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THE NEEDS OF CHILDREN WITH AUTISM AND THEIR PARENTS OR CARETAKERS

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

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by

Dannely Hernandez

Soé Myrna Cortez

September 2006

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ABSTRACT

This study was a needs assessment of the parents or caretakers of children with autism. Twenty-one participants received surveys that helped identify their needs. In addition, four randomly selected participants were chosen to participate in oral interviews, to measure the validity of the instrument. The motivation to conduct research on autism evolved from the lack of knowledge of social workers in developmental disabilities agencies. Parents in the study revealed that more parent involvement in therapies is a great tool for families to overcome the stressful situation. In addition, educational trainings and support groups can assist parents in becoming more skilled in dealing with negative behaviors. Furthermore, this study will help social workers and other professionals specializing in developmental disabilities become aware of the needs of children and their parents or caretakers.

ACKNOWLEDGMENTS

We would like to thank Focus Psychological and Educational Services Agency and their clients for participating in this study. Without their help this study would have not been possible. In addition, a special thanks to Tim Thelander, Professor Judy Hails, and the faculty and staff of the Social Work Department at California State University of San Bernardino.

DEDICATION

I dedicate this study to my son Isaac Anthony Fuerte. You have been my motivation and the light at the end of my tunnel. Thank you for your patience, smiles, and hugs because they inspired me. I love you Baby.

Soe′ Myrna Cortez

I dedicate this study and all my efforts for accomplishing a higher education to my greatest supporters, my family. Thank you for your dedication, patience, and support that kept me going. I love you.

Dannely Hernandez

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CHAPTER ONE

INTRODUCTION

This chapter will introduce the problem, purpose, and significance of this study as it relates to the field of social work practice. The area of specialization for this study was developmental disabilities. Within that field of practice this study examined the needs of children with autism and their parents or caretakers. For the purpose of this study a caretaker was defined as anyone who was intimately involved in the raising of a child, including members of an extended family.

Problem Statement

The birth of a child is a new beginning in the life of a couple. It is a momentous occasion because it marks the passage from being a couple to becoming a family. Couples approaching parenthood find the arrival of a baby to be a major transition that marks a change in everyday life. The anticipation and optimism that surrounds birth make it one of life's most joyous transitions.

Parenting is a busy, hectic, and sometimes frustrating job that creates stress for couples. However, when a parent or caretaker is given the diagnosis of a developmental disability for their child it is devastating and heartbreaking.

According to Slater and Wikler (1986), the Developmental Disabilities Assistance and Bill of Rights Act Law 95-602, defines a developmentally disabled person as having a "severe, chronic disability that results in substantial functional limitations in three or more of the following major areas: capacity for self-care, receptivity to language and use of language, learning ability, mobility, self-direction, capacity for independent living, and economic self-sufficiency" (p. 385). In accordance with Kids Together Inc. (2005), individuals who are developmentally disabled include persons with mental retardation, cerebral palsy, epilepsy, autism, and other disabling conditions that require treatment similar to individuals who are developmentally disabled.

Macro and micro policies that have evolved from the Civil Rights Movement in the 1950's and 1960's created the Developmental Disabilities Movement. Parents of people with disabilities were under voiced in the 1950s; therefore parental advocacy groups were formed to empower the parents of children with autism (Mary, 1998). Policy makers began to support parental advocacy for people with disabilities throughout the 1950s. This decade marked a significant change in society when people started to move toward the inclusion of disabled people in all aspects of life. Non-profit organizations such as Regional Centers were established to assess, diagnose, and offer resources to families (Mary, 1998).

California's Regional Centers established a new developmental model in the 1970s. The Regional Center perspective moved away from having "patients" to having "clients" and "treatment" became "interventions" (Mary, 1998). The change was to mobilize clients to achieve their fullest potential and capacities. As the government took more responsibility, social workers played a more important role for those who were disabled in order to ensure their welfare. Social workers and case managers assisted in involving the family in helping the client achieve objectives and goals. They identified and created the "circle of support," which included family, friends, neighbors, and other acquaintances (Mary, 1998). The primary role of the social worker was to facilitate and meet the needs of the client and the family.

The government provides two programs for people with disabilities: The Individuals with Disabilities Education Act and Medicaid Title XIX of the Social Security Act. The Individuals with Disabilities Education Act provides the educational component for children diagnosed with autism and other disabilities. Medicaid Title XIX of the Social Security Act is the health benefit component that serves the medical needs for people with disabilities (Ruble, Heflinger, Renfrew, & Saunders, 2005).

Historically, social workers have been interested in the field of developmental disabilities since the turn of the century. McDonald (1987) describes their interest as being primarily with mental retardation at the clinical, teaching, and research levels. However, in 1913 when the concept of the intelligence quotient (IQ) was introduced, the active involvement of social workers in this field diminished for nearly twenty years, until the 1950s and 60s when several associations were established, e.g., the Association of Retarded Citizens (ARC) and the National Institute of Child Health and Human Development (NICHD) (McDonald, 1987). The roles of social work in the field of developmental disabilities according to the National Association of Social Workers (NASW) (1982) have increased drastically due to the critical involvement of social workers offering services at the community-level to developmentally disabled clients. To this day social workers across the nation are actively involved in this field and according to McDonald (1987) representatives of NASW are shaping the philosophy, basic principles, standards and procedures used for accrediting programs that serve people with developmental disabilities. The primary goal of social workers working in this field of practice is to enhance the development and well being of individuals with developmental disabilities and their families, while maximizing their achievement of self-determination.

Purpose of the Study

This study was focused on the specialization of developmental disabilities within the social work profession. Furthermore, within that specialization the interest was on the needs of children diagnosed with autism spectrum disorder and their parents or caretakers. The needs of children with autism and their parents or caretakers have been understudied in the field of social work.

Autism is considered to be one of the most devastating developmental disabilities and its cause is unknown. According to Zastrow and Kirst-Ashman (2004), autism spectrum disorder is a condition that is characterized by intense inner directedness, and individuals diagnosed with autism pay little or no attention to what is happening around them. Furthermore, autism is a complex brain disorder that often inhibits a person from having the ability to participate in communication with other people and respond to surroundings. Moreover, problems that autistic individuals are confronted with include repetitive self-stimulating movements of extremities, sensory distortions, and lack of emotional reaction to others, including attachment (National Alliance for Autism Research [NAAR], 2005). In addition, Rosenhan and Seligman (1995) describe some manifestations of the autistic diagnosis including a failure to cuddle, lack of eye contact, and downright aversion to physical contact and affection. Additionally, they point out that children with autism in most cases fail to develop language, and if language is acquired it is often characterized by the tendency to echo or repeat what they have just heard.

