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Victoria Rivera Martinez

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Julie R. Miller
Major Professor's Signature

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THE ECOLOGY OF EXPERIENCES AND SUPPORTS OF MOTHERS WITH CHILDREN WITH AUTISM SPECTRUM DISORDER DURING THE CHILDREN'S EARLY YEARS

By

Victoria Rivera Martinez

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ABSTRACT

THE ECOLOGY OF EXPERIENCES AND SUPPORTS OF MOTHERS WITH CHILDREN WITH AUTISM SPECTRUM DISORDER DURING THE CHILDREN'S EARLY YEARS

By

Victoria Rivera Martinez

The objective of the research study was to explore the experiences, perspectives, influences and challenges of selected mothers with children with autism spectrum disorder (ASD) as they live, work, advocate, access information, gain assistance and support for their children. The population trends indicate a marked increase in the prevalence of autism spectrum disorder in our country and state (U.S. Department of Education, 2009; Michigan Public Schools Prevalence Report, 2004). These trends are significant enough that we need to provide research that will study the families who are directly involved in caring for children with autism spectrum disorders (ASD). Research has shown that mothers have the primary responsibility for taking care of the child with a disability (Traustadottir, 1991; Leiter, Krauss, Anderson and Wells 2004). Since the mother's central responsibility is caring for the child, it is very important to study the social support networks and experiences of mothers who care for a child with ASD.

The study utilized a qualitative design to allow for the systematic collection, organization, interpretation and analysis of rich data about human experiences through open-ended, semi-structured, interviews. The phenomenological approach is used for collecting, coding and analyzing the data. In- depth interviews explored and examined the participant's perspectives and experiences that occurred during 1) pre and postdiagnosis of the child's ASD; 2) identification of participants' social support systems; 3) participants' perceptions of levels of support in the ecological systems in which they participated; and 4) evaluation of the intensity of participants' perceived social support.

The study was conducted utilizing a small sample of thirteen mothers across different racial/ethnic groups, age, family compositions, locations, and socio-economic status. Research results indicate that the mothers are very involved in caring for the child and accessing services in support of themselves and their children framed in Bronfenbrenner's ecological systems theory. Mothers reported getting strong support with varying degrees of perceived stress from parents, spouses and significant partners, friends, social affiliations/networks and service providers. Perceived barriers included lack of financial, medical, and educational supports and access for the child's health condition, lack of support services for second language speakers, lack of compassion from service providers, and miscommunication in service delivery.

A strong family- based support approach needs to be applied in servicing the needs of families and children with autism spectrum disorder, with consideration and attention to the ecological support systems attending to the needs of the mothers and the children. Mothers could be empowered to engage with other families and practitioners in the planning and implementing of service delivery for their children with ASD. Service providers should recognize the emotional, social, educational, and financial support needs and rights of parents and children. Promoting constructive feedback, compassionate interactions and nurturing relationships between parents with service providers should be the hallmark of an effective support and service delivery system for parents with children with autism spectrum disorder.

DEDICATION

To my husband, Art, and my sons, Adam and Aaron, you have been my constant inspiration, my happiness, and my life. Thank you for always being so loving, patient and understanding throughout this journey. Art, what a privilege and an honor to be your wife and mother of our children!

I dedicate this work in loving memory to my father, Dominador T. Rivera, who strongly believed in education, honesty, and hard work. I also dedicate it to my mother, Victoria V. Rivera, who instilled in us the joy of learning, optimism, and prayerful life.

Thank you, Lord, for all your blessings to our families.

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INTRODUCTION

Statement of the Problem

According to the federal government and the provision contained in the Developmental Disabilities Assistance and Bill of Rights Act Amendments of 1990, the term "developmental disability means a severe, chronic disability of a person 5 years of age or older which is attributable to mental or physical impairment or combination of mental and physical impairments; is manifested before the person attains age twenty-two; is likely to continue indefinitely; results in substantial functional limitations in three or more following areas of major life activities of self care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living and economic self-sufficiency. When applied to infants and young children from birth to age 5, developmental disability means substantial delay or specific congenital or acquired conditions with high probability of resulting in developmental disability if services are not provided (Wolfe, 1992). Autism spectrum disorder (ASD) is a category under developmental disabilities.

Numerous studies have reported a high increase in the diagnosis of autism spectrum disorder in the past twenty years with ASD representing the most common neurodevelopmental disorder (Lawler, 2008). In the United States, the Center for Disease Control and Prevention (2007) has found that one out of one hundred and fifty children in its multi-site study in 2002 had autism spectrum disorder (ASD). This disorder is four times more likely to occur in boys than girls. Autism spectrum disorder is the fourth most commonly diagnosed disorder after specific learning disabilities, speech/language impairment and mental retardation.

In 2004, there were 693,245 children ages 3-5 years old who were served under the Individuals with Disabilities Education Act (IDEA). The number and percentage of children and youth ages 3-21 receiving special education services in regular classrooms increased nearly every year since the inception of IDEA (U.S. Department of Education, 2009).

The Center for Disease Control and Prevention conducted two national surveys of parental report of diagnosed autism with children 4-17 years of age in 2003-2004. The National Health Interview Survey (NHIS) covered 18,885 children and the National Survey of Children's Health (NSCH) had 79,590 children with data similar across, sex and racial/ethnic populations. The results showed consistency and suggest high reliability with NHIS reporting prevalence rate of 5.7 per 1,000 children and a rate of 5.5 per 1,000 children for NSCH. There are at least 300,000 children from ages 4-17 with autism in the United States in 2003-2004 (CDC, 2006). In 2005, the Center for Disease Control and Prevention (2009) recorded that there are 193,637 children aged 6 through 21 years receiving services for autism up from a reported 22,664 children from 1994.

The Institute of Medicine (IOM, 2007) Report stated that" the trend showed that over a 40 year period, the proportion of children reported to have major limitations in their activities related to play and school had gone from less than two per cent (2%) to close to seven per cent (7%). The trends in the epidemiology of childhood illness and functioning includes a marked increase in the treatment of learning-related disabilities like autism spectrum disorder with its broader range of conditions (Asperger's syndrome, other childhood disintegrative disorders, pervasive developmental disorder, unspecified), and better identification of medical and health professionals of disorders (IOM, 2007).

The U.S. Department of Education reported that there are 3,449 children aged 6-21 served by the Individuals with Disabilities Education Act (IDEA) in Michigan who had autism in 1999-2000, up from 288 children reported in 1992-1993 (U.S. Department of Education, 2009). In another Michigan report, it stated that there are 7,259 children in the state between the ages of 3-22 years old with autism in 2003 with the increase in prevalence attributed to younger children with autism, and a 437% cumulative growth rate in autism diagnoses from 1992-2003 (Michigan Public Schools Prevalence Report, 2004.)

In 2005, the Michigan Birth Defects Registry Vital Records reported that there were 10,762 cases of birth defects for children less than one year of age for a rate of 840.0 cases per 10,000 live births. For the same children born during 2005, there were 12,095 cases reported for children less than two years of age. This translates into a prevalence rate of 944.0 cases per 10,000 live births (Michigan Department of Community Health, 2005).

Population trends indicate the prevalence of developmental disabilities of children in general, and autism spectrum disorder, in particular, is a continuing concern for our families, communities, and country. The marked increase in autism prevalence is systemic across the United States (Michigan Public Schools Autism Prevalence Report, 2004). These trends are significant enough that we need to provide research that will study the families who are directly involved with caring for children with autism spectrum disorders (ASD). There are social, economic, and moral dimensions to this problem. There is a need to study the role of families, especially mothers, in assisting their children with autism spectrum disorder, and to identify the social support systems that will assist the families in accessing early intervention services. Furthermore, there is a need to involve and engage the families in programs that will assist them in caring for the children, and making sure that the children have equal opportunities to education and societal opportunities for possible employment and independence.

This research study highlights the important role of mothers in caring for children with ASD. The birth of a child is a source of great anticipation in the family and the awareness that the child may have been born with challenging characteristics, especially for the mother, is a source of utmost concern. Research has shown that mothers have the primary responsibility of taking care of the child with a disability. Following the trends that roles of caring for children with disabilities are still assigned according to gender, women still traditionally hold this status even in current society (Traustadottir, 1991). The research of Leiter, Krauss, Anderson and Wells (2004) indicated that "maternal caregiving could reach almost 20 hours a week of home health care to children with special needs and that this intense caregiving occurs largely during the child's early and formative years." With the mothers' central responsibility of caring for the child, it is very important to study the social support networks that will scaffold them in assisting their children with a disability. Social supports may come from the immediate family, the extended family, medical and professional communities, schools and institutions. In family theory and therapy, studies are being conducted on the positive and negative influences of persons around the nuclear family (Seligman, Goodwin, Paschal, Applegate and Lehman,1997). According to Dunst, Trivette and Deal (1997), the presence of different forms of support to families with identified needs enriches parent and family well being, decreases time demands on the family with a disability, and provides the parents with positive perceptions of the child's abilities. This study will significantly contribute to research on maternal roles, experiences, and social support systems with families of children with autism spectrum disorder.

