), foster parents who dealt with foster children with special needs have a greater need for additional resources and have more challenges to deal with than foster parents with typically functioning children- all with the added stress of having to make a family function in a normative fashion. Foster parents who had foster children with disabilities focused on the need for training, increased communication with professionals, counseling services, respite care, peer encouragement, and community resources. In the study, the researchers indicated that specialized training on taking care of a foster child with a particular disability would increase the confidence in the foster parent's ability to help the child (Burry as cited in Brown, Mayhew & Moraes, 2005). Foster parents of children with special needs found that having a social worker who was skilled, committed, warm, reliable, listened, and competent in advocacy matters, with increased communication throughout the placement

period was very important (Hudson & Levasseur, 2002; Jivanjee, 1999 Mason & Linsk, 2002 O'Hara, 1986 as cited in Brown, Mayhew & Moraes, 2005). Additional financial resources are also a challenge when fostering children with disabilities. Foster parents indicated that transportation services were needed, and specific education programs were found to be beneficial to the foster parents.

Better communication with teachers of their foster children, having a good relationship with the child's social worker, more information about child's history and medical information, and more advocacies in dealing with the medical aspect of the child's life were very important to the foster parents that were interviewed. Foster parents indicated that therapy for the whole family would be beneficial to the wellness of special needs foster children. Parents interviewed, stated that having support for themselves as well as the child in transitional services was very important (Brown, Mayhew, & Moraes, 2005).

Kern and Siklos (2006) found in their qualitative study, that foster parents emotional, physical, and social needs must be assessed; especially when these parents

were dealing with autistic children who required additional attention, energy, and resources than children of other special needs and typically developing children. The findings showed that parents with special needs children needed social support from spouse, family, friends to the necessity of free time, support from the community in which they reside, professional help, availability of services and access to them, respite care, education and advocacy (Kerns & Siklos, 2006). Parents of children with ASD reported that stress and aggravation came from the lack of services for their children in the realm of early intervention and insufficient communication between the service providers. Parents of the study also reported that part of their stress came from not being able to socially interact with their autistic child. The study also found that the important needs that parents with autistic children had were for reliable therapy for their children and service providers with extensive knowledge about ASD. Parents of children with ASD also reported having increased level of stress due to the child's externalizing repetitive behavior (Kerns & Siklos, 2006). The study also found that professionals who work with the family must keep in

mind the amount of stress families with ASD children go through. The final suggestion of the study was to focus on diagnosing and treating the child; they also emphasized needed focus on helping the family cope with the disorder.

A focus of this research would be to know how the well being of foster parents affects their ability to adequately care for foster children with ASD. In a quantitative study concerning the self-perceived health of parents with autistic children with ASD versus parents with non-disabled children, researchers Benjak, Mavrinac and Šimetin (2009) indicated that in all the aspects of health, excluding physical health, parents of children with ASD had considerably inferior self-professed health than parents of non-disabled children. The article speculated that providing care for children who required a high level of long-term care became arduous and impacted the mental health of the parents. The purposes of this research was important to look at the health of these parents because their quality of life directly impacts the quality of life of these children that depend on them.

Foster Parents' Roles and Responsibilities in Caring for an Autistic Child

Part of being a foster parent of a child with special needs is being able to be involved in the special education process. There is an increased need for parental advocacy and participation to ensure that a child with special needs does not fall behind (Geenen & Powers, 2006). A study by Geenen and Powers (2006) showed that having the status of being in foster care and being placed in special education increased academic obstacles and more difficulties. The study found that 30 to 40 percent of foster care youth were in special education, and the needs of these youth were often ignored because the primary focus was the reunification status of the child or for their placement protection. The study also found that the primary reason that children with special needs usually perform well in school was because of advocates (usually biological parents), and usually many of these foster children do not have educational advocates (Geenen & Powers, 2006). Geenen and Powers (2006) suggested that training be required and offered to foster parents and educational surrogates for youth with

special education services so that they can be their advocates.

Paztor, Hollinger, Inkelas, and Halston (2006) affirmed that in general, children within foster care have health, mental health, dental, and overall care but the system fails to hit the core issues concerning the abused, neglected or emotionally mistreated past. The study concluded that having ASD and being placed in the foster care system increased the vulnerability of a child who was not being treated for their ASD and the reason why they were placed in foster care system. They reiterated that foster parents were crucial in the successful distribution of sufficient health care to foster children (Paztor et al., 2006). Paztor et al. (2006) conducted a national survey for *Child Welfare* in 2001, that thirty seven percent of agencies that participated in the study said that they require no training on healthcare issues for foster caregivers (Risley-Curtiss & Kronenfeld as cited in Paztor et al. 2006). They found that there were role limitations of being a foster parent; meaning that they had no educational or medical rights of their foster child; this

affected their roles to help children get access for their health care needs (Paztor et al., 2006).

Paztor et al. (2006) speculated that if staff and foster parent responsibilities were explicit, written down and agreed upon and if their relationship were more active and engaging that could help a foster child tremendously. Increased interagency exchange and relationship would improve a child's access to health and mental health services. The authors also suggested that further research on the part of the foster parent to educate self on the problems the foster children were dealing with and the increased use of kinship care were becoming increasingly important (Paztor et al., 2006).

Challenges of Receiving Adequate Services for Foster Children with Special Needs

Diaz, Edwards, Neal, Elbirt, Rapport, Kierstead, and Colon (2004), of The Children's Aid Society in New York, conducted a program evaluation that showed that extensive training for foster parents in medical education for a child's particular condition is a must. The program evaluation concluded that being extensively trained helped the foster parent train the child's natural parents to make for smoother reunifications. The study

also stated that foster parents with special needs children should be more compensated than other foster parents due to their time and energy that is greatly needed for the kind of foster parents they have.

Shannon (2004) studied perceptions of obstacles to family-centered services, using twenty-two family members and twenty service providers in a particular center, with questionnaires. Both families and professionals reported barriers in insurance and the type of services available through them. The article stressed that a family who needs services must stay motivated and makes a point to always keep it a priority- which is hard for families with more than one child, to not drop out of programs. Shannon (2004) also concluded that professionals also need to help empower families to know what their rights are and how to train the families to take care of their child and be an integral part in the intervention process.

Pecora, Jensen, Romanelli, Jackson, and Ortiz (2009) stated that in general, children in the foster care system have higher behavioral, developmental, and emotional problems, than children not in the foster care system. The concern of the study was that children in the

foster care system had inadequate access to high-quality mental health services, and it was troubling because forty to eighty percent of foster youth show significant behavioral or mental health issues that requires interventions of elevated quality.

Three out of four foster children, who have been documented to need mental health services, generally did not receive it within the first 12 months of their placement. They also indicated that the likelihood of a child being referred to mental health services was dependent on their racial/ethnic background, type of maltreatment, age, and type of placement. African Americans were less likely to have services for mental health because of racial biases in the assessment period and referral procedures (Pecora et al., 2009). Many times it is up to the foster family/parent and social worker to advocate for the child to receive these services, and if neither party believed that there is a problem when there is, many times the child does not receive help.

Theories Guiding Conceptualization

There are a few theories that helped to guide this study in the form of how the services that are being provided to autistic foster children.