The Diagnostic and Statistical Manual of Mental Disorders (American Psychiatric Association, 2000) describes characteristics of autistic disorder as the presence of noticeable abnormal or impaired development in social interaction and communication, and a limited repertoire of activities and interests. Manifestations of the disorder are apt to change according to the developmental level and age of the diagnosed individual. In addition, autistic disorder is also known as early infantile autism, childhood autism, or Kanner's autism according to the American Psychiatric Association (2000). The diagnostic criteria for autistic disorder in the American Psychiatric Association (2000) include:

1) A total of six or more impairments in social interaction, communication, and restrictive or repetitive and stereotypical patterns of behavior,
2) Delays or abnormal functioning in social interaction, language as a means for communication, or symbolic or imaginative play, and

3) Symptoms that cannot be described as Rett's Syndrome or Childhood Disintegrative Disorder. (p. 75)

Today, much research has been conducted on autism. Most literature and information on autism is Focused on impairments, difficulties, and practical interventions. Moreover, studies that have been conducted are limited in how they involve parents or caretakers. Previous research that has involved parents of children with autism has been focused on the child's behavior. Yet, much research fails to take into account the needs of children with autism and their parents or caretakers, who are the experts and know their children best.

According to Fleischmann (2004), after a child has been diagnosed as autistic parents may suffer from feelings of anxiety, disbelief, shock, and depression, which emerge from the constant challenges of raising an autistic child. Furthermore, the challenge becomes greater as parents confront the fact that there is no known cure for autism, and that their child will need lifetime care (Fleischmann, 2004). Because of these circumstances parents or caretakers have a limited support system and therefore feel socially isolated and need emotional support.

The needs of children with autism and their parents or caretakers were assessed through a qualitative and quantitative study. A qualitative study gathers data in written words, spoken words, and observable behaviors (Grinnell & Unrau, 2005). Having conducted a qualitative research study was beneficial for the field of social work, because it clearly defined the needs of children with autism and their parents or caretakers.

Quantitative studies according to Babbie (2004) are numerical representation and manipulation of observations for the purpose of describing and explaining the phenomena that those observations reflect. In addition, he states that these studies use quantitative devices for systematically collecting data from populations, programs, or samples of populations or programs, and they employ personal interviews, mailed questionnaires, survey sampling procedures, or other rigorous data gathering devices (Babbie, 2004). For the purpose of this study a needs assessment survey was created and mailed out to parents or caretakers of children with autism asking ordinal and open-ended questions about what they perceived their child(ren) and themselves as needing.

The cohort of study for this research experiment was children diagnosed with autism. Cohort studies focus on specific groups of people who share certain characteristics (Grinnell & Unrau, 2005). The selected sample was gathered from Focus Psychological and Educational Services Inc. (Focus). Focus is a non-profit organization in the city of Los Angeles founded in 1985. Staff is composed of mental health and education specialists who provide developmentally based psychoeducational services to special needs children and their families. The main objective of Focus is to provide behavior intervention and related services to special needs children (Focus, 2005). Focus was chosen as the agency because they provide services that are directed to children with autism. Currently, Focus serves eighty-six children with autism and their families (Personal Interview, Crystal Pierci, Ph.D. Candidate, Nov. 7, 2005). The parents of these children received mailed surveys. Mailing out surveys is cost efficient and participant time is free (Grinnell & Unrau, 2005). The data collected from this study gave the social workers a clearer picture to what clients need.

Significance of the Project for Social Work

The motivation to conduct research on autism evolved from the lack of knowledge of social workers in developmental disabilities agencies. The researchers were particularly concerned with autism and its manifestations in children. Since there is limited research on this subject, this research provided the opportunity to expand knowledge and understanding of the needs of children with autism.

This study is useful for helping social workers and other professionals specializing in developmental disabilities become aware of the needs of children and their parents or caretakers. It is beneficial for social workers to be aware of the challenges faced by parents in order to provide more meaningful services for these children and their families. In addition, social workers and other professionals working with children with autism can become cognizant of and recognize the needs of children with autism. Moreover, this study will aid social workers to become aware of the difficulties that families, schools, and government have and the different demands that each encompass.

Parents of children with autism often lack emotional support and feel socially isolated. A study by Billington, McNally, and McNally (2000), narrate the dissatisfaction of a couple toward professionals who left them feeling hopeless and helpless, confused, angry, and disempowered. Professionals in that study failed to provide dialogue with the parents, which caused the couple to become distant and isolated from their families, friends and one another. Parents of children with autism often feel lonely and misunderstood. Thus, parents of special children need encouragement and moral support from social workers that would go a long way in empowering and enriching their lives.

Overall the goal of this study was to incorporate a partnership between parents and social workers throughout the generalist intervention process and especially during the engagement phase. The engagement process focused on building rapport with the client in order to identify the presenting problem, and gave social workers insight into the needs of the client. This empowered the parents/and caretakers of children with autism to work with professionals and together examined the needs of their children.

Working with disabled children and their families can seem like a complex and demanding task for professionals. Hence, it is important that social workers interested in developmental disabilities have the knowledge to diagnose and help intervene in this developmental disorder. The research question was, "what are the needs of children with autism and their parents or caretakers?"

Social workers have the responsibility to determine what clients and their families need in order to intervene or refer. Therefore, understanding and "starting where the client is," is vital to the profession. This study gave first hand information from client's families about what services they thought they were lacking or needed. The information gathered was beneficial to professionals who can then propose a resolution plan.

CHAPTER TWO

LITERATURE REVIEW

Introduction

Much research has been conducted on the broader issue of autism. This chapter entails some critical research knowledge including prevalence, interventions, resources, theoretical perspectives, and family support as it relates to the autistic individual.

Prevalence

In recent years the prevalence of autism spectrum disorder has significantly increased, and it is estimated by the National Alliance for Autism Research (NAAR) (2005) that one child in every 166 births will be diagnosed with autism today. In addition, the median rate of autistic disorder in epidemiological studies according to the American Psychological Association (2000) is five cases per 10,000 individuals, with reported rates ranging from two to 20 cases per 10,000 individuals. The onset of autistic disorder is prior to age three. However, developmental abnormalities are usually noted within the first year of life. Autism is estimated to occur in 4 out of 100,000 children, and boys are diagnosed three times more than girls according to Zastrow (2000). The disorder is not related to race or socioeconomic class, and thus affects people of all racial, ethnic and socioeconomic backgrounds.

According to NAAR (2005) autism was identified more than 50 years ago, and to this date the cause or causes of autism are unknown and there are no specific medical treatments or cure. However, NAAR (2005) points out that medical researcher's think that there is a strong genetic pre-disposition to autism. In addition, other researchers are investigating problems during pregnancy or delivery as well as environmental factors (Autism Society of America, 2005).