Background of the Study

Definition of Developmental Disabilities and Autism Spectrum Disorder

The Centers for Disease Control and Prevention (2008) states that people with developmental disabilities have problems with major life activities such as language, mobility, learning, self help and independent living. These disabilities usually last throughout a person's lifetime. This position aligns with the mandated definition of the federal government. Autism spectrum disorder is a neurological developmental disability that affects the individual's cognitive development, social communication, behavioral skills and sensorial integration processes. The broad category of autism spectrum disorder includes autism or "classic" autism, Asperger Syndrome, pervasive developmental disorder not otherwise specified, Rett syndrome and childhood disintegrative disorder (Volkmar et al, 2005)

Legislations in support of persons with disabilities

There were major legislations affecting individuals with developmental disabilities in the period from 1970 onwards. The Developmental Disabilities Services and Facilities Construction Act (P.L. 91-517) in 1970 first established the concept of "developmental disabilities. The Education for All Handicapped Children's Act (P.L. 94-142) in 1975 guaranteed a free and appropriate education to all children. In 1990, this Act was reauthorized by Former President George H.W. Bush into the Individuals with Disabilities Education Act (IDEA). The Act included people before the onset of the disability, expanded the definition of disability to include children with autism and traumatic brain injury, and provided support for students with serious emotional disturbances. The Individuals with Disabilities Education Act Amendments of 1990 (IDEA) required all states to provide free and appropriate education for all children age 3 through 5 years with disabilities, and required states to provide services to infants and toddlers from birth through 2 years of age with disabilities. These services are called early intervention services that were directed for prevention and intervention (Anderson, R. & Littman, R., 1992). The U.S. Department of Education and each state's Department of Education was required to record and report specific childhood disabilities including autism every school year by virtue of IDEA. The autism spectrum category was included in the reporting requirement in 1991, and it was only until 1992 that most states started reporting the number of diagnosed cases of autism to the federal government (Michigan Public Schools Autism Prevalence Report, 2004). Since then, every state has reported an increase in the number of students with autism (Yazbak, 2003).

The American with Disabilities Act strengthened the rights of persons with disabilities by extending the civil rights for individuals and providing access in employment settings, public transportations and public establishments (Wolfe, 1992).

In 1997, Congress passed amendments to IDEA that required states to collect data on race/ethnicity of students identified as having special education needs. The most recent reauthorization of IDEA was in 2004 (U.S. Department of Education, 2008).

These legislations made an impact in political rights of parents with children with disabilities, and mandated schools and institutions to comply with the standards of the law. But, much needs to be done in the area of applying the law to the practice of caring for children with disabilities and their families.

Purpose of the Study

The purpose of this research study is to explore the experiences, perspectives, influences and challenges of mothers with children with autism spectrum disorder as they live, work, advocate, access information, assistance and support for their children. Specifically, the following research questions are addressed in this research study:

1. What are the mothers' experiences and perspectives during the period of early detection and period of diagnosis of the child's autism spectrum disorder (ASD)?
2. What are the mothers' experiences of social support systems that affect, influence, assist and challenge mothers in assisting their children during their early years (birth to early years)?
3. Using Bronfenbrenner's ecological systems theory, what are the mothers' levels of social support in the four systems: microsystem, mesosystem, and exosystem and macrosystem?
4. What are the mothers' perspectives of the relationships and support systems that offered the highest degree of support to the mothers with children with autism spectrum disorder?

Significance of the Study

Although there is a lot of research on parental engagement and family involvement especially with the general education population, there is still much to be studied regarding the research on maternal perspectives of parents with children with autism spectrum disorder during the child's early years of birth. Dale, Jahoda, and Knott (2006) indicated that there is a need to explore the mothers' experiences as they try to make sense of their children's condition and diagnosis. This research study will address the mothers' experiences during early detection and diagnosis of the child's autism spectrum disorder. It is important to study the mothers' experience at this early stages since this will provide a basis of understanding their perspectives, responses, intensity of reactions, and sources and intensity of supports in particular settings. This will be a qualitative study for the researcher to capture the richness of the mothers' experiences and perspectives as they navigate their way through the special education system.

This research study will be invaluable to the academic community, medical/ healthcare specialists, special education community and mental health professionals. The research will provide information for families with children with autism spectrum disorder, and will assist them with wrap-around, consistent care and support services. Potentially, a level playing field for families with children with disabilities can be provided. In addition, professionals that are involved in early intervention could use this information of effective informal and formal support systems to improve best practices.

The study will make a contribution to the knowledge base of maternal and familial perspectives regarding autism spectrum disorders, generate research interest in this area of special education, and establish the trustworthiness of utilizing human ecology theories in framing the experiences of families with disabilities. Furthermore, it will positively contribute to the improvement of support systems and service delivery to families with children with autism spectrum disorders and other developmental disabilities.

Rationale for the Qualitative Study

The qualitative design of this research study will document the mothers' experiences and perspectives in detail, and provide a holistic, contextual approach to collecting, categorizing and analyzing data. Cresswell (1994) defined the qualitative method as process of problem solving utilizing a holistic approach of detailed views of participants conducted in natural settings. By using semi-structured interviewing the study will be able to guide, provide probing questions, and enable the participants to share their experiences, perspectives, and social support systems in context, and explain the phenomenon of living with autism spectrum disorder. The research will utilize the phenomenological analysis as the means of collecting data on experiences and meanings, coding data, and integrating themes to provide a holistic interpretation of the experiences of the participants (Willig, 2001).

Theoretical Framework/Conceptual Model

The concept of social support human networks is closely tied to the ecological systems theory of human development. The mothers' experiences as they relate to their relationships with their children, their spouses, their immediate and extended family members, and institutional service providers will be closely explored. The mothers' interrelationships in the context of schools, neighborhoods and communities in which they live and raise their families are included in the context of their experiences living with their children with autism spectrum disorder. The mothers' experiences, perspectives, influences, and support systems will be framed and examined within the theoretical framework of Bronfenbrenner's ecological systems theory.

The ecology of human development is defined as the "scientific study of the progressive, mutual accommodation between the developing person and the changing properties of the immediate and broader contexts in which the person lives (Bronfenbrenner, 1979, p.21)." The lives and experiences of the mothers with children with autism spectrum disorders will be described utilizing the ecological systems approach as it provides a multi-perspective, multi-layered analysis of the research.

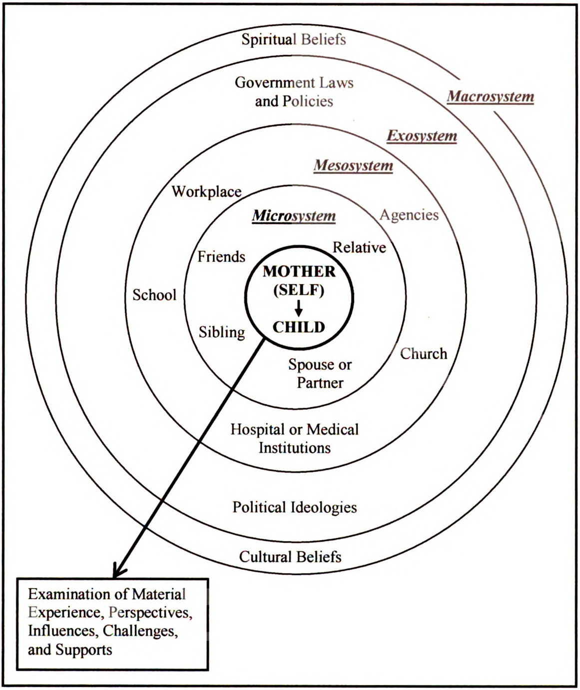


Figure 1: Theoretical Model: Mother's experiences and supports nested in Bronfenbrenner's Ecological Systems Theory

Bronfenbrenner (1979, pp. 23-26) defines the different systems, thus:

> *A microsystem is a pattern of activities, roles, and interpersonal relations experienced by the developing person in a given face-to face setting with particular physical and material features containing other persons with distinctive characteristics of temperament, personality and systems of belief.*
>
> *The mesosystem comprises the linkages and processes taking place between two or more settings containing the developing person (relations between home and school, school and workplace). It is a system of microsystems.*
>
> *The exosystem encompasses the linkage and processes taking place between two or more settings, at least one of which does not ordinarily contain the developing person, but in which events occur that influence processes within the immediate setting that does contain that person (for a child, the relation between the home and the parent's workplace; for a parent, the relation between the school and the neighborhood group).*
>
> *The macrosystem encompasses the culture as a whole in forms of social organization and associated beliefs and lifestyles.*

The microsystem consists of the mother, child, siblings, and spouse (as applicable) having the immediate family in the very first layer of this ecological systems theory. By examining the mesosystem, the study allows the researcher to examine the mothers' relationships with extended families, friends, workplaces, schools or non-profit agencies, and their networks of support. The exosystem is another layer that is pertinent to the discussion because it encompasses the state and federal government's policies and directives regarding children with autism spectrum disorder and other developmental disabilities. The macrosystem consists of the beliefs and value systems of the bigger culture that affects the families' successes in accessing services and opportunities for the children with autism spectrum disorder.