The therapies that autistic individuals generally receive are based from the behavioral theory. According to Lesser and Pope (2007) behavioral theory is based on classical, operant, and social learning modes. To treat an individual using behavioral theory there needs to be reinforcement as an incentive system, when a desired behavior is displayed then there is a reward for the individual. Behavioral theory incorporates social skills training, which is essential for a child who suffers from ASD, and assertiveness training. Rational, cognitive behavioral and developmental theories are all major theoretical perspectives of play therapy (Lesser & Pope, 2007). Many of the services provided to children with ASD incorporates play therapy as a way for children to learn interpersonal social skills, role playing, rational play, cognitive behavioral play, and developmental play. The goal is that the child will learn how to interact appropriately with his or her environment through playing with a therapist or development teacher.

Lesser and Pope (2007) defined the social systems theory as an individual or a group of people who operate interdependently of each other to complete similar goals over a period of time. To be able to work with an individual a practitioner needs to see human behavior through a perspective that allows evaluation of the client as a person, a member of the family, and a member of the community. There needs to be an understanding of an individual's biological operation, psychological operation, and sociocultural operation as interacting forces, a disorder in one aspect affects the whole system (Wapner & Demick, 1998, 1999 as cited in Lesser & Pope, 2007). A social worker practitioner must know the psychosocial assessment process to understand a client's problem to best figure out which part of a person's system is in most need of intervention, also called focal system (Hollis, 1972 as cited in Lesser & Pope, 2007). This research aimed to determine whether a Social Service Practitioner in the county takes into account the interacting multifaceted forces in the life of an autistic foster child and offers services that mediate those forces.

Psychoeducation gives an all around basic kind of intervention that tries to give information to families going through problems with a single individual. This type of model educates so that have families create skills for understanding and coping with a family member that is troubled- these issues are usually life long and greatly distress the family (Rolland, 2003 as cited in Goldenberg & Goldenberg, 2008). According to Goldenberg and Goldenberg (2008) this model relies on the traditional and modern experimental techniques to create reproducible interventions. The mission of the psychoeducational theory is to build and maintain a therapist and family partnership that is supportive and collaborative. The models within psychoeducation include stress management, skills building techniques that help families to increase their sense of control and retain their strength and resiliency. This model is supportive and seeks to enhance family relationships. The interventions in this model are a step-by-step process that is reproducible which is great for practitioners and families to follow. Because an individual's mental illness is not isolated to that individual but affects an entire family, teaching the affected family members how

to gain mental health, welfare, and medical services is a part of this model (Lefley, 1996 as cited in Goldenberg & Goldenberg, 2008). This research aimed to see if this psychoeducation model has been incorporated in service delivery for families and foster parents who must: care for these children, understand the disorder of an autistic child and must be active in helping maintain the child's stability. The foster parents and their families must be trained to do all of those activities so that they can too cope with this child's disorder.

Summary

The literature that was presented in this research did convey that parents and foster parents have challenges when trying to help children that have developmental disabilities. However, there were no literature and studies that have examined the problems that foster parents have with dealing with foster children with ASD and the services that are provided to them. This study did not encounter literature that talked about the effectiveness of services provided to autistic foster children, from any population's perspective, let

alone the foster parents. This research project attempted to fill in the gaps.

CHAPTER THREE

METHODS

Introduction

This section will present the methods that will be used in conducting this study. The study's design, sampling, interview instrument, data collection, procedures, and protection of human subjects will be described in this chapter study. Then this chapter will end with the qualitative data analysis and a summary.

Study Design

The purpose of the study was to examine foster parents' perceptions of services that are rendered to their foster children with autism and how these services affect the children's safety and quality of life. The study used a qualitative design, with in-depth face-to-face and telephone interviews with nine foster parents of children diagnosed with ASD in child welfare agencies in San Bernardino and Riverside County. Face-to-face and telephone interviews was used to elicit a comprehensive insight of the experiences foster parents have with their autistic foster children. This study hoped to know 1) demography of foster parent and the

foster placement, 2) demography of the autistic foster child, 3) caregiver's prior experience with Autistic foster individuals, 4) inquiries on training or education of Autism Spectrum Disorder, 5) the challenges of raising a foster child with ASD 6) foster parent perception of support from social workers 7) foster parent's thoughts and challenges concerning the services that are provided to autistic foster child 8) foster parent's thought and challenges concerning the autistic foster child. Using the qualitative method helped to cross case comparisons and analysis in this study; these face-to-face and telephone interviews had open ended questions that when answered yielded common themes and showed inconsistencies between each participant. Further more, the open ended lead to follow up questions that created new topics and focuses for the study. The qualitative methods were used for this study because the targeted population of this study was relatively small; however as a consequence, the specialized nature of this study limited its generality. The qualitative method was good for this research because it helped to understand the foster caregivers' experiences and their viewpoint in the way child welfare handles autistic foster children and assists the foster

parents. The face-to-face and telephone interviews were done in convenient and naturalistic setting for the participant. They were done in the participants' home or over the phone so that they could be relaxed able to further confide.

Sampling

The sample of the study consisted of nine foster parents who were fostering children diagnosed with ASD in placements such as licensed county foster homes, family foster agencies, small foster homes and kinship placements. Convenience sampling was used to recruit participants for this study. The interviewer visited the foster parents in their homes in San Bernardino County and over the phone. The Legislative and Research Department of San Bernardino Children and Family Services was contacted for a list of children in the county that have been diagnosed with ASD, with information about how to reach their care providers. The care providers were first contacted with a letter asking them to participate in the research (Please see Appendix D and Appendix E for the sample of the letter that was given to the foster parents). They were then called at a later time to

schedule a time to be interviewed. The participants were assured that the identity of the child and their identity would be kept confidential and that the child would not be interviewed as a part of this study. The challenge with this sampling method was the availability of participants to interview; there was an insufficient number of foster parents who have foster children with ASD in the county system (a total of sixteen cases), and only nine people who wanted to participate in the study.

Data Collection and Instruments

This study collected data through face-to-face and telephone interviews with foster parents of children diagnosed with ASD. Participants of this study were asked for permission to be tape recorded for the interview, two declined to be tape-recorded. The interview guide consisted of approximately twenty questions and follow up questions within the interview. The questions were constructed to be open ended in order to elicit the detailed information from the foster parents. Participants were asked questions regarding their personal experiences, challenges, and attitudes with fostering their autistic children, and their opinions on

how their actions have contributed to the child's development. The questions were sequenced in the following order: the demography of the foster parent and autistic foster child, previous experience with children with ASD, foster parent's perception of support, and foster parent's perception of effectiveness with services provided to their autistic foster child. The questions covered areas regarding: foster parent's self-assessment of involvement, their view of support from the social worker, and the competency level of the foster parent. The goal of the questions was to find out how the services provided to autistic foster children promote their quality of life. Great care was taken into protecting the interview guide; the researcher put the interview contents into a locked drawer so that access to the information was limited to the researchers in this study. (Please see Appendix A, for a list of questions on the interview schedule).

Procedures

Request was granted to conduct the study for Children and Family Services in San Bernardino, CA in November 2010. In the month of January 2011, the

Legislative and Research Department of Children and Family Services was contacted to request names of foster parents with foster children with ASD. During the month of January 2011 to March 2011, the interviewer contacted the foster parents to solicit their participation in the study. From January 2011 to March 2011, the interviewer interviewed nine foster parents that were located all throughout San Bernardino County and over the phone. Through this three-month period, the interviews were conducted at a rate of one to two sessions a week. The interviews were around twenty questions, not including follow up questions. The interviews were approximately half an hour to forty-five minutes long. Subsequent to the interviews, the interviewer will asked permission to contact the foster parents at a later time for more information that could be needed. Completing the interviews, data analysis, and amalgamation of the material was organized during April 2011 to May 2011.