The University of California in Davis Sacramento is currently launching a study focusing on 2,000 participants diagnosed with autism. Researchers will examine the genetic and environmental factors that affect the development of autism, mental retardation, and other developmental delays and environmental factors (Alcott, 2002), such as exposure to chemicals during pregnancy and birth, medications, and vaccinations. This research will help determine the cause of autism (Alcott, 2002).

In most cases, autism is associated with cognitive disabilities or other abnormalities that hinder cognitive skills and development. The degree of autism varies from mild to severe in different cases. It is also known that individuals with autistic disorder have a range of behavioral symptoms, including hyperactivity, short attention span, impulsivity, aggressiveness, self-injurious behaviors, and temper tantrums, specifically in young children (Zastrow, 2000).

In general, typical developing children learn from their environment through exploration, play, modeling, conversation, and so on according to Bredekamp and Copple (1997). Unfortunately, Spradlin and Brady (1999) state that children with autism have a limited knowledge of and interest in learning like ordinary children. Yet, professionals and service providers working with children with autism must learn diverse methods to increase the child's learning opportunities, as well as their motivation to learn new skills.

Only a small percent of autistic individuals grow up to live and work independently as adults. Zastrow (2000) points out that 60 percent of autistic individuals are unable to lead an independent life as adults, and only one in six will improve enough to hold a job. It is estimated by the American Psychological Association (2000) that only one-third of the cases have some degree of independence possible.

Family and Autism

Families of children with autism face obstacles such as the unknown progress of the child's development, behaviors associated with the diagnoses, tantrums, and self-stimulatory behaviors (McCandless, 2003). Coping with a child's diagnoses is difficult for parents, but it is more difficult not being knowledgeable about services available to people with disabilities (Kozloff & Rice, 2000).

Mothers have a greater stress level compared to their counterparts because of the responsibility associated with caring for an autistic child (Scherzer, 2004). Mothers of children with autism are more likely to show depression and anxiety (Scherzer, 2004). Parents caring for a person with autism are more likely to experience psychological distress compared to parents raising individuals with other developmental disabilities (Bromley, Hare, Davison, & Emerson, 2004). Sixty-eight mothers of children with Autism Spectrum Disorders (ASD) were examined to measure their level of social support, mental health status, and service satisfaction (Bromley, Hare, Davison, & Emerson, 2004). Half of the mothers reported feeling distressed because of low levels of family support while raising an autistic child. Unmet needs were a contributing factor to the high level of stress (Bromley, Hare, Davison, & Emerson, 2004). Fathers on the other hand, were more likely to suffer from schizoid like symptoms (Scherzer, 2004). Furthermore, marital satisfaction is lower in parents raising children with autism due to depression and high levels of stress (Scherzer, 2004).

Siblings of children with autism are equally affected by having a loved one diagnosed with autism. Gross (2004), conducted a study which revealed that siblings also experience psychological distress. This psychological distress develops as the siblings are exposed to tantrums, aggressive, and self-injurious behaviors. The study pointed out that support groups and therapeutic interventions for children with autistic siblings are the best solution for family members (Gross, 2004). In addition, the lack of parental attention for these siblings is troubling, because it leads to feelings of loneliness (Ward, 2004). Furthermore, these siblings are at greater risk for developing emotional and behavioral problems (Scherzer, 2004). Research also reveals that higher stress has been linked with families of Autism Spectrum Disorders compared to families with children with mental retardation (Ward, 2004).

On the other hand, there has been a lack of research on the well being of family members and children with autism. Service providers need training in helping families and individuals with autism meet their needs to ensure an enhanced quality of life (Ward, 2004). Empowering the client and the circle of support in a warm and empathetic way is crucial (Mary, 1998). Professionals need to target and identify any emotional or mental issues and link clients to appropriate treatment. This is important because it ensures the client's well being. Assisting a client with autism requires the professional to see the broader picture of the needs of the family in general rather than Focusing on the diagnosed child (Scherzer, 2004).

The family is the most important advocate for children with autism. Laws, regulations, funding sources, and education plans (Kozloff & Rice, 2000) are offered to the child with the disability, but the client's family are the first to identify the client's strengths and weaknesses. This information is crucial since it helps professionals know the child's behaviors. Thus, this helps to ensure that the best intervention is used for the child (Kozloff & Rice, 2000). The data collected from this study provided additional information to identify what the needs of children with autism and their parents or caretakers were.

Interventions for Autism

Treating autism is difficult because patients have communication impairments, social impairments, and sometimes, self stimulating behaviors. Different therapy approaches are used such as therapy for parents, family therapy, drug therapy, and behavior modification. Applied Behavioral Analysis (ABA) has shown to be the most successful when treating autism using Discrete Trial Training (DTT) (Green, 1996). Early intervention has also proven to increase successful outcomes for people diagnosed with autism. Applied Behavioral Analysis focuses on social and communication skills in a teaching environment by setting boundaries, limits, and following through with all tasks (Miller, 1997). Family involvement is crucial while applying behavioral therapy because parents have to coincide with therapy techniques to provide the client with consistent rules. Even though behaviors such as "stimming" (self stimulatory behaviors) may decrease with ABA, social impairment generally remains (Sue, Sue, & Sue, 2003).

Drug therapy is another common treatment plan for clients suffering from Autism Spectrum Disorder. Antipsychotic medications can reduce feelings of withdrawn, self-stimulation behaviors, or hyperactivity levels (Sue, Sue, & Sue, 2003). The most common drug treatments used are Risperidone, which is an anti-psychotic that decreases aggression and hyperactivity (Springen, Pierce, Raymond, & Hontz, 2005). Prozac is an antidepressant that reduces repetitive behaviors (Springen, Pierce, Raymond, & Hontz, 2005). Anticonvulsants like Depakote are being tested and used to treat aggression, while stimulants such as, Ritalin help decrease hyperactivity (Springen, Pierce, Raymond, & Honzt, 2005). Medications have not shown promising results, but many people with autism take medication in combination with behavioral modification.

Predicting the functioning level of an autistic person is problematic because of the unpredictable cognitive dysfunctions, language impairment, social and behavioral issues that are associated with the disorder (Howlin, Goode, Hutton, & Rutter, 2004).

Theories Guiding Conceptualization

Early psychodynamic theory implied that autism was caused by a parent-child interaction (Kanner, 1943). Kanner thought the disorder resulted from cold and unresponsive parenting styles, which resulted in the illness. Later, research has focused on genetics and brain abnormalities relating to autism. In addition, today's researchers have become fascinated with treating autism since there is no known cure for the developmental disability to this day.