The mothers' experiences will be explored in the context of their relationships with their immediate and extended families and maternal perspectives of social supports from the circle of friends, schools, institutions, and governments. The study will examine their perspectives as they advocate, support, and assist their children for equal opportunities to support services, education and placement.

Terminology

American with Disabilities Act (ADA)

The Americans with Disabilities Act protects the civil rights of individuals with disabilities similar to those provided to individuals on the basis of race, color, sex, national origin, age, and religion and the law guarantees equal opportunity for individuals with disabilities in public accommodations, employment, transportation, State and local government services, and telecommunications (ADA, 2009).

Autism Spectrum Disorder (ASD)

Autism Spectrum Disorder is a complex neurological developmental disorder classified into five broad categories of disorders namely: autistic disorder, Asperger syndrome, pervasive developmental disorder not otherwise specified, Rett syndrome and childhood disintegrative disorder (Daniels, 2006; O'Brien & Daggett, 2006)

Center for Disease Control and Prevention (CDC)

The Center for Disease Control and Prevention is an agency under the U.S. Department of Health and Human Services responsible for developing and applying disease control and prevention activities, environmental health, health promotion and education in order to improve the health of the United States population (CDC, 2009).

Developmental Disability

Developmental disability means substantial delay or a specific congenital or acquired condition with a high probability of resulting in a developmental disability if services are not provided (U.S. Department of Health and Human Services, 2009).

Ecological Systems Theory

Ecological systems theory defines the person's development within a complex system of relationships affected by multiple levels of the surrounding environment into four nested structures: microsystem, mesosytem, exosystem and macrosystem (Bronfenbrenner, 1979).

Individual with Disabilities Education Act (IDEA)

The Individuals with Disabilities Education Act (IDEA) is a law ensuring early intervention, special education and related services to children with disabilities throughout the country by state governments and public agencies (IDEA, 2009).

Phenomenology

Phenomenology is a qualitative research approach that explores subjective experiences and defines the meaning, structure and essence of the lived experience or "phenomenon" by a person or group of people (Moustakas, 1988; Spinelli, 1989; Patton, 2002).

Limitations of the Study

The study is limited geographically to residents of Michigan so it cannot be generalized to the population. The small number of participants may limit the significance of conclusions that may be derived from the research study. The use of purposive sampling discourages the generalizability to the population due to the focused research on mothers with children with autism spectrum disorder.

The data collection design of using face-to-face interviews where the researcher is present may encourage socially acceptable responses to the questions. Additionally, the participants' responses may also be affected by the disclosure of the researcher being a mother with a child with autism. The use of the phenomenological method of analysis has limitations in terms of interpretation due to the "representational validity of language" (Willig, 2001). By using the phenomenological method, the participants will express the experience in context and the researcher will transcribe the experience based on the words used and expressions conveyed by the participants during the interview and will be subject to the interpretation of the researcher.

Summary

The study utilized a qualitative design with semi-structured interviewing that focused on experiences, perspectives, influences and social support systems of mothers as they live, work, advocate, support, and acquire assistance and supports for their children with autism spectrum disorder. It explored their actual experiences and perspectives and detailed the phenomenon of being a mother with a child with autism spectrum disorder. It focused on capturing the lives and experiences of mothers who journey with their children with autism and create a picture of their everyday realities, challenges, supports, and their dreams for the future of their children.

The study framed the mothers' experiences using Bronfenbrenner's ecological systems theory. Population data, public policies and trends in research are discussed to provide a general background of the state of disabilities. The study included information on the significant changes in the past couple of years in the area of children's disabilities in general and autism spectrum disorder in particular such as: inclusion of diagnoses, awareness of medical and professional practitioners, newer research on special education, and government regulations.

The study can contribute to the understanding of maternal perspectives of having a child with autism spectrum disorder and provide ways for families to be able to relate more effectively with immediate and extended networks of relationships in support of their families and children. Furthermore, the study identified and explored the similarities and differences of the mothers' experiences. This information can assist in identifying positive patterns in families and community relationships and improve service delivery. The study can contribute to the body of knowledge by enabling and empowering the parents to be able to access support services with solid knowledge of policies and best practice, and assist families to effectively work with schools, agencies, governmental institutions, and healthcare professionals.

CHAPTER 2

REVIEW OF LITERATURE

The concept of social support human network is closely tied to the ecological approach to the study of human development. The ecology of human development has been defined as the "scientific study of the progressive, mutual accommodation between the developing person, and the changing properties of the immediate and broader contexts in which the person lives (Bronfenbrenner, 1979, p.21)." The lives and experiences of mothers with children with autism will be described utilizing the ecological systems approach as it provides a multi-perspective analysis of the research. The review of literature will address the following topics: 1) Discussion of developmental disabilities and autism spectrum disorder; 2) Research on Autism Spectrum Disorder; 3) Quality of Life; and 4) Role of the Mother as the primary parent; 5) Support Systems.

Discussion of Developmental Disabilities and Autism Spectrum Disorder

Childhood disability is defined in many different ways depending upon the intent of the policy, program or research for which the term is being used (Aron, Loprest and Steuerle, 1996). These definitions can be based on self-reports of limitations, particular conditions, or program involvement, for example, enrollment in Supplemental Security Income (SSI). The definition developed by Hogan, Msall, Rogers & Avery (1997) for children ages 5-17 using the National Health Interview Survey-Disability Supplement or NHIS-D is based on having a limitation in at least one of the four domains: 1)learning; 2) self care; 3) mobility; and 4) communication. The population characteristics of the sample of children in the NHIS-D report are as follows: approximately, 3.9 million (8%) of children between the ages of five and seventeen experience some sort of disability with the top categories of limitation in children reported as follows: learning limitation, 88% of the total number of children with disabilities, communication limitation (25%), a mobility limitation (15%) and self care limitation (9%) (Hogan, Msall, Rogers & Avery, 1997).

The federal government defined the term "developmental disability" as a severe, chronic disability of a person 5 years of age or older which is attributable to mental or physical impairment or combination of mental and physical impairments; is manifested before the person attains age twenty-two; is likely to continue indefinitely; results in substantial functional limitations in three or more following areas of major life activities of self care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living and economic self-sufficiency. When applied to infants and young children from birth to age 5, developmental disability means substantial delay of specific congenital or an acquired condition with a high probability of resulting in a developmental disability if services are not provided (U.S. Department of Health and Human Services, 2009). There is still a lot of ambiguity regarding the definition of developmental disability even after the term was stated and legislated by the federal government. Hamner and Turner (2001) stated that the research of Hahn and Kauffman (2000) defined developmental disabilities as kinds of diagnoses that may overlap with other conditions. The diagnoses may change over time. Furthermore, many exceptional children remain undetected, and often parents resist having their children identified as exceptional because of the stigma attached to labeling their children with the diagnosis.

The term "autistic" was first used as an entry in the 1912 American Journal of Insanity indicating "instances where thought is divorced from logic and reality" as stated in the Oxford English Dictionary (O'Brien & Daggett, 2006). In 1922, the Swiss scientist Eugen Bleuler used the term "autism" and "autistic thinking" to describe "loss of contact with reality" (Asperger, 1991). Leo Kanner in 1943 described the syndrome of childhood autism in a clinical seminal study of 11 children with "autistic disturbances of affective contact" (Volkmar et al, 2005). Kanner indicated that children with this syndrome have a constitutional disorder lacking in social interaction and affective communication. The condition was labeled early infantile autism often misdiagnosed as having mental retardation or schizophrenia (Volkmar et al, 2005; O'Brien & Daggett, 2006). Hans Asperger elaborated on autism disorder in 1944 and called it "autistic psychopathy" (Asperger, 1991). Individuals diagnosed with Asperger syndrome have problems in communication and social skills but have better language abilities and may achieve more successful adaptation (Frith, 1991).

There is a wide continuum of ranges of severity for the autism spectrum disorder with some children exhibiting severe language disorders but good motors skills and no sensory problems while others are challenged socially but gifted with language skills (O'Brien & Daggett, 2006).