Protection of Human Subjects

Every imaginable attempt was made to protect participant's identity and protect the confidentiality of the foster parents that were interviewed, as well as the

identity of the autistic foster children. The informed consent explained to the participants the purpose of the study, the benefit of participating in the study, the confidentiality process, the potential risks of participating in the study, where the results of the study will be located, and who to contact if they have any questions regarding the study. (Please see Appendix B, for the informed consent form). After the interview process, participants were debriefed about the intention of the study. (Please see Appendix C, for the debriefing statement). There was not a moment during the interview process and any other period of this study that a participant, or their foster child, was identified with the data collected. An arbitrary number between one and nine were given to each interview to correspond with the notes. As a result no connection was made to the participant's identity and information that would be gained through that interview; all of this was done in order to maintain the privacy of the interviewees. The interviewees were given an informed consent form to sign and date before the interview was carried out. The data was also kept in a way that the information that was gained through the interviews was not available to

anyone. The raw data, the interview notes and tapes, was destroyed after the study was completed.

Data Analysis

This study employed qualitative data analysis techniques. Interviews were tape-recorded. The study prepared the data collected into transcript form by typing the words from the interview verbatim into word processing software and notes were typed from interviews not tape recorded. Great care was taken to protect the participants' confidentiality so that the ethical issues in the research project were decreased. The transcript was formatted for analysis for flow of information. A journal was used to keep all of the coding and formatting of data analysis. After putting data into transcript form, the next step was to establish a plan for data analysis (Grinnell & Unrau, 2008). Here, the researcher previewed the transcripts to be familiar with its contents; a journal was used to write notes identifying meaning units and establish definitions of categories that appeared from the interviews. The next step in the qualitative analysis was coding for the meaning units to fit them into categories then assigned codes to the

categories. There was a second level of coding that identified comparisons and distinctions between the categories to make relationships. Then there was an interpretation of the data and theory building from the themes that immerge by a constructed diagram and matrix that described the major categories (Grinnell & Unrau, 2008).

In this qualitative analysis the last step was to evaluate the trustworthiness of the results from the study. The first step in this process was to ensure consistency by member checking the data with the research participants. The way to control biases and preconceptions was to show that the conclusions of this study were shaped by data rather than the researchers' bias (Grinnell & Unrau, 2008). This stage also included making sure the researchers' reliability had not been compromised in the study. This was done by making sure the researcher had sufficient experience, adequate training, accurate recording of the journal entries, and that the procedures were followed precisely.

Summary

This chapter was created to give an overview of the methods that will be used in this study. The research method that was used for data collection was an interview schedule. The interviewees were chosen from the Children and Family Services Department in all of San Bernardino and Riverside County. All of the participants were foster parents of children with ASD in the foster care system; the participants varied in: marital status, ethnicity, and foster parenting experience. The interviews targeted areas of past experience or training of children with ASD, the foster parent's perception of social support, and their attitudes on the efficacy of the services provided to their autistic foster child in promoting the child's safety and wellbeing. A qualitative analysis was conducted after the interviews to analyze the collected data.

CHAPTER FOUR

RESULTS

Introduction

Chapter four describes the data that was collected from interviews. This chapter summarizes the findings that have been categorized in the following order: demographics of foster children, demographics of foster parents, challenges of raising a foster child with Autism Spectrum Disorder, previous experience and training with children with Autism Spectrum Disorder, perception of support from foster child's County Social Worker, and services of autistic foster child. At the end of the chapter there will be a summary about the chapter.

Presentation of the Findings

Demographics of Foster Children

The participants were asked questions regarding the characteristics of their autistic foster children. The first question was regarding the age of the foster child. The age ranges of the children were from as young as 3-5 (5 children, 56%) and 11-13 (2 children, 22%) then to as old as 17-20 (2 children, 22%). The average age of the children in this study was 9 years old. The great

majority the children in this research were male; seven out of the nine participants, 78%, were male and two, 22%, were female. In regards to the ethnicity of the children, four of the children (44%) were African American/Black, three were white (33%) and one Hispanic (11%) autistic foster child. The average number of years the foster children have been living with their foster parent was 2.72 years. The range of the years were broken down as followed: .5-1 years (2 participants, 22%), 2-3.5 years (5 participants, 56%), and 4-5 years (2 participants, 22%). In terms of placement type the children were in; five of the children were in a relative placement foster home, two were placed in a county licensed foster home, one in a small family foster home, and one in a foster family agency.

Out of the nine participants two of the participants wanted to adopt the child in their care, six were not going to adopt, and one was not sure if they wanted to adopt at that time of the interview. Out of the participants who stated that they would not like to adopt the child, four of the participants reported that their child was to be reunified with their biological parent in the near future and the other two feared losing adequate

and comprehensive services for the child if they were to adopt the child. The participants were then asked how the decision to adopt or not to adopt has influenced the relationship with their autistic foster child. The two that wanted to adopt the child stated that they were more determined to see the child "get better," receive all of the services that the county could provide, and were more outspoken in their advocacy. The other participants stated that there was no change in the relationship. One participant stated, "I have always seen them as my kids" (Participant #4, Personal Interview, February 2011).

Several foster parents stated that there was always an understanding that the child would be reunifying with their biological parent. For example, one participant said, "They've always known they were going back home. The dad already has custody of them, he is just now looking for a place to live and take back his kids" (Participant # 1, Personal Interview, February 2011).

Demographics of Foster Parents

The foster parents were then asked questions about themselves. The average age of the participants was 56 years old. Eight out of the nine participants interviewed were female and one male. Seven of the participants

described themselves as African American/Black, one self identified as white, and one self identified as Hispanic. The marital status of the caregivers interviewed is as followed: six were married, one in a long time partnership, one divorced, and one single. The employment status is as followed: six were full-time caregivers (one described herself as disabled, one a student) one was a business owner, one was a pastor, and one was a full time nurse. They were asked how long they have been a foster parent; the average of the years of experience was about eight years. The range of the years are broken down as followed: 1-4 years of foster care experience (4 participants), 5-8 years (3 participants), 16 years (1 participant), and 30 years (1 participant). Out of the nine participants, five of them stated that it was their first time being a foster parent.

When the parents were then asked if they had any biological children, seven out of the nine reported that they had biological children. Three out of the seven participants had three biological children, out of the seven participants, one had a biological child, one had four biological children, and one had five biological children. Out of the seven participants who stated that

they had biological children in the home, three of them stated that they had a child that lived in the home. When the participants were then asked if any of their biological children had special needs, two out of the seven said yes, one participant had a nineteen year old son who was medically fragile and another had two children who were autistic. When the participants were then asked if there were other foster children in the home, seven out of the nine participants (78%) indicated that they had other foster children in the home. Six out of the seven (86%) that stated there were other foster children in the home, elaborated that the other children were the siblings of the autistic child in their care and one participant had other children in the home that she previously adopted. The participants were then asked if any of these other foster children had special needs; two said yes. One participant was caring for an autistic child and a legally blind sibling and diagnosed with Autism Spectrum Disorder (ASD). The other participant was a caretaker to two brothers who had ASD.

Challenges of Raising a Foster Child with Autistic Spectrum Disorder

The participants were asked their opinion on what they considered their autistic foster child's level of functioning and if they knew the level of severity their child's disorder was. Out of the nine participants; two (22%) were considered high functioning, two (22%) were considered middle level of functioning, five (71%) were considered severely autistic, and one participant's functioning level could not be determined. One participant stated that her autistic foster child was "severely autistic and there is no way of knowing right now just how he will be able to function as he gets older, he cannot hold a fork to feed himself and still wears a diaper at the age of 20" (Participant #5, Personal Interview, February 2011).