The inability to function interdependently in society may lead to developmental issues that apply to Eric Erikson's (1950) psychological development theory. This theory focuses on how personalities develop throughout a person's life span. It also focuses on the interaction between social environment and personality development of an individual (Zastrow & Kirst-Ashman, 2004).

Applying Erikson's developmental stages to autistic individuals is difficult because they are developmentally delayed. The more aware a person is the higher the chances that they will experience shame and doubt, because they will be more conscious of the skills they lack (Zastrow & Kirst-Ashman, 2004). A child that is mainstreamed in a typical classroom may also experience inferiority during his or her school years, because they may feel unsuccessful compared to their peers. Research has shown that individuals with autism can learn to read and write, and those who do, have a wider range of educational, social, and vocational options throughout their lives (Erickson, Koppenhaver, & Yoder, 1994). Identity is established during the adolescent years.

The stage of Identity versus Role Confusion is the transitional period from childhood to adulthood (Zastrow & Kirst-Ashman, 2004). Research indicates that individuals require someone to assist them with personal care, medical needs, supervision, and in many cases, individualized treatment programs (Slater & Wikler, 2001)

Due to autistic people requiring a caregiver it is more likely that the individual will suffer from role confusion. In the last stage of Intimacy versus Isolation an adolescent establishes sexual relationships (Zastrow & Kirst-Ashman, 2004). In contrast, people who do not attain intimacy are likely to suffer from isolation, because they have not been able to resolve the crises of earlier stages of development (Zastrow & Kirst-Ashman, 2004). Individuals who are autistic lack emotional reaction and are unable to attach according to NAAR (2005), therefore they suffer from isolation.

Raising a developmentally delayed child tends to increase stress within the family. If individuals suffer from isolation at a young age then it is likely that they will not resolve the crises in each stage of development. Determining when an autistic child will encounter a crisis is close to impossible because of their developmental delays.

Erikson's stages of development guide professionals to determine the child's developmental stage and their needs. Social workers in the broker role refer the child and parent or caretaker to their local Regional Center and local school district in order to attain services to meet the child's developmental need.

Summary

The literature presented in Chapter Two was important to understand, as it was an essential component of this research study. The literature stated that autism is a disorder that affects not only the diagnosed individual, but also the entire family. This chapter also identified various therapy approaches that are used in the treatment of autism today.

CHAPTER THREE

METHODS

Introduction

Chapter Three introduces the steps that were used in developing this study and how it was conducted. Specifically, this study collected data from clients of Focus Psychological and Educational Services Agency. The participants were parents or caretakers of the child client(s) served by Focus Psychological and Educational Services Agency. The needs assessment survey was administered to parents or caretakers who have a child diagnosed with autism. Staff from Focus Psychological and Educational Services Agency mailed out the needs assessment surveys in order to protect the participants' privacy, and no identifying information was used throughout this study. The data that were gathered from these needs assessment surveys was information about the needs of children with autism and their parents or caretakers.

Project Design

The purpose of this study was to explore the needs of children with autism and their parents or caretakers.

This particular topic was of great interest to the researchers because autism and its origins remain a mystery, and it needs to be investigated further. In addition, it is the ethical and professional responsibility of social workers to promote the well being of clients. In this study, the participants were parents or caretakers of children who are autistic. By conducting this study the researchers empowered the families of children with autism to have a say in what they and their children need. Moreover, this study educated social work professionals and other disciplines that work with children with autism and their parents on what their needs are.

This study was conducted using a quantitative and qualitative approach that was focused on the needs of children with autism and their parents or caretakers. For the purpose of this study, a needs assessment survey was created and mailed out to the parents or caretakers of autistic clients that are served at Focus Psychological and Educational Services Agency. Four randomly chosen participants were asked to participate in oral interviews. The purpose of the oral interviews was to test the validity of the created instrument (needs assessment survey).

Possible limitations to this study included researchers' biases, small sample and lack of honesty by participants, which may have influenced the way the data were gathered and analyzed. The needs assessment instrument was written in comprehensive language that used common terminology, so all participants were able to understand the questions in order to prevent barriers and limitations. In order to test the terminology the researchers randomly pre-tested the instrument with colleagues and Focus staff to ensure that the survey was comprehensible.

Overall, this study was an assessment of the needs of children with autism and their parents or caretakers. Therefore this study did not have a hypothesis. The purpose of this study was to gather information for professionals in the field of social work. In addition, Focus was particularly interested in the data that were gathered in order to better accommodate and serve their clients and their families. Moreover, the particular interest of the researchers was to further research on the needs of children with autism and their parents or caretakers.

Sampling

The participants in this study were clients of Focus Psychological and Educational Services Agency. Focus is a non-profit organization in the city of Los Angeles founded in 1985. Staff is composed of mental health and education specialists who provide developmentally based psychoeducational services to special needs children and their families. The main objective of Focus is to provide behavior intervention and related services to special needs children (Focus, 2005). Focus was chosen as the agency because they provide services that are directed to children with autism. Currently, Focus serves eighty-six children with autism and their families (Personal Interview, Crystal Pierci, Ph.D. Candidate, Nov. 7, 2005). Focus currently uses many different interventions such as Discrete Trial Training (DTT), behavior modification, and Floor Time with the eighty-six clients that are diagnosed as autistic.

The surveys were given to the staff of Focus to mail out to the eighty-six participants. The surveys were inside a large envelope that included the informed consent, debriefing statement, and a smaller self-stamped return envelope. In addition, four randomly selected participants by Focus staff were chosen to participate in oral interviews. These participants were selected from a monthly parent support group meeting held at Focus. All the parents or caretakers of clients who are diagnosed with autism were invited to attend these monthly meetings. Therefore, it was unknown to the researchers who would attend the parent support group meeting.

The selected parents were given an informed consent that described all the details of the study and ensured confidentiality. The researchers reviewed the consent and confidentiality forms prior to beginning the interviews. Participants were given the option to be part of the interviews and were not obligated to participate. Participation for this study was strictly voluntary and did not affect services provided by Focus to clients or family members. There were no monetary or other types of compensation for research participation.

Since Focus staff granted verbal permission the researchers then attained written permission. During an oral interview, Crystal Pierci, Ph.D. candidate and

Discrete Trial Training Coordinator gave direction to the researchers to write a letter requesting permission to conduct the study using the clients of Focus. The letter was composed of details of the study, confidentiality and how it was protected, and the risks of participating in the study. Dr. Susan Brown, co-executive director of Focus, reviewed the details of the study and determined if the study was to be conducted at the agency.