Autism spectrum disorder is one of the thirteen categories of developmental disabilities. It is a complex neurological developmental disorder with three classifications, namely, autistic disorder or classic autism, Asperger syndrome and pervasive developmental disorder not otherwise specified (Daniels, 2006). However, according to O'Brien and Daggett (2006), the Diagnostic and Statistical Manual of Mental Disorders Fourth Edition has classified the autism spectrum disorders (ASDs) into five broad categories of disorders namely: autistic disorder, Asperger syndrome, pervasive developmental disorder not otherwise specified, Rett syndrome and childhood disintegrative disorder. The autistic disorder or "classic autism" is Kanner's original diagnosis of children having social communication difficulties, repetitive and patterned behavior and restrictive range of activities. Asperger syndrome shows social deficits and repetitive behavior but shows no communication or cognitive delay. Children with Asperger syndrome often score high on Intelligence Quotient (IQ) tests and show high general intelligence but struggle in social situations. Pervasive Developmental Disorder-not otherwise specified is a variable diagnosis depending on the degree of severity and subjective professional evaluations. This applies to children who meet some of the criteria of autism, but not the social, behavioral or developmental core areas. These children may exhibit degrees of social problems in peer interactions, or a range of speech language delays and behavioral challenges. Rett syndrome is a rare, genetic, disorder most commonly found in girls that causes physical, mental and neurological decline. Lastly, childhood disintegrative disorder is a rare condition diagnosed with children who suffer developmental decline in language, motor or social development. This developmental decline results in severe autism disorder with concurrent mental retardation and seizure disorders (O'Brien & Daggett, 2006).

The Center for Disease Control and Prevention (2009) describes autism as a disability that affects social interaction, communication, sensory integration, and consists of unusual behaviors and interests with varying ways of learning. The disorder begins before the age of three years old and lasts through adulthood (CDC, 2009). The autism spectrum disorder is a behaviorally based diagnosis ranging from mild to severe with the low functioning person with autism exhibiting non-verbal characteristics, cognitive impairment, self-injurious and social disconnection to higher functioning abilities of persons with autism consisting of above average cognitive ability, verbal and social interactions but with idiosyncratic tendencies (Newschaffer & Curran, 2003).

Nevertheless, there are considerable needs for services and supports for children with autism since it is a lifelong impairment, and may have concurrent medical conditions such as Fragile X syndrome, tuberous sclerosis and neurofibromatosis (Gilberg & Coleman, 1996). According to the CDC report (2009), there was a marked increase in 2005 of 193,637 children aged 6 through 21 years receiving services for autism up from a reported 22,664 children in 1994.

The Autism and Developmental Disabilities Monitoring Network (ADDM) of the CDC (2009) through its seven sites (Arizona, Georgia, Maryland, New Jersey, South Carolina and West Virginia) in the United States reported that the average autism spectrum disorder (ASD) prevalence was 6.7 per 1,000 for 8 year olds in the year 2000 and 6.6 per 1,000 8 year olds in 2002 which amounts to 1 in 150 children. This study disclosed that the ASD prevalence was higher among boys than girls with median age of earliest ASD diagnosis around the ages of four years and four months to four years eight months. Internationally, the study reported that countries in Europe and Scandinavia found 12 in 1, 000 children diagnosed with autism (CDC, 2009).

Research on Autism Spectrum Disorder

The last two decades have seen a surge of public interests in the area of autism spectrum disorder. There are national and international research currently ongoing to address its causes with risk factors that are both genetic and environmental. Research in early intervention programs has also showed marked increase in funding (Lawler, 2008).

With greater funding allocated to research and higher public attention to autism, there has been a higher number of diagnosed cases of autism in children making it the fourth most diagnosed developmental disability after specific learning disability, speech/language impairment and mental retardation.

According to Lawler (2008), increased funding for autism spectrum research can be accounted for due to increased changes in awareness, diagnostic practices and availability of services. There is a need to discuss environmental agents such as pesticides, agrichemicals, pharmaceuticals, nutrition and lifestyle (Lawler, 2008). Family studies have indicated that there are genetic implications related to the cause of autism (CDC, 2009). The studies among identical twins have shown that there is a 75% probability of the other twin being affected if one child has autism; in non-identical twins, the probability is 3%. Additionally, there is a 2%- 8% chance that parents with children with autism could have other children that would have the disorder (CDC, 2009). In 1944, Asperger wrote that there is evidence of genetic predisposition and similar familial characteristics of autism in family members. Recent findings indicated that "autism spectrum disorders have a high degree of inheritability (Volkmar et al, 2005). The cause of autism in children has also been reported to be linked to the measles-mumps-rubella (MMR) vaccine and the diphtheria-pertussis-tetanus' (DPT) use of thimerosal, a type of mercury used in childhood vaccines. Parents were very concerned about its causal implication to autism spectrum disorders. According to O'Brien and Daggett (2006), studies in Denmark, United Kingdom and California had shown no causal connection of measles-mumps-rubella (MMR) to autism spectrum disorders. In 2004, the Institute of Medicine of the National Academy of Sciences with its Immunization Safety Review Committee reported that there is no causal link between vaccines and autism spectrum disorders, and not vaccinating against diseases poses a greater risk to children (O'Brien & Daggett, 2006).

Various agencies have started promising research projects on the autism spectrum disorder. Research funding for autism has increased from $11 million in 1995 to $56 million in 2001 (Newschaffer & Coleman, 2003). In 2001, the National Institute of Environmental Health, U.S. Environmental Protection Agency funded the University of California Davis' Center for Children's Environmental Health and Disease Prevention. This Center conducted the Childhood Autism Risks from Genetics and the Environment Study (CHARGE) using the large scale population epidemiology study of genetic and environmental risk factors for autism (Hertz-Picciotto et al, 2006).

The Center for Disease Control and Prevention (2009) started the Centers for Autism and Developmental Disabilities Surveillance and Epidemiology (CADDRE) to work on a large population based study called SEED (Study to Explore Early Development). This study examined the physical and behavioral characteristics of autism, health and scientific conditions, causes, and risk factors of autism. The SEED study participants included 2,700 children ages 2 through 5 years of age and their parents. The CADDRE Network, with site locations in California, Colorado, Georgia, Maryland, North Carolina and Pennsylvania, are working together to track the prevalence of autism, improve public awareness to comprehensive care of children and undertake epidemiologic research on autism and other developmental disabilities.

Hume, Bellini and Pratt (2005) wrote that the National Institutes of Health Interagency Autism Coordinating Committee (IACC) developed a 10- year research plan and matrix of goals and activities supporting autism research. The National Research Council (2001) conducted a systematic study on early educational interventions for children with ASD and found significant progress with the majority of children from birth through 8 years in response to the intervention. In 2007, the National Institute of Health Genes, Environment, and Health Initiative started funding research in joint effects of genetic and environmental factors in complex disorders advancing the awareness about environmental influences in the autism spectrum disorder (Lawler, 2008).

There is an international research project in Norway called the Autism Birth Cohort (ABC) involving the collection of information from pregnant Norwegian mothers with a projected 100,000 infants in a large, longitudinal, prospective designed study measuring the natural history and risk factors of autism from birth to early childhood (Szpir, 2006). Funded by the United Stated Institute of Neurological Disorders and Stroke, the study is cooperatively led by Columbia University and the Norwegian Institute of Public Health. The study of autism spectrum disorder has shifted from the psychological examination of behaviors and diagnostic tools to epidemiological studies examining genetic causes and environmental factors (Szpir, 2006).

Quality of Life and living with Autism Spectrum Disorder and other Developmental Disabilities

The concern for quality of life takes into account the factors that affect persons who are living with autism spectrum disorder and other developmental disabilities. Quality of life "takes into account the effects of the disability on the quality of life of significant others particularly the immediate family (Bendell, Stone, Field and Golstein, 1989). The family, especially the mother, bears the responsibility of caring, nurturing, and raising the child with a developmental disability (Traustadottir, 1991). Primarily, there will be understandable adjustments in the family responsibilities depending on the severity of the condition of the disability. There will be changes in the roles of the family, and challenges and stresses to family members which are factors that will affect the quality of life of the family and the child with the developmental disability (Weisberger, 1991). According to Gallagher and Powell (1989), the diagnosis of a child with a disability becomes an emotional burden for the parents and siblings in the family dynamics. Often, the siblings and immediate family feel a sense of guilt, failure, and lowered self-esteem (Gallagher & Powell, 1989). The emotional stresses, altered lifestyles, and financial burdens for expensive direct services and intensive intervention considerably affect families (Newschaffer & Coleman, 2003).

The Role of the Mother as the Primary Parent

Legislation of the Individuals with Disabilities Education Act P.L. 94-142 (IDEA) brought family involvement in the educational process to light with the legislative mandate for parental participation. Recent legislation has also emphasized the importance of family support and input in service provisions. Parents have been given the right to informed consent, due process, and the educational planning of their children's curriculum (U.S. Department of Health and Human Services, 2009). Wolfe (1992) in her research reported parents undergo a process of professionalization taking the roles educator, decision maker, advocate, teacher, case manager, and program evaluator. The philosophy behind the IDEA legislation is the inclusion of families in early intervention and prevention, with the key areas of family involvement and adaptation to the child with special needs, assistance to the access and utilization of services and facilitating service delivery to the parents and families (Anderson & Littman, 1992). The role of the parents is a very important factor in accessing services for children with developmental disabilities. Weisberger (1991) indicated in his research that successful adults with disabilities reported that parental supports contributed towards their development of independence as adults. Parents have an important role in facilitating and supporting their children's learning by positive attitude, patience and support. Research shows that mothers hold a primary role in the care of children (Traustadottir, 1991) especially in families with children with special needs (Traustadottir, 1991; Leiter, Krauss, Anderson and Wells, 2004; Inocenti, Huh & Boyce, 1992).