The participants were encouraged to talk about the challenges that come with dealing with their autistic foster child in the home. Several of the participants stated that most of the challenges were the child's destructive behaviors. One participant stated, "[child] is so destructive in the house, he is so violent and combative with his sibling, he will hit them and laugh

and forget about trying to discipline him, discipline is a joke to him" (Participant #2, Personal Interview, February 2011). Many of the challenges were similar for most of the foster parents. The main challenge was the added attention and time it took to care for, groom and parent their autistic child; time and attention that took away from other children who required much less.

Some of the challenges that were cited by the participants include: learning about the services that the child needs, the child being incapable of doing any life skills independently so the caregiver must constantly be with child to do basic living skills like brushing teeth, using bathroom, feeding, put on clothes and others. Other challenges reported by the parents included: the child's inability to get along with other people in the home and in school, acts of aggression and disruption in the home and in school, and learning deficiencies. Many of them have issues in school and have been kicked out of school because of their violent behaviors and put into special county licensed school. Many of these children cannot sit still and have low attention spans. Another major issue was the child not able to socialize properly, one participant stated "he

has a hard time making friends because he does not know how to relate to the children around him and often times he gets so teased that I won't let him play with the neighborhood kids outside" (Participant #1, Personal Interview, February 2011). Other issues include: having a hard time eating, communicating, throwing tantrums, repetitive disruptive behaviors, and lack of awareness in the environment so child is constant danger of hurting themselves.

There is a challenge of always needing to be consistent with the child so that the child can have structure, the parents must often repeat basic commands several times until the child can understand and act on the command. For example, one participant said,

he had to be taught how to eat with a fork correctly. It was hard trying to teach him because you have to be consistent with him, doing the same thing with him every single day, trying to get him to do it. After about a year now, we have been working on how to put a belt on correctly, but he still has problems trying to tightened the belt so we have problems and have to do it over and over and

over again. (Participant #5, Personal Interview, February 2011)

Another participant stated that,

Anyone who wants to take care of an autistic child must realize that it is more involved than having to take care of a child with no disabilities. It is more time consuming and you have to be more consistent with the child so that the child can understand their boundaries. (Participant #3, Personal Interview, February 2011)

Another challenge cited by one foster parent was not considered was the issue of older children not being able to take care of their most basic grooming skills. One participant articulates the challenge,

other people would say that it is the disabilities and the bed wetting. But it is her cycle that is of concern to me right now, for her to be as old as she is and not being able to change herself, to me that wasn't a challenge in having to raise her, to me it is more of a routine thing. (Participant #6, Personal Interview, February 2011)

Many of the parents see themselves as a protector for the child because of the child's poor communication

skills. The children are often in need of someone to stand up for them when it comes to other children in or out of the home. One participant stated

he looks to me for everything, you know for food and with other people. Just a certain demeanor and he looks to me to protect. I feel like I have to stand up for him with other people when they say that I am pretty much spoiling him and it is true that I am kind of spoiling him but he needs that extra attention that the other children don't need and I have to remind them of it and tell them they have to be patient with him. (Participant #4, Personal Interview, February 2011)

The participants were asked what kept them from having the child transferred to another home. All of the relative caregivers stated that it was because the child was a family member and they would not abandon them. Others were waiting for the child to reunify with their family. Six out of the nine (67%) stated that they feared that the child would not receive the same level of attention and care if they were to be put into another placement. One participant stated,

People take so much advantage of children like her and I wouldn't want that to happen to her. I would like to see that she gets proper services and that she does well. I think that is my biggest fear, if something were to happen to me, who will take the responsibility of taking care of her, I would like to know that somebody out there would be able to take care of her, that is what I would want most for her. (Participant #4, Personal Interview, February 2011)

The caregivers were then asked to describe the communication with their autistic foster child. The responses varied based on the level of severity the child's autism was and the age of the child. Three out of the nine participants (33%) stated that there was good communication; they stated that for the most part the child can communicate what he or she desires well and can understand basic and complex demands. Four out of the nine participants (44%) answered that communication with their autistic child very was limited. They stated that they would many times have to repeat themselves until the child could know what was happening, with the help of sign language and pointing. The child with limited to no

cognition of words often relied on familiarity and consistency of the parent to be able to communicate desires to the caregiver. One participant stated, "he doesn't talk and he doesn't point but I know what he wants. If he goes to the kitchen I know what food he wants but he is not looking at anything but I know what he wants" (Participant #4, Personal Interview, February 2011). Two out of the nine answered that there was no communication; the use of sign language was very limited because the child cognitive functioning was severely compromised; the way that communication is done is through "stomping, yelling and making noises."

Previous Experience and Training with Children with Autistic Spectrum Disorder

When the participants were asked if they had ever been a foster parent or parent to a child with autism or a child with special needs before; eight out of the nine (89%) participants stated that they had never been a parent or a foster parent to children with ASD and four out of the nine (4%) participants stated that they had experience with special needs children. The one participant with experience parenting an autistic child had two biological high functioning autistic children.

However her previous experience did not prepare her for how severe her foster child was; she stated,

I thought that I had to do it all over again with trying to help him. It was easier with my own kids because I have worked with them from when they were babies, it was okay and it wasn't hard to help them do things. With him, his mom did not teach him anything so he never learned how to do anything; she felt that it was better for her to do things herself instead of teaching him how to do things, so that made it hard for me when he came here. It was like dealing with a little baby all over again.

(Participant #5, Personal Interview, February 2011)

One participant owned a daycare center in the past had some experience with children with special needs. One participant stated that she had foster children who were alcohol/drug exposed, diagnosed ADHD, blind children, children with psychological disorders, and medically fragile children. Another participant stated she had experience with counseling families with special needs children in his church. Another participant was a pediatric nurse for twenty-five years dealing with

medically high risk children and special needs children in the hospital setting.

The participants were then asked their definition of ASD based on what they have learned in research and in their classes. Initially, many of the participants had a hard time coming up with definitions, they were then encouraged to give an example based on the experiences they have had with their autistic foster child. The responses varied based on their understanding. Many of them describe ASD as a detachment from the child's mind and the reality around them. One participant state, "the struggle between getting a grasp of what is real and what is not" (Participant #7, Personal Interview, March 2011). Others described the disorder as a learning disability. For the most part, many of the responses were similar: child being overly fixated on certain object or subjects, the joys of the familiarity, the need of repetitious behaviors, problems with communication and socializing, the child prefers to be by themselves, the child can't be touched, child doesn't like loud noises, the isolation of themselves with other people, wanting to be in "their own little world."