This letter was personally given to Dr. Susan Brown, co-executive director of Focus, requesting her permission to conduct the study by using the agencies clients. This needs assessment was beneficial for Focus, because the agency was able to use the collected data to determine the areas of service they lack. In addition, Focus was then able to provide these needs and better serve their clients and their families or caretakers.

Data Collection and Instruments

The study had no identified dependent or independent variables. Rather, it focused on gathering data about what the clients of Focus and their families or caretakers need. The collected data gathered from the surveys were compared to the interviews, in order to test the validity of the instrument.

The needs assessment consisted of ordinal and open-ended questions. Once needs were identified they could guide the agency to develop therapeutic interventions to assist with those needs. The study was culturally sensitive and asked nominal demographic questions regarding ethnicity and the relationship of the person filling out the survey to the child. The child's chronological age (in months) was an interval measure. Nominal questions included in the survey were, "What do you think is the appropriate school placement for your child?" and "Where do you receive services for your child with autism?" These questions gave the researchers and other professional's insight into how knowledgeable the parents or caretakers are about services for their autistic child. The survey questions are given in Appendix A.

The open-ended questions for the needs assessment survey were based on requests by the administrators of Focus and the interest of the researchers. An oral interview was previously conducted with administrators of Focus. Crystal Pieri, Ph.D. Candidate and Discrete Trial

Training Coordinator gave her ideas for questions that interest the agency.

The survey (Appendix A) was mailed out and collected. The oral interviews consisted of the same questions asked in the survey and tested the validity of the study. The oral interviews confirmed if the surveys were answered in a similar manner. In addition, the interviews determined if the surveys measured the needs of the parents or caretakers and the clients. Additionally, the oral interviews determined the accuracy of the surveys. The oral interviews were compared to the survey responses and determined that the answers were similar.

Procedures

The instrument, consent, and debriefing statements were delivered to Focus along with self-stamped envelopes, so the agency supervisors were able to mail the surveys to all eighty-six parents or caretakers of children with autism. This was done to protect the confidentiality of these clients. The researchers did not have access to the clients' files, therefore, the clients' names were unknown and the surveys were completely anonymous. Participants mailed back the survey instrument to Focus with attention to Soé Myrna Cortez. The surveys were given to Focus supervisors on the second week of February. Focus supervisors mailed a reminder letter along with a duplicate copy of the survey the first week of March to those participants who did not respond. If, after the second attempt, participants did not respond, they were terminated from participating in the study.

The oral interviews were conducted during a Focus parent support group held at the YWCA in the city of Glendale. Four parents were randomly selected to participate in the oral interviews. The participants were given the consent and debriefing statements prior to being taken to an isolated room where they were interviewed to protect confidentiality.

Protection of Human Subjects

After the surveys were collected from the agency, they were stored in a locked file cabinet in a secure room. The participants' confidentiality was maintained and no identifying information was recorded or available to the researchers, as participation was completely anonymous. All participants received informed consent and debriefing statements for both survey and oral interviews (See Appendices B, C, & D). After all surveys were gathered they were numerically coded for further phases of the study.

Data Analysis

This study utilized quantitative and qualitative analyses and the data collected were processed and interpreted. The qualitative questions gathered data in written and spoken words. Conducting a qualitative research study was beneficial for the field of social work because it clearly defined the needs of children with autism as seen by their parents or caretakers. Some survey questions were quantitative, and were scaled using "most of the time, sometimes, rarely or never, don't know, and check if this is a concern" as choices for answers to the instrument. The overall collected scores from the surveys were graphed using numbers and tables.

The interpreted qualitative questions provided insight to know how satisfied and knowledgeable parents or caretakers of children with autism were with services provided. In addition, qualitative questions allowed parents or caretakers of children with autism the opportunity to voice their concerns and needs.

Summary

This chapter discussed and identified the methods by which the study was conducted. It introduced the agency that was used to collect the data. This chapter identified the modalities in which the data were gathered. Moreover, it established the instrument that was used and introduced the debriefing statement and letters of consent.

CHAPTER FOUR

RESULTS

Introduction

This chapter will introduce the results of the study and will describe the findings regarding needs of children with autism and their parents or caretakers. This needs assessment specifically targeted clients of Focus Psychological and Educational Services Agency. The participants were parents or caretakers of the children served by Focus.

Presentation of the Findings

The needs assessment was composed of closed and open-ended questions ranging from child development and developmental milestones to what parents or caretakers thought they and their children needed. The study was composed of fifteen ordinal questions and six open ended questions. This needs assessment study did not have a dependent or independent variable. The study was conducted to determine what needs children diagnosed with autism and their parents or caretakers have.

Demographics

The sample was composed of twenty-one (n = 21) parents or caretakers who completed the survey. Mothers completed the majority of the surveys (n = 16), totaling seventy-six percent of the total respondents. Nineteen percent (n = 4) were completed by the client's father, and five percent (n = 1) were anonymous. Thirty-three percent (n = 7) of the participants were Hispanic, forty-three percent (n = 9) Caucasian-white, and nineteen percent (n = 4) from the Middle Eastern culture. Children ranged in age from eleven months to fourteen years old with a mean age of five (s.d. = 48.736).

Quantitative Data

The quantitative data consisted of ten ordinal questions. The following table describes the findings and percentages of responses for each category.

Table 1. Quantitative Questions

	Most of the time	Sometimes	Rarely or never	Don't know	Check if this is a concern	Sometimes "and" this is a concern	Rarely or never "and" this is a concern
Does your child talk and/or play with adults he/she knows well?	47.6%	33.3%	14.3%	0	0	0	4.8%
When upset can your child calm down within 15 minutes?	57.1%	19.0%	14.3%	0	0	9.5%	0
Does your child cry, scream, or have tantrums for long periods of time?	9.5%	42.9%	38.1%	4.8%	0	4.8%	0
Does your child do what you ask him/her to do?	19.0%	66.7%	4.8%	0	9.5%	0	0
Does your child use words to tell you what he/she wants or needs?	33.3%	19.0%	33.3%	0	4.8%	0	9.5%
Does your child hurt his/her-self on purpose?	0	28.6%	61.9%	4.8%	0	4.8%	0
Does your child follow rules at home, at childcare?	28.6%	57.1%	0	0	9.5%	0	4.8%
Does your child like to play with other children?	19.0%	42.9%	28.6%	0	9.5%	0	0
Has anyone expressed concerns about your child's behaviors?	4.8%	52.4%	38.1%	4.8%	0	0	0
Can your child stay on task with activities he/she enjoys for at least 15 minutes (not including TV)?	33.3%	57.1%	9.5%	0	0	0	0

The needs assessment revealed that there was a highly significant correlation between a child's chronological age in months and the child being able to calm down when upset within a fifteen-minute timeframe (r = .596, p = .004). A child's chronological age and a child being able to follow rules were found to be significant (r = .448, p = .042). In addition, a correlation was found between a child's chronological age and a child liking to play with other children (r = -.483, p = .027).