Weisberger (1991) stated that the parents play a key advocacy role for children disabilities especially they are young. The parents are taking steps to protect the rights and responsibilities of the persons with disabilities especially when they are minors. Since the mother holds the primary responsibility of caring for the child, then the role of the mother grows in importance as the child grows (Traustadottir, 1991). Weisberger (1991) stated if the child is in infancy or early childhood, the parent acts as an advocate by noting any unusual delays or imbalances in the development of the child.

Support Systems

Research of Marcenko and Meyers have reviewed Gottlieb's (1983) definition of support systems which. Gottlieb defined social supports as verbal or non verbal information, advice, and aid or action with beneficial, emotional or behavioral effects. House (1981) has indicated four types of social supports as follows: 1) emotional support which provides care, esteem, empathy, love, trust, concern and listening; 2) instrumental support which provides aid, direct help, money, labor or time; 3) informational support which covers advice, suggestions, and information to problems; and lastly, 4) appraisal support which provides affirmation, feedback, comparison, and self evaluation. Mothers of children with autism spectrum disorder need these types of support for their children to thrive.

Furthermore, the research of Marcenko & Meyers (1991) discussed the outcomes of several researchers which included the influence of social supports of families of children with disabilities, positive adaptations of families, fewer out of home placements, lower maternal stresses, and better parent-child interactions (Cole and Meyer, 1989; Kazak & Marvin, 1984; Dunst, Trivette & Cross, 1986; Marcenko & Meyers, 1991).

Hamner and Turner (2001) stated the positive relationships between social supports and the family's level of stress with critical spousal support. The authors reported that several researchers have concluded that there is a relationship between the mother's well being on depression, marital adjustment, child-mother relationships and parenting and the partner's support. The authors also indicated that Trivette and Dunst (1992) has found that greater informal social support relates to positive parental emotional and physical well being, less time demands, and integration of family units with more parent-child interactions and positive perceptions of children's behavior.

Claire Tregaskis (2006) of the Economic and Social Research Council in London, England was involved in a research project called Parents, Professionals and Disabled Babies: Identifying Enabling Care. The purpose of the project was to explore family experiences of health and social care of babies or young children who required specialist support in identifying practices that support enabling care for families (Tregaskis, 2006). According to Tregaskis, the research, which is still in process, disclosed that there are still fundamental inequalities, structural and attitudinal barriers that persist which prevents families from accessing health and social care. This makes it more significant and important to examine the experiences of mothers with autism spectrum disorder. This research study is necessary in order to identify the assets that provides support and access and examine the barriers that prevent the mothers and their children from getting help, assistance and access to much-needed special education services (Tregaskis, 2006).

CHAPTER 3

RESEARCH METHODS

The study utilized a qualitative research design. The targeted study sample was thirteen mothers (n=13) residing in Michigan who are parents of children with autism. They were recruited through formal means (nonprofit agencies, schools and institutional contacts) and informal means (parents' networks). This study used an exploratory approach to gain a broader and deeper understanding of the parental experiences, perspectives, influences, supports, and challenges of parents with children with developmental disabilities specifically during the children's early years. The study utilized semi-structured interviews with open ended, in-depth, and probing questions as the primary form of data collection. The researcher is a doctoral candidate from the Department of Family and Child Ecology, College of Social Sciences, majoring in Family and Child Ecology. The researcher is a parent of a child with autism. This fact was disclosed to the study participants prior to the interviews. The researcher exercised utmost care not to contribute her perspectives, bias or experiences to the study participants. This required special sensitivity to the issues facing parents of children with developmental disabilities and consideration for their values and perspectives in the formulation of methods and process of interviewing participants. Validity was addressed by utilizing "pattern-matching" (Campbell, 1975) by working on periodic review of transcriptions for accuracy, and careful review and analysis of interview and field notes.

Qualitative Research Design

The researcher utilized qualitative design as the method of inquiry since this will allow the systematic collection, organization, interpretation and analysis of data through interviews. Babbie (2001) stated that a qualitative interview "is an interaction between an interviewer and a respondent in which the interviewer has a general plan of inquiry ... at the same time, it is vital for the qualitative interviewer to be fully familiar with the questions to be asked."

Phenomenological Analysis

Edmund Husserl defined transcendental phenomenology as "a philosophic system rooted in subjective openness" (Moustakas, 1988). Patton (2002) clarified Husserl's view by stating that the person's subjective experiences and reality focuses on meaning-making as the essence of his/her human experience. Phenomenological inquiry implies the importance of knowing and understanding the person's experiences and his/her interpretation of the reality of the world. The phenomenon should be methodologically experienced as directly as possible by the researcher through participant observation and in-depth interviewing (Patton, 2002).

The science of phenomenology was defined by Moustakas (1988) as a research method framework, thus:

1. *Phenomenology focuses on the appearance of things, a return to things just as they are given, removed from everyday routines and biases of what we are told is true in nature and in the natural world of everyday living.*
2. *Phenomenology is concerned with wholeness, with examining entities from many sides, angles and perspectives until a unified vision of the essence of experience is achieved.*

3. *Phenomenology seeks meanings in the way things appear, and arrives at essences through intuition, perception, feelings and reflections on conscious acts of experience, leading to ideas, concepts, judgments and understandings.*
4. *Phenomenology is committed to descriptions of experiences, not explanations or analyses.*
5. *Phenomenology is rooted in questions which give a direction and focus to meaning, and in themes which sustain an inquiry, awaken further interest and concern, and account for our passionate involvement with whatever is being experienced.*
6. *Subject and object are integrated – what I see is interwoven with how I see it, with who I see it with and with who I am.*
7. *At all points in an investigation inter-subjective reality is part of the process yet every perception begins with my own sense of what an issue or object or experience is and means.*
8. *The data of experience, my own thinking, intuiting, reflecting and judging are regarded as the primary evidences of scientific investigation.*
9. *Every method relates back to the question and is developed solely to illuminate the question, give the phenomenon rich, layered textures and meanings on the journey of looking again and again and elucidating the essence of whatever is being examined and explored.*

The research utilized the phenomenological approach as a means for collecting, coding and analyzing the data. According to Patton (2002), "phenomenology is a focus on exploring how human beings make sense of experiences and transforms experiences into consciousness, both individually and as shared meaning … it describes how people experience some phenomenon – how they perceive it, describe it, feel about it, judge it, remember it, make sense of it, and talk about it with others." The phenomenological analysis will consist of descriptive narratives synthesized into master themes that reflect the shared experiences of the participants (Cresswell, 1994; Willig, 2001).

The qualitative phenomenological design is the most appropriate analytical method to utilize in capturing the experiences of mothers of children with autism, since the in-depth interviews will be conducted with mothers who are directly experiencing the phenomenon of autism spectrum disorder within themselves, their children, families, and social institutions. The interviews will serve as "windows" through which other families without children with autism can understand the complexity of the situation.

Subjects/Participants Selection

The targeted study sample was thirteen mothers (n= 13) residing in Michigan who are parents of children with autism spectrum disorders. The study recruited participants through purposive sampling. Purposive sampling is defined as selecting a sample "on the basis of the population and the purpose of the study" (Babbie, 2001). In this case, the researcher interviewed mothers who have, specifically, children with autism spectrum disorders and explored their experiences as the "phenomenon" of the study. The eligibility requirements for the research study were: a) the participant has a child with autism spectrum disorder as diagnosed by a medical professional, school official or special education specialist; b) the participant's child age is within the range of 2-10 years old; c) the participant's gender is female. The participants were recruited through formal and informal means. An information letter was sent to agencies or organizations that had access to mothers of children with autism spectrum disorder. These agencies included, but were not limited to, Head Start Programs, public and private early childhood centers, nonprofit agencies, schools, special education support offices, and parent support networks, associations supporting families with special needs and specialists' offices (speech therapists, occupational therapists and physical therapists).

Instrumentation

The interview documents consisted of demographic data sheet, list of interview questions and eco-map document for the participant. The researcher took field and observation notes during the interviews.

The demographic data included the participants' names, ages, s, ---highest level of educationl, religion (not mandatory), marital statuses, employments, household incomes, races/ethnicities, family compositions and locations of domicile. It also included the participants' children's information such as ages, genders, sibling composition, and autism diagnoses. The interview questions were conducted in a semi-structured, open procedure (See Appendix D). The participants' responses to the interview questions and probes were audio-taped or digitally recorded with informed consent from the participants. The participants were informed and requested to complete an eco-map (Appendix E). The researcher wrote field and observation notes during and after the interviews.