One participant stated,

I think that they are not processing, their brains aren't processing the way we think they are suppose to process. Um and um that's what I think, I have tried to study and I try to get different opinions and like every case is different. I think that he is far away and talking and there are so many things going on in his mind and he cannot compute everything that is going on around him. (Participant #2, Personal Interview, February 2011)

Another participant saw it as a gift,

I think that autism is some kind of mental challenge where a child is not able to work in the capacity that he could work in his level. I know it is dealing with the brain, where the child is not able to comprehend and be as smart as they can be. But I feel like they have gifts, I believe that when anyone is lacking in one area there could be something else in their brain that becomes more powerful. (Participant #6, Personal Interview, February 2011)

The participants were then asked if they have received any training on ASD and how to handle their

autistic foster child. Five out of the nine (56%) participants interviewed stated that they have had some kind of training or information given to them by a mental health or foster system agency. Seven out of nine (78%) participants were required to take classes to keep their license for their homes or to have their home cleared. The participants were also asked to describe the kind of training they have received. Two of the participants took some classes at the junior college level in addition to the classes they have already taken. Several of the participants got some education from the Inland Regional Center (IRC) or foster placement agencies. One participant stated that she just received paperwork about ASD from the Department of Behavioral Health. Four participants were required to take weekly classes on different special needs. One participant stated,

The classes that we take and took help us to gave us the assurance that we needed as far as experience. As far as changing them, dealing with all of their different problems. It was many classes, classes that dealt with medically fragile children or behavioral classes with the training we had to take,

and kinship care that gave additional support.

(Participant #7, Personal Interview, March 2011)

Overall the type of training these participants received was in the education of the disorder.

The participants were then asked if they felt like they needed some type of training or if they would be open to some kind of training. All of the participants stated that they would like they needed additional training and would be very receptive to the training. Participants wanted training in how to comfort their upset autistic child, to learn how to be stern and firm with the child, how to better discipline the child, how to be more confident in their parenting ability, increased training in sign language and different ways to communicate with the child, how to handle disruptive behavior, teaching different techniques on motivation, and an overall increased knowledge on the disorder. One participant stated,

I think that having a group type thing where you have parents that bring the children and it be something that they could be involved with other people that have the same situation. Inviting the

community of you know of others that share.

(Participant #5, Personal Interview, February 2011)

The participants were then asked the ways that they were independently learning and having a better understanding of autism. Three out of the nine (33%) participants stated that they had been actively learning about ASD on their own. One participant started to take courses at the local junior college on child psychology. All three of them research information online and read books on ASD. Two out of the three participants went to seminars that were autism themed. One of them actively takes advice from other foster parents with autistic foster children. One participant stated,

I also had taken some classes as child care provider but I took child development over at valley maybe about two years ago. So I did get a lot of information and I studied autism in the classes. Yeah, so I have taken three or four classes at Valley about it and I did other little things when I was doing volunteer work, working with children at a child care facility. With the owner of that business she would take me out to some of those classes and that was one of the ways. Because I have always been

interested in children and I always want to help them so. (Participant #2, Personal Interview, February 2011)

The other participants that did not independently learn about ASD stated that they did not have enough time and enough energy on top of their current responsibilities.

Perception of Support from Foster Child's County Social Worker

The participants were then asked to reflect on the relationship they had with their autistic foster child's social worker. The responses that were given varied greatly; there were no uniformed or similar answers among the participants. Six out of the nine (67%) participants had face to face contact with their child's social worker once a month and talked to them over the phone roughly one to two times a month. Three out of the nine (33%) saw their social worker about once every six months and talked to the social worker about once a month over the phone. Five participants (56%) were satisfied with the support and the quality of direct service given to the child and the caregiver. Most of the participants stated that they thought that the social worker "is a good person" and that they were sure that they social worker

was doing what they could for the child to get their services. Most of the time the caregivers were occupied with debriefing the social worker on what is going on in child's life than what could be happening with the child's services. For example, one participant stated, "so um once we do talk, as you can see I am a talker, then I bring her up to date on pretty much everything I try my best to let her know when things are going on" (Participant #2, Personal Interview, February 2011). Many of the caregivers articulated that their social worker was busy and usually have a hard time being able to get paperwork done on time and their lack of being attentive to the increased needs of the child. One participant felt fully supported and satisfied with their child's social worker, she stated,

well I have really good social workers, they have all been very helpful and especially when it is time to switch her medications and when things need to be done in court relationship. The social worker came to the doctor's office with me and helped me so much by getting the prescriptions that she needed.

(Participant #6, Personal Interview, February 2011)

The participants were asked to talk about how they were prepared by the social worker about caring for a foster child with ASD and if the social worker talked about the foster parent's responsibility in making sure the child received services. Six out of nine participants (67%) stated there was no discussion because the diagnosis did not occur until after the child was in the participant's care. Six out of the nine participants (67%) stated that there was no discussion on what would be expected of the caregiver when dealing with their autistic foster child. These caregivers stated that they saw something wrong with the child and took it upon themselves to take the child to the doctor to get them help, and the doctor was able to diagnose the child. One caregiver stated, "you don't know what they are going to place in your home or the type of children they are going to place in your home" (Participant #3, Personal Interview, February 2011). Three out of the nine participants stated they had a discussion of what would be expected of them now and that they would be taking care of an autistic foster child. One of the participants stated, "The social worker explained to me that I would have to take some classes; I would be expected to take

her to the doctor, follow through the medication"

(Participant #6, Personal Interview, February 2011).

The participants were asked to talk about how the responsibilities with their autistic foster children. All of the participants stated that there was discussion with the social worker on the visitation that the children would have, how often they would so and see the doctor and dentist; but the discussion on the added responsibilities that the caregivers were required to do for a child with ASD was very limited. Seven out of the nine participants (78%), have to take the child to therapy at least once a week. The types of responsibilities that the participants stated they were responsible for: talking the child to their psychologist/psychiatrist, taking the children to their art class, speech class, occupational therapy, counseling, neurologist appointment, group therapy sessions, in home development training, play therapy, RSP in school, tutoring services, behavioral modification sessions, physical therapy, wraparound services, and importantly the follow through and added attention to the child's medication intake.

All of the participants stated that their autistic child needed extra attention in regards to their behavior, their educational needs, and the child's safety. Six out of the nine participants (67%) stated that they regularly utilize the help of others in order to take care of the child in question. One participant stated, "part of it is being a record keeper and knowing what appointment is coming up and be organized for them" (Participant #3, Personal Interview, February 2011). Another participant stated,

anyone who wants to take care of an autistic child must realize that it is more involved than having to take care of a child with no disabilities. It is more time consuming and you have to be more consistent with the child so that the child can understand their boundaries. (Participant #5, Personal Interview, February 2011)

The participants were then asked to describe the kind of compensation they were receiving for having a foster child with ASD. Five out of the nine participants (56%) were willing to talk about how much they were given from Social Security, Inland Regional Center and the county Children and Family Services. Three participants

stated they felt they were grossly underpaid for the amount of attention and added compensation that it took to groom and care for the child as well as take them to their various therapies and appointments. One participant stated that,

if something is taking most of your day and most of your time then you should be compensated for that not just for room and board. But you need to be compensated for the care that you give, and they all give you enough for them but they don't give you enough for the care that you give to them, that is where they went wrong and that is what I have a problem with. (Participant #7, Personal Interview, March 2011)

The other two participants stated that they were adequately compensated, it was noted that their children were Inland Regional Center clients, who were known to properly compensate their clients and their needs.

Services of Autistic Foster Child

The participants were then asked to describe the kinds of daily challenges that come with making sure their autistic foster child received adequate services. Seven out of the nine participants (78%) stated that they

did not have any challenges when it came to getting their autistic child services because the child was either an IRC client or they were receiving services in their special education classes. One participant was having issues because there were no services that could compensate her for the extra tutoring services she was providing for her foster child for his learning disability and she was not being compensated due to "lack of funds available to get him those special services." For some participants, the challenges did not come from trying to get the services. Rather the issues came with the child actually being able to benefit from the services. One participant stated although the child qualified for the services and that the services for him existed, but because of his autism "as far as him being able to do the services, I don't think he is capable of it" (Participant #6, Personal Interview, February 2011).