A significant correlation was found in a child calming down within fifteen minutes and a child talking and/or play with adults he/she knows well" (r = .462, p = .035). There was highly significant correlation between a child talking and/or playing with adults he/she knows well having lengthy tantrums(r = .000, p = .751), as well as with a child using words to tell you what he/she wants or needs (r = .727, p = .000). A highly significant correlation was also discovered in a child talking and/or playing with adults he/she knows well and a child hurting him/herself on purpose (r = .835, p = .000), and a child following rules (r = .717, p = .000).

A significant correlation was found between a child crying, screaming, or having tantrums for long periods of time and a child being able to calm down within fifteen minutes (r = .541, p = .014). In addition, a significant correlation was also discovered in a child being able to follow rules and a child being able to calm down within fifteen minutes (r = .532, p = .013).

A highly significant correlation was found between a child crying, screaming, or having tantrums for long periods of time and a child hurting him/herself on purpose (r = .801, p = .000). In addition, a highly significant correlation was found between a child crying, screaming, or having tantrums for long periods of time and a child following the rules (r = .610, p = .004).

Another highly significant correlation was found between a child doing what you ask him/her to do and a child following rules (r = .555, p = .009). A highly significant correlation was found between a child using words to tell you what he/she wants or needs and a child hurting him/herself on purpose (r = .561, p = .010). A highly significant correlation was also found between a child hurting him/herself on purpose and a child following rules (r = .634, p = .003), and a significant correlation between a child following rules and using words to express wants(r = .510, p = .018).

Many variables had significant correlations with "does your child follow rules?" These included the child talking and/or playing with adults he/she knows well, being able to calm down within fifteen minutes, crying, screaming, or having a tantrum for long periods of time, the child doing what is asked of him/her to do, and a child using words to tell what he/she wants or needs. Table 2 illustrates the correlations and significance levels of these.

Table 2. Significant Correlation for Does Your Child Follow Rules

	Does your child follow rules?	Pearson Correlation	Sig. (2-tailed)
Does your child talk and/or play with adults he/she knows well?	and	.717	.000
When upset, can your child calm down within 15 minutes?	and	.532	.013
Does your child cry, scream, or have tantrums for long periods of time?	and	.610**	.004
Does your child do what you ask him/her to do?	and	.555**	.009
Does your child use words to tell you what he/she wants or needs?	and	.510*	.018

* Significant < .05.
** Highly Significant < .01.

Table 3. Significant Correlation for Chronological Age

	Chronological age	Pearson Correlation	Sig. (2tailed)
When upset, can your child calm down within 15 minutes?	and	.596**	.004
Child following rules	and	.448*	.042
Does your child like to play with other children?	and	-.483*	.027

* Significant < .05.

** Highly Significant < .01.

Table 4. Significant Correlation for Does Your Child Talk and/or Play with Adults

	Does your child talk and/or play with adults he/she knows well?	Pearson Correlation	Sig. (2tailed)
When upset, can your child calm down within 15 minutes?	and	.462*	.035
Does your child cry, scream, or have tantrums for long periods of time?	and	.751**	.000
Does your child use words to tell you what he/she wants or needs?	and	.727**	.000
Does your child hurt his/herself on purpose?	and	.835**	.000

* Significant < .05.
** Highly Significant < .01.

Table 5. Significant Correlations for When Upset can Your Child Calm Down

	When upset, can your child calm down within 15 minutes?	Pearson Correlation	Sig. (2tailed)
Does your child cry, scream, or have tantrums for long periods of time?	and	.541*	.014
Does your child follow rules?	and	.532*	.013

* Significant < .05.
** Highly Significant < .01.

Table 6. Significant Correlations for Does Your Child Stay on Task

	Does your child stay on task with activities he/she enjoys for at least 15 minutes (not including TV)?	Pearson Correlation	Sig. (2tailed)
Does your child hurt his/herself on purpose?	and	.801**	.000
Does your child follow rules?	and	.610**	.004

* Significant < .05.
** Highly Significant < .01.

Table 7. Significant Correlations for Does Your Child do What You Ask

	Does your child do what you ask him/her to do?	Pearson Correlation	Sig. (2tailed)
Does your child follow rules?	and	.555**	.009

* Significant < .05.
** Highly Significant < .01.

Table 8. Significant Correlation for Does Your Child use Words to Tell you What He/She Wants or Needs

	Does your child use words to tell you what he/she wants or needs?	Pearson Correlation	Sig. (2tailed)
Does your child hurt his/herself on purpose?	and	.561*	.010
Does your child follow rules?	and	.510	.018

* Significant < .05.
** Highly Significant < .01.

Table 9. Significant Correlation for Does Your Child-Hurt His/Herself on Purpose

	Does your child hurt his/herself on purpose?	Pearson Correlation	Sig. (2tailed)
Does your child follow rules?	and	.634**	.003

* Significant < .05.
** Highly Significant < .01.

Qualitative Data

Question #1: Where do you receive services for your child with autism?

The question was answered in two different forms. The majority of the participants listed a site where the therapies take place and other participants listed the source that provides the therapy. A total of eight out of twenty-one participants responded that the Regional Center was a source that provided the services for the child with autism, seven participants listed the school district, and two participants reported that they self fund the services that their child receives.

The larger percentage of participants listed a location where the services take place. A total of twelve out of twenty-one participants reported receiving therapy in the home. Three listed the child's school setting as a location where the services are being provided, and five listed the private office of a speech therapist. In addition, one participant receives speech therapy in their home.

Three participants listed the Occupational Clinic Center as a location where the child receives therapy and another three reported receiving services in a clinic but no specific details were reported. Two reported receiving services in a gym setting where the child receives gymnastics classes.

Question #2: What is your understanding of who pays for the services that your child receives?

All twenty-one participants answered the question appropriately. The majority of the participants listed the Regional Center and local school district as the funder for the services their child receives. Nineteen participants listed the Regional Center as the provider for the services, and thirteen listed a local school district. One participant claimed that their medical insurance paid for some of the services their child receives. Two listed state funds as the source and four claimed that the services were self-funded.

Question #3: What therapy treatment(s) do you think your child needs?

This question had a variety of different answers. The most common answers were Speech Therapy, Occupational Therapy, and Behavioral Therapy. Fourteen participants stated that Speech Therapy was the therapy their child needs; twelve participants stated that their child needs Behavioral Therapy, and nine participants stated needing Occupational Therapy for their child.