Data Collection Procedure

Recruitment procedure

Information and consent letters were given to the interested participants following the policy of the Institutional Review Board of Michigan State University regarding the research of human subjects. The researcher met with the interested participants, oriented, and debriefed them regarding their participation in the research study. The researcher thoroughly discussed the Institutional Review Board policy regarding human subjects for research and its confidentiality agreement.

The participants were informed that participation in the study is voluntary. The researcher assured the participants of confidentiality. The researcher informed the participants that the research will: protect the participants' privacy by assigning pseudonyms or participant codes to each participant, keep all interview data confidential, assign numbers to the participants' interviews so no identifying information is attached to the data, and keep all interview data confidential. The participants were informed that all data collected will only be used for academic purposes.

The researcher disclosed that she is a mother of a child with autism prior to participation in the study. The researcher took the role of acquisition of knowledge and did not contribute her perspectives, bias or opinions to the research study.

Participants were informed about the purpose of the study, schedules and timeline for the research project. They were asked to sign the informed consent agreement to confirm participation in the study, after which time the interview was scheduled.

The participants were informed that if there are any inquiries or concerns about the research, they can contact the researcher, the Chair of the Dissertation Committee, or the Chair of Michigan State University Institutional Review Board. Furthermore, the participants were informed that, at any time, they can withdraw without penalty.

Interview Procedure

Participants were asked to complete a demographic data sheet, eco-map, and to answer a series of open-ended questions. Each interview was audio taped or digitally recorded and transcribed verbatim. The interview sessions lasted 1.5- 2 hours. The researcher also recorded field notes and observations. Approval of the project was secured from the Institutional Review Board of the University Committee on Research Involving Human Subjects, Michigan State University. The participants' consents were obtained before conducting the interviews.

The researcher asked the participants for a site that would be most convenient for the interview. The site was to be a natural setting where the participant would be most comfortable. The researcher offered three office sites located in Lansing, Detroit and/or Oakland County for the interviews. The researcher made every effort to establish a relationship with the participants that was neutral, professional, and as objective as possible in the conduct of the research project.

The study utilized semi- structured with open-ended, in-depth, and probing questions as the primary form of data collection. The researcher conducted all interviews in order to establish rapport and trust with the participants. There were a total of 13 interviews conducted during the study. . The interviews were conducted using the questions that were designed to investigate, and examine maternal perspectives regarding their experiences of being mothers of children with autism spectrum disorder, and probing for their ecological support systems. Responses to the interview questions were audio-taped or digitally voice recorded, transcribed and analyzed by researcher. The researcher asked the participants to complete an eco-map. The eco-maps served as visual diagrams of the participants' social support systems. The researcher took field notes divided into empirical observations and subjective interpretations during the interview sessions and recorded additional observation notes immediately after leaving the interview sites.

Data were transcribed from the participants' audio-taped or digitally voice recorded interviews. Emerging themes were identified from the specific interviews. The data were rigorously analyzed and confirmed using the transcriptions and field notes during and immediately after leaving the interview sites. By utilizing transcribed audio - recorded data, completed eco-map, and field notes, the researcher was able to capture as much thematic categories and establish the reliability and validity of data.

Research Audit Trail

Researcher kept a calendar of day-to-day activities and corresponding methodological notes about the project. The data were from participants' interviews and rigorously transcribed. The data included participants' answers to probing questions, field notes and researcher observations. Each participant was assigned a participant code immediately after the consent form had been signed. The participant codes were subsequently used by the researcher on all documents (demographic information, interview transcriptions, field notes and observations) to maintain confidentiality and privacy of proceedings. For example, the first participant to be interviewed was assigned A1; the second participant was assigned B1 for her interview and so forth. The documents were only reviewed and made available to the researcher, Chair and members of the Dissertation Committee, and the Institutional Review Board as necessary. All documents were kept in a locked storage in the Dissertation Faculty Chair's office.

Data Analysis Procedure

The researcher had the following documents for data analysis: demographic information, transcripts of the interviews, completed eco-map by the participant, field notes, narrative documents, thematic analysis notes of the researcher, and examination records of thematic output documents.

The research utilized the phenomenological approach as a means for collecting, coding and analyzing the data. The data collected were periodically reviewed and categorized by participants' findings and initial themes based on the theoretical framework of the study. The qualitative data analysis looked for patterns in the data by identifying frequencies, magnitudes, order of occurrences and processes, causes and consequences (Loffland & Loffland, 1995). The analysis searched for patterns, themes, relationships, significance, meanings, and degree of parental affect of the maternal perspective of the support systems available to parents with children with developmental disabilities. The researcher used open coding by examining, reviewing, naming, and categorizing the data. This procedure broke down the data into distinct parts, was reviewed and examined for similarities or differences, and was questioned about the phenomena that the data is presenting (Strauss and Corbin, 1990). The researcher used index cards and charts in the process of coding the data. The researcher charted the reconstruction of data by developing the categories and themes, analyzing the statements and findings, connecting the data to existing literature and integrating the concepts. The procedure employed cross-analyzing the data by methodically reviewing the interrelationships between and among the data (Huberman & Miles, 1994). The outputs for analysis included transcripts of the interviews, narrative documents (field notes and observations), thematic analysis notes and output documents of the researcher. All of these outputs were cross referenced to improve the reliability and validity of data.

Reliability and Validity of Data

The research assured the reliability and validity of the qualitative data by comparing the transcribed participant interviews with participants' completed eco-maps, the researcher's field notes and the thematic research documents. With the use of interviews, eco-maps, and field notes, the researcher will be able to check for consistencies of what people say overtime (Patton, 2002). With the use of audio or digital voice recording during the interview as part of the process, the researcher was able to review the findings in the data for accuracy and fair reporting of the phenomenon. Through this process, the records and answers of the participants were confirmed. These methods increased the reliability and validity of the data.

CHAPTER 4

RESULTS

The researcher informed the participants about the research study, explained the nature and background information of the research, and notified them of the informed consent form. All the participants read, reviewed, and signed the informed consent forms as approved by Michigan State University Institutional Research Board (IRB) prior to participation in the study. This chapter covers the following topics: 1) Demographic Data; 2) Mother's Experiences and Perspectives; 3) Identification of Mothers' Support Systems; and, 4) Mother's Types and Levels of Supports based on Ecological Systems Theory.

Demographic data were collected from the participants to secure the following information: age, race/ethnicity, highest level of education, religion (not mandatory) marital status, socio-economic status, employment status of participants and spouses, their household incomes, family composition at home, and location of domicile (urban, suburban, rural or other specified). Additionally, participants' child demographic data information included age of child at time of interview, gender/sex of child, number of siblings or sibling composition, and nature of diagnosis based on mothers' self reports from educational agencies, schools or medical institutions . The interview questions covered the major research questions regarding the mothers' ecology of experiences and supports of parenting children with autism spectrum disorder.

The data were organized and analyzed in a careful, detailed and logical manner. All informed consent forms, completed demographic questionnaires, participant eco-maps and interviewer's notations were carefully filed after each every interview. Each interview was carefully logged in a participant document list. Researcher listened to the audiotapes twice in order to be familiar with the data. Each interview session was carefully transcribed from audiotapes. These transcripts were carefully re-checked by listening to the audio tapes for accuracy.

The transcripts were read and re-read for content analysis in which "both the content and context of documents are analyzed: themes are identified with the researcher focusing on the way the theme is treated or presented and the frequency of its occurrence (Ritchie and Lewis, 2003)." The transcripts were coded for accuracy and researcher developed a preliminary framework of codes based on the major research questions. Ritchie and Lewis (2003) further indicated that the use of a framework is significant in explanatory analysis because it has the "ability to look within cases across a range of different themes and phenomena and ability to move rapidly between thematic and case based analysis because of the matrix display." Based on the framework, each case was carefully read, re-read, reviewed, analyzed, and coded. Data were coded and charted within a matrix display. Coding was done by identifying each participant's responses into clusters. The clusters of responses were categorized into themes which were directly linked to the major research questions. The clusters were derived from the participants' interviews and explanations of their experiences with the phenomenon of parenting children with autism. Furthermore, clusters were derived from participants' interviews with similar qualities or characteristics of responses. The researcher used the actual words of participants' responses in order to code and integrate the results of the interviews into the themes for analysis. The themes of analysis consisted of emergent themes, contextual factors and thematic sections.

Demographic Data

Demographic Data of the Participants/Mothers

Results of the demographic data of the participants (see Table 1) are as follows: four (4) of the participants are ages 26-35 years and nine (9) ages 36-45. The results reveals race/ethnic composition of eight (8) Whites or Caucasians, two (2) African-Americans, one (1) Asian-American, and two (2) Hispanic-Americans/Latino. The religious affiliations of the participants are three (3) Protestants, five (5) Catholics, two (2) Lutheran, one (1) Unity, one (1) Christian, and one (1) marked other but no specific religion. The marital statuses of the participants were 11 married, 1 single and 1 divorced/separated.