All of the foster parents stated that the challenge the services included: the stress of having to take the child to multiple appointment in a week, being overwhelmed with so many things that must get done, and having to be in constant contact and being aware of so

many information from many different agencies. One participant stated,

It is like being an octopus. I felt like I had to have all kinds of arms and that was back then I it was really stressful and there was times that I have cried because I just didn't know that it was that challenging...the scheduling was very difficult but we managed. The gas has been really costing me and sometimes feels like I am just wasting money.

(Participant #3, Personal Interview, February 2011)

The participants were then asked to talk about how these services have affected the child's communication, social, behavioral, and academic abilities, and overall daily life. Six out of the nine participants (67%) stated that they saw some kind of improvement. Participants saw improvement in: child's reading level, speech and word recognition, ability to walk, sit up right, socialization with other children, aggression level, sign language, living and grooming skills and overall behavior. One participant stated that because the child's level of functioning was already high there was no improvement for the child's overall which added to the caregiver's stress and frustration. One participant stated that the services

were able to help the child "know that he has consequences for his actions. He is able to sit still for longer periods of time, He is more aware of his surroundings and understands the concept of danger and that things can actually hurt him" (Participant #8, Personal Interview, March 2011).

Summary

This chapter described the data that was collected from interviews. This chapter summed up the findings relating to the demographics of foster children, demographics of foster parents, challenges of raising a foster child with Autism Spectrum Disorder, previous experience and training with children with Autism Spectrum Disorder, perception of support from foster child's County Social Worker, and services of autistic foster child.

CHAPTER FIVE

DISCUSSION

Introduction

Chapter Five contains the discussion and interpretation of the data that was collected. This chapter discusses significant findings that were presented in the Result section. It will discuss the limitation of the study, suggestions for further study, recommendations for social work practice and conclusions.

Discussion

There were many characteristics in this study that could have affected its results. The first characteristics of the study that should be acknowledged is the overrepresentation of older African American female caregivers; most of these women were in their fifties and had similar backgrounds in marital and employment status, as well as similar previous experience as being a caregiver in the foster care system. The children in this study had differences in their race, age, length of time in the foster care system, and level of severity with ASD. However, most of the children that were talked about in this research were male, about 78%.

This fact is consistent with the literature that this disorder affects mainly males (Child Trends, 2010). So when looking at this study, one is getting the perspective from mainly older minority full-time caregivers with limited previous experience, training, and/or education of ASD. However, the types of issues that these participants experience with the children can be generalized, the demography of the children in this study was diverse in age, level of disorder severity, number of years in the foster care system, and the type of placement within the system.

This study found that many of the children in the study were receiving the speech-language, occupational therapy, physical therapy, and other behavioral modification. This finding is consistent with the literature of the types of services that children with ASD need for their interventions (Blackwell & Niederhauser, 2003). One of the major findings of this study was that although some of the caregivers were educated in the disorder, they felt they were not being adequately trained to deal with the disorder to help the child improve their language, cognitive and social ability. Many of the participants did not take an active

part in the therapy sessions to learn the interventions steps and apply them in the home. Many of what the parents could do, in terms of intervention, was through behavior modification to deal with the disruptive behaviors. The participants stated that the interventions took place in the child's school, in various agency offices, or in the home.

So the services that some of the children were receiving being compromised because of the inexperience and inactivity of the lessons, learned in the therapy sessions, were not being taught with the caregiver present. Therefore the caregiver could not learn and apply the strategies in the home. The previous studies showed that in order to have adequate intervention for the child and for a parent to be fully trained and prepared to deal with a child with ASD, the parent should: have a school based education, be trained in behavior management, have respite care available, have support from the community in which they reside, availability of services and access to them, and increased skill in advocacy. Most importantly these families and parents must be trained and be an essential

part of the intervention process (Blackwell & Niederhauser, 2003; Kerns & Siklos, 2006; Shannon, 2004).

Part of what this study set to find out was to find if these caregivers were able to distinguish between the quality of services their foster child was receiving and if they were active and had an opinion in the types of services that the child was receiving. The result is that these parents were not being trained to know what each service given to the child was actually accomplishing; as a result many could not able to change or alter the therapies for their foster child if it would be necessary. Many of participants stated that although the various services were improving the child's diverse deficiencies, some felt that there was no hope for their foster child. Many of these participants did not know what to do to get alternative treatments of therapy to help the child. A previous study showed that a group should be provided to children with ASD which includes: a social worker, speech and language therapist (McConachie & Robinson, 2006). This type of group is available to foster children in San Bernardino County. However, the literature has reiterated that caregivers must use the newly learned skills from the therapy sessions at home to

ensure that the interventions will improve the child's development and quality of life. This important step is not being followed because these foster parents are not a part of the therapy process, which is not the fault of the parent but just how the therapy sessions are set up. Some sessions take place in school where the foster parent is absent and when the sessions are taking place in the home, many of these parents have other children in the home that they must take care of.

The study also found that there were major stressors for the caregivers of children with ASD. One of the major stressors had to do with the monetary challenges of raising and caring for a child with ASD. This stressor is consistent with the findings of a study that showed the need for these caregivers to be reimbursed for the many expenses provided to the child (Szymanski & Seppala, 1995). If the caregiver feels adequately supported for all of their efforts, it takes away some of the stress of having to take care of a highly needy child. There is a big challenge for some of these parents to take the child to their various appointments, especially when dealing with the high cost of gas. Many of these children have issues with toilet training so diapers are expensive.

These children have been reported to destroy property in and out of the home that often times these expenses are not going to be reimbursed by the county.

Another stressor that is consistent with literature is the externalizing behaviors these children have (Kerns & Siklos, 2006). These externalizing behaviors tend to be violent and disruptive in the classroom setting. It is stressful for these caregivers to worry if and when these children are going to act out in class, possibly hurt themselves or other children. Many foster parents have had to come to the school repeatedly, have had to explain why their foster child is acting out inappropriately in public settings, or have had to find an alternative education situation for their autistic foster child.

Kerns and Siklos (2006) found that a major stressor for parents, discussed many times, was the stress and irritations that came from lack of services for the autistic child and not enough communication with the service providers. This is not consistent with the findings of this study. In this study, many of the participants were satisfied with the amount of services their autistic foster child was receiving and relayed that they talked regularly with the child's service

provider as well as the social worker. It is possible that they may not really know what they should be talking to with these service providers.

Another finding of this study was that there were no resources for families and caregivers to cope with the individuals with ASD or know how to deal with the individual. This finding is consistent with the previous study finding that there needed to be focus on helping families cope with the disorder and for the wellbeing for the individual with ASD (Brown, Mayhew & Moraes, 2005). The participants indicated that their families, as well as themselves, were not taking part in the intervention process so they were not fully informed on the child's disorder and how to help. Many participants stated that they would like some kind of support group that would help them talk to other people in the same situation and get advice on how other parents were dealing with their autistic child. Many of these participants felt alone and were not able to interact with other people because they cannot leave without taking their autistic child with them (the children were high risk to self-injure if they were not constantly watched).