Eight participants listed social skills as a needed therapy for their child with autism. One participant listed needing school shadowing for their child, another cited Educational Therapy, and one said they needed Sociological Therapy, Physical Therapy, Academic tutoring, vision, Gymboree, and preschool for their child. One participant listed APE as a form of therapy, but this form of treatment is unknown to the researchers. Three participants listed Floor Time as a needed therapy treatment.

Question #4: How can Focus improve their services?

Multiple answers were given as responses for this question. Four participants suggested having Focus hire trained and passionate therapists, and ensure that existing clients are served before taking on new clients. Four participants requested keeping parents and families informed of program and therapeutic plans for their child with autism. Three participants responded by wanting the child's therapy schedule kept constant. One participant would like Focus to go into the community and educate other parents about autism. One respondent reported, "feeling okay" about the services Focus provides, while another respondent stated "unknown" as a response to how Focus can improve their services.

Question #5: List different therapy treatments that you know exist for children with autism.

Thirteen participants listed Occupational Therapy as a known therapy treatment. Eleven participants listed Speech Therapy, thirteen participants listed Behavioral Therapy, and ten listed Floor Time. Five participants reported social skills group, eight reported music therapy, and six gave feeding therapy as an existing treatment. One participant reported dietary, auditory treatment, and APE therapy, while three respondents left the question blank.

Question #6: What are your needs as the parent or caretaker of a child with autism?

Six participants identified needing support as a parent or caretaker of a child with autism. Four participants reported needing respite care for the child. Three respondents reported needing parent training and educational classes. Two participants reported needing more "therapy" for their child. One participant out of twenty-one participants would like consistent services from Focus. Finally, two respondents out of the twenty-one respondents would like to have less stress.

Question #7: How can Focus help you meet your needs?

Eight participants would like Focus to continue services without a lapse (break) and to provide services of a trained and skilled therapist. Two participants would like a parent support group, and one listed wanting professional services, referrals, and education. Three participants are satisfied with current services, and two participants left the question blank.

Summary

Chapter Four consisted of an overview of the findings of the qualitative and quantitative questions of the study. The chapter identified the frequencies and percentages of the demographic questions. This chapter included the correlations and their significant levels. This chapter also identified the findings on the needs of children with autism and their parents or caretakers.

CHAPTER FIVE

DISCUSSION

Introduction

Chapter Five consists of an overview of the results revealed from the study conducted at Focus Psychological and Educational Services. The results were based on a total of twenty-one participants. This chapter also includes the limitations and recommendations for future social work practice in the field of developmental disabilities.

Discussion

The study was conducted to determine the needs of children with autism and their parents or caretakers. The researchers were given insight into needed services identified by parents or caretakers of children with autism. The information gathered was important for the researchers as well as for Focus Psychological and Educational Services agency. Focus agency was interested in finding out how they can improve and better meet the needs of their clients and their families. By conducting this research study the researchers as well as the agency received valuable information that will help the agency, as well as advance research based on the needs of children with autism and their families.

The surveys collected from the parents or caretakers of autistic children revealed that they were knowledgeable about many services available for children with autism, but lacked emotional support. Many participants stated in the surveys that they lacked parent training, educational classes, and support groups. Parents identified services that can be provided or improved by Focus in order to better meet their needs. These parents recognized that having well skilled and trained therapist would help them meet the needs of their child with autism. In addition, parents identified that having a child with autism significantly increased their stress levels and they reported needing respite care when stressed.

The findings revealed that there was a highly significant correlation between a child being able to talk and/or play with adults he/she knows well and being able to calm down in fifteen minutes. In addition, a child crying, screaming, or having tantrums for long periods of time is more likely to verbalize what he/she wants or needs. A child who can verbalize needs or wants is also able to follow rules more easily. In conclusion, when a child is able to verbalize his/her wants or needs then these behaviors will be minimized.

Parents in the study revealed that more parent involvement in therapies is a great tool for families to overcome stressful situations. In addition, educational trainings and support groups can assist parents in becoming more skilled in dealing with negative behaviors.

A child being able to calm down in fifteen minutes had a highly significant correlation with a child's chronological age. The study revealed that the younger the child is the easier it was for a child to stop crying in fifteen minutes or less because of the lack of communication and not being able to communicate effectively with others, as well as the inability to interact appropriately with known people. Since the child's behaviors are a major concern for parents, providing parent training, education and support will help these parents learn strategies for dealing with these behaviors. Parent training, education, and support groups are empowering to the parents or caretakers because they gain control of situations in their environment, therefore meeting their needs.

The study also revealed a highly significant correlation between a child using words to tell what he/she needs or wants and a child hurting him/herself on purpose. Additionally, being able to communicate correlates with a child being able to follow rules, communication is an important tool for life and the majority of the parents or caretakers stated that their children needed more speech therapy in order to increase language skills.

Limitations

Several limitations were identified in this study. A significant limitation was the cost and time required to complete survey studies. Surveys were mailed out including a self-stamped return envelope to eighty-six Focus clients. A considerable limitation was the small sample received of only twenty-one participants. Grinnell (2005) stated that the primary disadvantage of a mail survey is its low response rate. A person who receives a questionnaire in the mail usually can opt not to participate by passive means such as setting it aside and forgetting it, deciding not to fill it out, or throwing it away.

In addition, four oral interviews were conducted at a Focus parent support group. The support group had a low turn out rate of parents of children with autism, which affected the study. Since response rate was small validity of the data may be in question (Grinnell, 2005).

Colleagues and Focus staff reviewed and determined whether the survey questions were written in simple terminology. Although the researchers, colleagues, and Focus staff agreed that the questions were not deceiving the surveys were returned with varying responses to the same questions. This was a limitation because the questions were not clear to the participants, resulting in a possibility of jeopardizing the validity of the study. A weakness of this study was that it only assessed the needs of children with autism and their parents or caretakers who were Focus clients, which means that the results of this study cannot be generalized to the needs of other children with autism and their parents or caretakers.

Recommendations for Social Work Practice, Policy and Research

The findings of this study have important implications for social workers and other professionals working with people with disabilities. The study furthered research in this area and identified needs that parent's or caretakers of children with autism have in addition to the current services the child is receiving.

The results demonstrated that parents or caretakers were knowledgeable about services available for their child with autism. Parents identified needing more parent training, educational groups, and support groups in order to be consistent with treatment plans. Parent involvement in a treatment plan is crucial in a child's development; therefore implementing more parent training, education, and support groups is important and empowers the parents or caretakers. Providing emotional support for these families and meeting desired needs may decrease their stress levels. Social workers can help parents and caretakers cope with the emotional stresses and responsibilities required to effectively care for a child with disabilities.