The majority of the mothers are over 26 years old at time of interview and married with varied race/ethnic composition. Most of the mothers are Christians.

Levels of education of participants include one (1) high school graduate, three (3) with Associate degree, seven (7) with Bachelors' degree, and two (2) with Master's degrees. The results of the participants' employment statuses are 8 employed, 8 unemployed and one (1) in-between job. Reported , household income data of participants are reported as follows: out of 13 participants, one participant reported an income within the range of $100,000.00 -$149,999.00; eight participants reported income within the range of $75,000.00 - $99,999.00; three participants reported income within the range of $35,000.00-$74,999.00 and one participant reported an income of $34,999.00 and lower.

Table 1: Demographic Characteristics of Participants/Mothers in the Study

Variable	Research Participants (N)	Variable	Research Participants (N)
Age		**Race/Ethnicity**	
19-25	0	White Caucasian	8
26-35	4	African American/Black	2
36-45	9	Asian American	1
46-55	0	Native American	0
Over 55	0	Hispanic American/Latino	2
		Other	0

Variable	Research Participants (N)	Variable	Research Participants (N)
Religion		**Highest Level of Education**	
Protestant	5	High School	1
Catholic	5	Associate Degree	3
Jewish	0	Bachelors Degree	7
Islamic	0	Masters Degree	2
Hindu	0	Doctoral Degree	0
Other	0	Other	0
None	3		

Variable	Research Participants (N)	Variable	Research Participants (N)
Marital Status		**Employment Status**	
Married	11	Employed	4
Not Married	1	Not Employed	8
Div/Sep	1	In Between Jobs	1

Variable	Research Participants (N)	Variable	Research Participants (N)
Household Income/Range		**Family Composition at Home**	
$200,000/up	0	Father /Partner	12
$150,000-199,999	0	Mother	13
$100,000-149999	1	Other Children	10
$75000-$99,999.00	8	Grandparents	2
$35000-74,999.00	3	Other Relatives	0
34,999/lower	1	Friends	0
		Other	0

Variable	Research Participants (N)
Locations of Domicile	
Urban	2
Suburban	8
Rural	3

The majority of the participants accomplished post-high school academic degrees with two mothers accomplishing graduate degrees. Most mothers have family incomes of over $75,000.00.

Marital statuses of the participants were 11 married, 1 single and 1 divorced/separated. Family composition at home consisted of twelve (12) mothers with fathers/spouses living at home, ten (10) with children other than the child with autism spectrum disorder (ASD), and two (2) of the participants with grandparents living at home (Figure 8). The participants' locations of domicile are as follows: two (2) urban, eight (8) suburban, and three (3) rural.. The results indicate that mothers have stable households with 12 spouses/partners living at home. One mother has a spouse and child's grandmother living at home. Another mother has a child's grandmother living at home. All the mothers have two- parent households with spouses and grandmothers serving as parents.

Demographic Data of Participants' Children

The demographic characteristics of children of participants are indicated in Table 2. There are eleven (11) boys and two (2) girls with ages as follows: one (1) 4-year old child, two (2) 5-year old children, five (5) 7-year old children, one (1) 8-year old child, one (1) 9 year old child, two (2) 10-year old children, and one (1) 11-year old child The sibling composition of the participants' children with autism spectrum disorder (ASD) is as follows: two (2) of the children have no siblings, eight (8) of them have one sibling, two (2) of the children have two siblings, and one (1) child had three or more siblings . The nature of autism spectrum diagnoses as reported by the mothers are as follows: 8 Classic Autism, 3 Asperger Syndrome and 2 Pervasive Developmental Disorder Not Otherwise Specified.

Table 2: Demographic Characteristics of Participants' Children in the Study

Variable	Research Participants (N)	Variable	Research Participants (N)
Gender		**Age**	
Male	11	4 years old	1
Female	2	5 years old	2
		7 years old	5
		8 years old	1
		9 years old	1
		10 years old	2
		11 years old	1

Variable	Research Participants (N)	Variable	Research Participants (N)
Sibling Composition		**Autism Diagnosis**	
None	2	Classic Autism	8
1 sibling	8	Asperger Syndrome	3
2 siblings	2	Pervasive DDNOS	2
3 or more siblings	1	Rett Syndrome	0
		Child Disintegrative Disorder	0

Most of the participants' children with ASD are boys, over 7 years old of age and have siblings in the family. Most of the mothers' self reported diagnoses of the children are categorized under Classic Autism.

Mother's Experiences and Perspectives during Early Detection and Diagnosis

Research question #1: "What are the mothers' experiences and perspectives during the period of early detection and period of diagnosis of the child's autism spectrum disorder (ASD)?

Two-thirds of the mothers have difficult pregnancies due to the children's premature birth or mother's sickness during pregnancy. Most of them have reported observing the children's developmental delays starting at 12 months. The children started exhibiting screaming fits, challenging behaviors, playing in isolation, and difficulty in socialization. The mothers' experiences ranged from feelings of uncertainty, insecurity, disbelief, and fear of the future. During the interviews, the majority of the mothers had a difficult time even sharing their first experiences with the child who later on received the diagnosis of autism. One mother said,

> *"Maybe a little bit of denial. So we figure okay we'll put him in a religious-based environment, and maybe that would help. Yeah. So he was doing okay there, but then the behavior started to run out the building, being disruptive, the screaming for no reason. So the director of the facility said, "Well let's call in the school district and have them meet you because something is not right. You really need to consider having them reviewed him." Maybe still a little bit of denial (for me) but more so, I think it's the mom. You kinda know something is not right."*

A majority of the parents expressed relief over finally getting the diagnosis. Most of them said that there is a sense of relief that they felt after getting the confirmation of diagnosis. On the one hand, they said they wished they were proven wrong. Nevertheless, after a period of grieving, most of them decided that they needed to move forward and find support and services for their children. One mother turned to her family for support and she shared,

> *"After the diagnosis, something changed in me. Because our family is a very much a part of our children's lives. You know helping us raise them. We firmly believe in "It takes a village." And quite frankly without them, we can't do what we do. So I just sat them down and said, "You know, this is what's going on. I mean, "Do you guys (wish to) participate in helping us? And this is how I need you to participate."*

Still, for three of the mothers, the journey was not easy. Their spouses or significant others were either busy with work and not engaged in the child rearing, or the spouses themselves were not accepting of the children's condition and its attendant implications. One mother said,

> *"Yes. Well, he's not as involved as I am with the children and he works a lot. He always traveled a lot. I was still working part-time at the time. Actually no, I wasn't at that time, I thought. As soon as I got laid off, as soon as (name of child) was born, you know, I wasn't, but he works a lot and this stuff all falls on me."*

Changes in Lifestyle

There were definite changes to the lifestyle of parents that included: adjustments to the different routines of the children with ASD (especially in the case of 2 or more children in the family), less time with spouse and other family members, administering medical procedures such as giving shots or prescription medicines to the children, learning to converse with medical and school professionals to obtain necessary help for the children, and learning to be more open to the public about the child's disability.

Most of the mothers felt emotionally challenged by the untoward treatment of their children by other people's intolerance or lack of compassion. Due to these challenging situations, the mothers report that they are more understanding of other people's children and their behavior. They continue to work through understanding other family members' reactions towards their children, especially during gatherings and social situations. The majority of the mothers attended national and local conferences/workshops/meetings to find out about cutting-edge programs. Two mothers participated in university research studies. The majority of the mothers volunteered at their children's schools and engaged professionals in order to obtain the assistance they need for their children.