This research found that although many of these parents were not trained to be advocates, they were excellent advocates to their foster child with ASD. Many of these individuals were responsible for their foster child being diagnosed; this maybe due to the fact that 95% of these participants have biological children of their own and foster children of their own. 50 to 70% of these participants have had to parent children with special needs so although they are not trained in this particular developmental disorder, they have had experience having to advocate for other children. One study found that many counties did not require their foster caregivers participate in training for a child's healthcare issues (Paztor et al., 2006). That finding is inconsistent with this study; however the quality of training and education to these caregivers are not universal and formal within the county and through out the different foster care agencies and Inland Regional Center.

Another finding of this research showed that although the caregivers described their social workers as warm, friendly, and "doing their best," many of these caregivers were not satisfied at the quality of

communication with their autistic foster child's county social worker. A previous study indicated that a social worker for children with special needs must be competent, skilled and trained in the disorders their client have, be competent in advocacy issues, be committed, be warm and be reliable (Hudson & Levasseur, 2002; Jivanjee, 1999 as cited in Brown, Mayhew & Moraes, 2005). The findings of the study indicated that although the social workers were doing their basic case management duties for their autistic clients, very few of them were able to step outside of their duties to cater to the client's and caregiver's needs for additional services, attention, support and advocacy to other agencies. Many of the caregivers interviewed for this study were the individuals responsible for getting the child diagnosed and getting them services. The social workers have an increased case load with other clients who also require additional attention and services. The participants stated that they had discussions with their child's social worker a few times a month and saw them either once a month or once every six months. The issue that arose was that many of these participants depend on the social worker to get paperwork done so that the child

could receive additional compensation and services. Many times it was up to the caregiver to advocate for the child and make sure that child was receiving some kind of service or special accommodation.

One interesting study finding was that the primary concern of the social worker's case plan was either placing the child in a permanent placement (i.e. adoptions or legal guardianship) or more importantly reunifying the child with his or her birth parents (Geenen & Powers, 2006; Pecora et al., 2009). Many of the participants commented that the social worker's goal in the county was to have the child reunified rather than addressing the child's therapy services and the caregiver's needs. This added to the stress of the caregiver because they were not feeling the extra support that they so very needed. This finding makes sense because the missions and goal of the county is to reunify families and that takes an amazing amount of time and energy in itself.

Limitations

There were some limitations to the study. The underrepresented participants in the study were individuals who were single and had either part time or

full employment; their unique struggles and point of view would have been invaluable to the direction that the study undertook. The Hispanic Spanish speaking caregivers were also underrepresented, due to the language barrier between them and this research. Their experiences with having a language barrier is speculated to be a major hurdle in the quality of services their autistic foster child receives and the caregiver's ability to take an active role in their foster child's interventions. There was only one male participant in this study and to get a perspective on what male caregivers thought about the services for their autistic foster child and what could have been improved would have good to know if the concerns that arose from this study could be universal in both genders.

Recommendations for Social Work Practice, Policy and Research

The main concern of this study was to get county social workers to understand that caregivers to autistic foster children require additional emotional, social, and monetary support. It is understandable that the average case worker does not have enough time to be able to devote to this special population with the caseload that

they have. It seems important to have a specialized unit with social workers devoted to children with ASD or other children with developmental disorders who be in the interest of the children, their caregivers, and the County of San Bernardino Children and Family Services.

The policy should be that the staff in the department and their foster parents should have clear, written down instructions and responsibilities of what each party are expected to do. These responsibilities will be talked about either before a child is moved into a placement or after a diagnosis is made. There should be increased exchanges between agencies for these special needs children in the foster system to share feedback and the progress of the child.

A more structured and highly detailed educational training division would greatly improve the confidence level of the parents and increase their chances of participating in their foster child's therapeutic interventions. The point of this specialized group is to have social workers train and properly debrief potential caregivers of children with ASD. In addition, these social workers could initiate support groups within the San Bernardino county area for these foster parents. One

of the purposes of this unit is to bring a heightened awareness of ASD and train other social workers on how to look for signs that a client might be autistic and show social workers how to advocate properly for these clients by directing them to resources and agencies within the community that could be beneficial. This unit would be a resource for other social workers who have any questions about ASD or think that their own clients might be autistic.

After conducting this study, there are some recommendations for future research in this subject. Having the perspective of non-English speaking foster parents would be beneficial. A longitudinal study could be conducted on the wellbeing and development of a autistic foster child once he or she is reunified with his birth parent or is adopted. Further research in gaining the autistic child's perspective would give a fuller depiction of how the county handles its special needs clients.

Conclusions

The purpose of the study was to examine foster parents' perceptions of services that are provided to

foster children with autism and how these services affect the children's safety and quality of life. The study used a qualitative design, with in-depth face to face and telephone interviews with nine foster parents of children diagnosed with ASD in child welfare agencies in San Bernardino and Riverside County. Face-to-face and telephone interviews was used to elicit a comprehensive insight of the experiences foster parents have with their autistic foster children. This study found that the caregivers were not as involved and trained in the area of ASD as they should be so that the autistic child's therapeutic interventions had a chance to more effective. A major recommendation to this study is for the county to make policies that will make the training of these caregivers more in-depth, universal, mandatory, and explicit. The county would need to establish policy that would obligate these caregivers to become a more integral part of the child's intervention process to aid their developmental journey.

APPENDIX A
INTERVIEW SCHEDULE

Interview Schedule

Thank you for participating in this study. To get to know you better, I would like to ask you a few general background questions about you and your family.

- **Demography of Child**
- How old is your foster child?
- What gender is your foster child?
- How long have you been a foster parent to your autistic foster child?
- What kind of placement was it?
 - Kinship? Foster family agency? County foster home?
- Do you have any future for adoption?
 - Tell me how the decision to adopt or not to adopt has influenced the relationship with your autistic foster child?
- **Demography of Parent and Foster Home**
- How long have you been a foster parent?
- What is your marital status?
- What is your employment status?
- Do you have any birth children? If yes,
 - Do any of them live in the home?
 - Do any of them have special needs?
- Do you have other foster children in the home? If yes
 - Do any of these other foster children have special needs?
- **Challenges of Raising a Foster Child with ASD**
- Tell me about the challenges that come with dealing with your autistic foster child and dealing with other foster children/children in the home
- How would you describe the communication between you and your autistic foster child is?
- **Previous experience and training with children with ASD**
- Have you ever been a foster parent or parent to a child with autism or a child with special needs before? If yes,
 - Tell me about your past experiences dealing with children with ASD in general
- Tell me what you think ASD is
- Tell me about your past experiences dealing with foster children with special needs
- Have you received any training on ASD before? If Yes,
 - Describe the kind of training you received
 - If No,
 - Do you feel you need some type of training?
 - Would you be open to some kind of training?
- What are the ways that you are independently learning and having a better understanding of autism?