This study was useful for helping social workers and other professionals specializing in developmental disabilities become aware of the needs of the parents or caretakers of children with autism. Overall, this study provided the opportunity to expand knowledge and understanding of the needs of children with autism.

Conclusions

The purpose of this study was to gather information for professionals in the field of social work, and to identify the needs of children with autism and their parents or caretakers. In addition, Focus Psychological and Educational Services staff was interested in this study and its findings in order to better accommodate and serve their clients and families.

APPENDIX A

NEEDS ASSESSMENT INSTRUMENT

Needs Assessment Instrument

What are the Needs of Children with Autism and their Parents or Caretakers?

Please provide the following information.

Chronological Age: ______________________

Childs Ethnicity: ______________________

Today's date: ______________________

Person filling out this survey, what is your relationship to the child?

____

Please read each question carefully and check (✓) the box that best describes the needs of your child and yourself.

	Most of the time	Sometimes	Rarely or never	Don't know	Check (✓) if this is a concern
Does your child talk and/or play with adults he/she knows well?					
When upset, can your child calm down within 15 minutes?					
Does your child cry, scream, or have tantrums for long periods of time?					
Can your child stay on task with activities he/she enjoys for at least 15 minutes (not including watching television)					
Does your child do what you ask him/her to do?					
Does your child use words to tell you what he/she wants or needs?					
Does your child hurt his/herself on purpose?					
Does your child follow rules (at home, at child care)?					
Does your child like to play with other children?					

	Most of the time	Sometimes	Rarely or never	Don't know	Check (✓) if this is a concern
Has anyone expressed concerns about your child's behaviors? If you checked (✓) "sometimes" or "most of the time," please explain:					

Open Ended Questions

Where do you receive services for your child with autism?

What is your understanding of who pays for the services that your child receives?

What therapy treatment(s) do you think your child needs?

Are you pleased with the services you are receiving at Focus?

How can Focus improve their services?

What do you think is the appropriate school placement for your child?

List different therapy treatments that you know exist for children with autism?

What are your needs as the parent and/or caretaker of a child with autism?

How can Focus help you meet your needs?

APPENDIX B

INFORMED CONSENT

Informed Consent

This study is designed to gather information on what children diagnosed with autism and their parents or caretakers need. It is being conducted by Dannely Hernandez and Soé Myrna Cortez under the supervision of Dr. Rosemary McCaslin, Social Work Professor at California State University, San Bernardino. The Social Work Sub-Committee of the Institutional Review Board at California State University, San Bernardino, has approved the study.

The survey is composed of twenty-three questions about the perceived needs of you and your child. This survey should take about 20 minutes to complete. All your responses will be held in the strictest of confidence by the researchers. Your name will not be required, as the survey is completely anonymous. You may request and receive the results of this study upon completion, and it will be available by September 2006 at the Pfau Library at Cal State University of San Bernardino or from the Focus office.

Your participation in this interview is completely voluntary, and will not affect the services you receive from Focus. There are no foreseeable risks to participating and no direct benefits. However, it may help to improve agency services. You are free not to answer any questions and withdraw at any time during this interview without penalty. You will also receive a debriefing statement that describes the study in a more detailed manner.

If you have any questions or concerns about this study, please feel free to contact Dr. Rosemary McCaslin at (909) 537-5507. By placing a checkmark in the box below, I acknowledge that I understand and have been informed of the nature of the proposed interview. I am a parent or caretaker of an autistic child and I am at least 18 years of age.

Place check mark here ☐ Today's date: ________________

APPENDIX C

INFORMED CONSENT FOR ORAL INTERVIEWS

Informed Consent for Oral Interviews

This oral interview is designed to gather information on what children diagnosed with autism and their parents or caretakers need. It is being conducted by Dannely Hernandez and Soé Myrna Cortez under the supervision of Dr. Rosemary McCaslin, Social Work Professor at California State University, San Bernardino. The Social Work Sub-Committee of the Institutional Review Board at California State University, San Bernardino, has approved the study.

The oral interview consists of twenty-three questions about the perceived needs of you and your child. This interview should take about 20 minutes to conduct. All your responses will be held in the strictest of confidence by the researchers. Your name will not be required, as the interview is completely anonymous. You may request and receive the results of this study upon completion, and it will be available by September 2006 at the Pfau Library at Cal State University of San Bernardino or from the Focus office.

Your participation in this interview is completely voluntary, and will not affect the services you receive from Focus. There are no foreseeable risks to participating and no direct benefits. However, it may help to improve agency services. You are free not to answer any questions and withdraw at any time during this study without penalty. You will also receive a debriefing statement that describes the study in a more detailed manner.

If you have any questions or concerns about this study, please feel free to contact Dr. Rosemary McCaslin at (909) 537-5507. By placing a checkmark in the box below, I acknowledge that I understand and have been informed of the nature of the proposed study. I am a parent or caretaker of an autistic child and I am at least 18 years of age.

Place check mark here ☐ Today's date: ______________

APPENDIX D

DEBRIEFING STATEMENT

Debriefing Statement

This study was conducted by Dannely Hernandez and Soé Cortez, two Masters of Social Work students at California State University, San Bernardino. The study will determine the needs of children with autism and their parents or caretakers. The data collected from the needs assessments will assist Focus Psychological and Educational Services to develop interventions to meet those needs.

Thank you for your participation and effort in assisting Social Workers with the needs of children with autism and their families. This information is crucial in helping us provide better services to our clients. You may request and receive the results of this study upon completion in the Pfau Library at Cal State San Bernardino or the Focus office it will be available by September 2006. If you have any questions or concerns you may contact Dr. Rosemary McCaslin at (909) 537-5507.

Thank you,

Dannely Hernandez, MSW candidate
Soé Myrna Cortez, MSW candidate

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ASSIGNED RESPONSIBILITIES PAGE

This was a two-person project where authors collaborated throughout. However, for each phase of the project, certain authors took primary responsibility. These responsibilities were assigned in the manner listed below.

1. Data Collection:

   Team Effort Dannely Hernandez & Soé Cortez

2. Data Entry and Analysis: Team effort

   Team Effort Dannely Hernandez & Soé Cortez

3. Writing Report and Presentation of Findings:

   a. Introduction and Literature

      Team Effort Dannely Hernandez & Soé Cortez

   b. Methods

      Team Effort Dannely Hernandez & Soé Cortez

   c. Results

      Team Effort Dannely Hernandez & Soé Cortez

   d. Discussion

      Team Effort Dannely Hernandez & Soé Cortez