- **Perception of support from foster child's County Social Worker**
- Please describe the occurrence of face to face and telephone contact with your autistic foster child's social worker
- Tell me about your discussion with the social worker, initially, about what was expected of you dealing with your foster child with ASD
- Tell me about the kind of responsibilities, on your part, the social worker expressed in making sure the child received services
 - With transportation? Taking part in the therapy component?
 - Tell me how these responsibilities are different from fostering other children who don't have special needs
- Please describe the kinds of compensation you are receiving for having a foster child with ASD
- **Services of autistic foster child**
- Tell me about your experiences with having to guide and parent your foster child with ASD
- Describe the kinds of daily challenges that come with making sure your autistic foster child receives services
- Describe the kind therapy, training, and services your foster child participated in
- Tell me how these services have affected the child's communication, social, behavioral, and academic abilities, and overall daily life
- Tell me how the services that have been given to your foster child include you and maybe your family. If you are involved,
 - Tell me the kinds of things that you are learning from the service providers on how to help you foster child
 - Tell me about the kinds of results have occurred with you being a part of training your foster child
 - Please describe how the services have impacted your family in the transition of having to deal with an autistic foster child
- Tell me how these experiences have affected how you see your foster child's service providers
- Tell me the kinds of things you do for your autistic foster child's educational needs
 - Tell me how different it is or similar from your other experience with your children and other foster children

APPENDIX B
INFORMED CONSENT

Informed Consent

California State University, San Bernardino
College of Social and Behavioral Sciences
Department of Social Work

You are invited to add your opinions to a study concerning autistic foster children and their caregivers. The study is being conducted by Uchechukwu Alozie, MSW student from California State University, San Bernardino (CSUSB) under the supervision of Professor Janet Chang at CSUSB. The study has been approved by the School of Social Work Sub-Committee of the CSUSB Institutional Review Board.

Purpose: The purpose of this study is to explore the perceptions of foster parents regarding the services given to foster children diagnosed with Autistic Spectrum Disorder (ASD) and how the lives of foster parents are changed as a result of parenting a child with ASD.

Description: If you take part in this study, you will be asked questions concerning your perceptions on: the challenges of raising a foster child with ASD, foster parent perception of support from social workers, foster parent's thoughts and challenges concerning the services that are provided to autistic foster child, foster parent's thought and challenges concerning the autistic foster child.

Participation: Participation is totally voluntary, and you are free to skip any questions you do not want to answer.

Confidentiality: The information you give will remain confidential, no record will be made or kept of your name or any identifying information. The confidential data from these interviews will only be seen by the researchers; the results will be conveyed to Children and Family Services, others in group form only.

Duration: Being interviewed for this study should take no more than one hour.

Risks: There are no foreseeable risks to taking part in the study and no personal benefits involved.

Benefits: Your personal benefit is that the information you give will better help the child welfare system understand the added stress and needed resources that foster caregivers require for taking care of an autistic child. Your opinions will help Children and Family Services to better help future autistic children placed in the foster care system.

Contact: If you have any questions or concerns about this study, you can contact Dr. Chang 909-537-5184.

Results: The results will be available at the PFAU Library after December of 2011.

By marking below, you agree that you have been fully informed about this interview process and are volunteering to take part.

Place a check mark here

Date

APPENDIX C
DEBRIEFING STATEMENT

Debriefing Statement

“Foster Parent’s Perspective on Foster Children with Autistic Spectrum Disorder in the Child Welfare System and How They Impact the Lives of Foster Parents Foster Parents”

Debriefing Statement

The study you have just completed was about evaluating the services that are given to foster children with Autism Spectrum Disorder (ASD) and defining the role you play in that child’s life. The researchers were interested in how children with ASD develop in the foster care system with the aid of behavioral intervention centered services. The researchers were also interested in how the child welfare system equips foster parents on how to aid these children. The researchers also wanted to know how having a child with ASD has impacted your life and your family’s dynamic. It is hoped that the findings from the study will help social workers make informed placement decisions based on the foster parents’ experience and knowledge of special needs children. Information obtained from the study will be used to teach social work students of the various needs and increased attention children with developmental disabilities have and the importance of placing them with capable foster parents that can aid to the wellness and stability of autistic foster children.

Thank you for participating in this study and for not discussing the contents of the interview with other people. If you have any questions about the study now that you have completed the interview, please contact Professor Janet Chang at 909-880-5184. If you would like to obtain a copy of the study, please feel free to contact Professor Janet Chang at 909-880-5184, after September 1st 2011.

APPENDIX D
LETTERS TO PARENTS (ENGLISH)

Letters to Parents (English)

February 11th 2011

Dear Foster Parent:

You're invited to add your opinions to a study concerning autistic foster children and their caregivers. The study is being conducted by me, Uchechi Alozie an MSW Intern at California State University, San Bernardino working with Children and Family Services under the supervision of Sally Richter, SSSP at the Gifford office.

The purpose of this study is to explore the perceptions of foster parents regarding the services given to foster children diagnosed with Autistic Spectrum Disorder (ASD) and how the lives of foster parents are changed as a result of parenting a child with ASD. The study has been approved by the School of Social Work Sub-Committee of the CSUSB International Review Board and by Children and Family Services.

If you take part in this study, you will be asked questions concerning your perceptions on: the challenges of raising a foster child with ASD, foster parent perception of support from social workers, foster parent's thoughts and challenges concerning the services that are provided to autistic foster child, foster parent's thought and challenges concerning the autistic foster child.

Participation is totally voluntary, and you are free to skip any questions you do not want to answer. The information you give will remain confidential, no record will be made or kept of your name or any identifying information. Being interviewed for this study should take no more than one hour.

The information you give will better help the child welfare system understand the added stress and needed resources that foster caregivers require for taking care of an autistic child. Your opinions will help Children and Family Services to better help future autistic children placed in the foster care system.

I would love to speak with you, please call me at 909-936-3237. If you have any questions or concerns about this study, you can contact my supervisor SSSP Sally Richter, 909-386-1378.

Thank you for your help and input!

Uchechi Alozie
MSW Intern

APPENDIX E
LETTERS TO PARENTS (SPANISH)

Letters to Parents (Spanish)

11 de febrero 2011

Estimados padres de crianza temporal:

Te invitamos a agregar sus opiniones a un estudio sobre los niños autistas de crianza y sus cuidadores. El estudio está siendo llevado a cabo por mí, Uchechi Alozie un pasante de MSW en la Universidad Estatal de California, San Bernardino trabajan con la Niñez y la Familia, bajo la supervisión de Sally Richter, SSSP en la oficina de Gifford.

El propósito de este estudio es explorar las percepciones de los padres de crianza temporal con respecto a los servicios prestados para fomentar los niños diagnosticados con Trastorno del Espectro Autista (TEA) y cómo las vidas de los padres de crianza se cambian como resultado de la crianza de un niño con TEA. El estudio ha sido aprobado por la Escuela de Trabajo Social de Sub-Comité de las CSUSB Internacional de la Junta de Revisión y Servicios para Niños y Familias.

Si usted participa en este estudio, se le harán preguntas sobre sus percepciones sobre: los retos de criar a un hijo de crianza con TEA, la percepción del padre de crianza de apoyo de trabajadores sociales, los pensamientos del padre de crianza y los desafíos relativos a los servicios que se proporcionan a los autistas hijo de crianza, el pensamiento del padre de crianza y los desafíos relativos a la crianza del niño autista.

La participación es totalmente voluntaria, y usted es libre de saltar cualquier pregunta que usted no quiere contestar. La información que usted proporcione se mantendrá confidencial y sin registro se hizo o se mantiene de su nombre o cualquier información de identificación. Al ser entrevistados para este estudio no debería tomar más de una hora.

La información que nos ayudará a dar un mejor sistema de bienestar infantil comprender el estrés añadido y los recursos necesarios que los cuidadores de crianza requieren para cuidar de un niño autista. Sus opiniones ayudarán a Servicios para Niños y Familia para ayudar a un mejor futuro de los niños autistas colocado en el sistema de cuidado de crianza.

Me encantaría hablar con usted, por favor llámeme al 909-936-3237. Si tiene cualquier pregunta o preocupación acerca de este estudio, puede comunicarse con mi supervisor PSSS Sally Richter, 909-386-1378.

Gracias por su ayuda y participación!

Uchechi Alozie
MSW Intern

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