Avoidance of Public Places

Most of the participants shared their uncertainty and avoidance to go to public places or social situations due to their child's diagnosis and possible behavior in public situations. One participant shared about not being able to go in public theatres. She shared,

> *"Yes, in the cinema, the supervisor, because she (the child) start to look the first movie and in the movie somebody say, "uh, oh," and she say, "uh, oh." So, in the room, in the movie ten people, we are four and when they say, "Could you stop your daughter because we don't want to hear it anymore?" (My daughter) doesn't stop she only say, "uh, oh, uh, oh!" The supervisor comes pull me out of the cinema, (my daughter) is crying, my son is crying because I am angry and my husband is angry."*

Similar to this experience, another participant said,

> *"I mean I would take him to my in laws or if I had to go anywhere, I didn't, I never took him with me. I was in grief. I didn't go to people's houses. I didn't take him to anybody's homes because he would destroy (things) and I would never be able to have a conversation because he was screaming the whole time, so it just wasn't worth it to me and I was -- it wasn't that I was embarrassed but yeah, at the same time, I felt it was constantly explaining his behaviors to people... constantly. "*

Difficulty in Social Relationships

Another participant discussed her difficulty of connecting with other mothers or joining in social situations. She said,

> *"I really didn't have (recreation time). It was hard to make friends. I tried to though they have a mom's club I tried to go to those but it's hard because they have play dates and he would hit other kids and poke other kids and I believe really frustrated for sure, I guess that's true. But it didn't work."*

One mother use to avoid going out in public and shared her story. She said,

> *"Now, I will say that we don't let things really stop us now. I mean -- See, I think one of the things I grieved was just having a normal family life because I love to do things with my kids. I mean they're my life and it was really hard for me to realize that, "Okay, (name of child with ASD) cannot." He can't function in a restaurant. He can't function on a family vacation. I mean it was just like I lost everything. I thought, "Oh my gosh!" I can't, you know, for (name of sibling of child). I thought she's going to really suffer and I'm just not. I'm one of those parents that if there's a will, I'm going to make it . . ."*

Allowance for more Medical Appointments and Specialists' Visits

Upon diagnosis, participants reported more medical appointments and specialists' visits. One mother indicated that,

> *"It was more like too many doctors' offices to go to. When he was diagnosed as you know, there's something with him, with the neck, with the eye, with the stomach, constipation, with the autism, with, you know, asthma. It took a*

> *lot of doctors to help (him), a lot of emergency (visits) for loss of breath, loss of, you know, shortness of breath."*

Mother's Perspectives on Recovery or Healing from Autism

One participant, who is a special education teacher, shared her perspective about the condition of autism. She said,

> *"When I heard that Dr. (medical doctor's name) said he could easily grow out of it, with autism, you can't grow out of autism, at least from my understanding. True autism you never outgrew it, and so I really questioned that and when I shared that with our pediatrician, I didn't share my thoughts on that but my pediatrician's response and me were the same. You can't really outgrow autism and so I'm glad I'm not the only one who have that thought you know, it just was like that proved me true."*

However, three participant s believed that autism spectrum disorder is a disorder that could be healed. One participant shared that,

> *"It's -- there are -- there's a movement in the United States...Okay. It's called DAN. Defeat Autism Now is the acronym...and it basically says that these kids have medical issues that have to be treated. It's not just a mental/psychological behavioral issue...and if you can heal those issues, then you basically heal autism and it is basically a detox program. It's detox. "*

This mother made a commitment to do the detoxification program for her son. Her son is taking prescribed vitamins and is on a gluten-free casein-free diet. For a while, she went through a period of pain while administering the program with her son's hallucinations, screaming fits, and challenges with verbal communication. She indicated that after a period of 14 days from start of treatment, he started showing improvements.

She said she believed in DAN's programs and will continue to follow their program of child recovery from ASD. One mother felt the organization motivated parents to be more involved in search for treatment of autism. She stated,

> *"Overwhelmed but excited, that I was doing something for my son, like okay we're being proactive and we'll get the right things, put them in place. We're gonna start. We're gonna beat this because a lot of those moms then were doing biomedical intervention. What the biomedical approach is usually overseen by a DAN doctor and DAN stands for Defeat Autism Now. This DAN doctor specializes in everything on physiological, biological level on the body. Initially, you do some blood work. They will look at everything - how the 'workings' are working in the body any signs of oxidation. You know, heavy metal toxicity. I mean lots of stuff they look at because what they have found by doing this biomedical is that each child of autism is very different. They may have the label of autism; but how it affects their body, no two children are alike. Everything about (name of child) is all information in the body, everything we have done to target (the disorder)."*

Feelings of Denial, Sadness, Uncertainty and Grief

One mother reported her sadness and uncertainty with her child. In retrospection, she shared her story, thus:

> *"Now, when she was young, when you look back, when she was younger around 2. . . Remember, when early on when (someone) talked to you about it, were you the one who felt there was something a little different? Or was it because somebody approached you because you were feeling fine and she was*

playing and she was quiet? Were there people around you who said, hmm, you know?"

One participant felt sad about how other mothers treat her and her child.

> *"I feel sad or worry but when passing time is like a family. You put out this people that you like . . . they say, "Oh, why do you think (it) happen(ed)?" I feel ignored. I have depression. But, after an hour, I say, "Yeah, okay, it is nothing new to me. It's okay. Time to get new friends."*

All of the participants expressed the feeling of grief over the experience of having a child with ASD and some are still not quite accepting of the situation. One participant deeply shared her grief and said,

> *"I just -- I felt like it wasn't fair. It wasn't fair that I couldn't have a normal experience with the two of them (her two children). I think I really grieved a long time, the fact that I didn't, I couldn't know what a real typical boy was like and what a brother-sister interaction...should be like, so I really did grieve out a lot."*

Another one said,

> *"I worry about the day something may happen to me. Who would be there for him?"*

Acceptance of the diagnosis and maternal empowerment: Tenacity for the present and hope for the future

One participant indicated that,

> *"There will always be bad times and good times with your child and always be there when they need help . . . that what you know is not just being out*

when they have fun but be there with them and have a good time and when they have you because that is always going to be until they grow up."

Creating Positive Experiences for Child

Two of the participants discussed about conducting summer program on social skills activities with other mothers with children with similar diagnosis. One of the mothers said,

> *"Like me and another friend, we made our own class and we let some other mothers, friends and their children participate on that and you know, after that year -that summer, he did not need some social skills anymore. I was amazed at the progress that he made. He still gets something through the school."*

Determination in obtaining information, resources and services for the children: The quest for researching the diagnosis

All participants were very proactive in researching information, resources and referrals about their children's diagnosis. They seek resource information through medical and educational professionals, professional and personal networks, national and local conferences on autism, books, and website/online resources. Most of the participants are internet-savvy and get their information about matters they do not understand by looking them up online. One mother said,

> *"I would say that 80% of it was our own research because when you have a child with autism, your doctors (can help you), your partner, but you really have to do (it) on your own. I believe you have to do your own research and you*

> *have to and then I use my doctor as a tool -- not as a tool but obviously -- but as a partner in healing (your child). I have another friend. It's kind of a longer way. The Lord kind of led me to this certain people and there's -- I have a friend who -- she became a friend of mine because I home-school and I went to a conference. This would have been the May after (name of child) was diagnosed, so about seven months later. She was doing a breakout session on autism and home-schooling kids with special needs and she was doing it from a medical perspective as well and so I started talking to her."*

Recapturing one's sense of being and maturity

Participants have reported not being able to take care of themselves as they parent their children with special needs. They found themselves in situations wherein they needed to renew themselves, to take stock of the situation and recapture their sense of self and direction. One participant was struggling with her marriage and herself and found it through therapy and exercise. Thoughtfully, she shared this experience.

> *"There was a lot of underlying issues that had occurred over the past ten years that needed to be addressed, but because I'm such I want to fix things I thought I could do on my own but I couldn't. The relationship I was having with my daughter at that time, it was turning into a relationship I had with my mom, and I didn't like that. There was more a lot of yelling and screaming, it just you know hard, hard discipline, I was just not liking the person I was becoming, so I had a lot of emotional stuff because finally at that time last year, I was able to sit down, relaxed and think about what had gone on . . . I went o my God and all the old emotions started to resurface, I have suppressed them for so many years, they*

started to resurface . . . Yeah, definitely it was the therapy, and actually exercise. I have been an athlete my whole life. You know, that was my medicine. Everything (was) put on hold because (it) is all about your kids; it is nobody else but your kids. And I have devoted myself so much that I have lost myself along the way of who I was, what I was and what I wanted, and I just saw myself as mom. I didn't see myself as (name of participant) anymore -the woman whom my husband chose to fall in love with for many years. But I know, I changed and matured but there is always that part of you that makes (you) who you are. "

Another participant shared her growth as a person through the experience of parenting a child with ASD. She shared,

> *"I don't attend church on a regular basis but I do pray and I do. My patience is a lot better as (I am not) a patient person . . . and I think this was in a strange way, part of a test in my development as a person. I needed to develop a lot more patience and a lot more understanding for people in general."*

Knowledge Sharing

All participants stated that they are willing to share their knowledge of what they have learned and are learning through the process of parenting a child with ASD. Although, some of them have expressed reservations that they would rather be asked and not initially offer their knowledge to other parents as those parents may not be in a place where the latter are ready to accept the diagnosis and receive help. One participant expressed her enthusiasm and optimism and said,

> *"Any chance I get, if I know I can help a parent this much, I'm all about it because knowledge is wealth. And you know, and it's power too - to have a confident parent of a child with autism is a thousand times better with a parent who has no direction and is complacent just accepting it for what it is. We know we have far too much available. We know so much more about it now. Just accept it for what it is and acceptable for me (but you) need to (go) forward and dive in and get in, and get information and say I have options. There is hope."*

Identification of Mothers' Social Support Systems

Research question #2: What are the mothers' experiences of social support systems that affect, influence, assist and challenge mothers in assisting their children during their early years (birth to early years)?"

All participants were asked to complete an eco-map to indicate and enumerate their sources of support. Sources of supports were as follows: parents, spouses, friends, specialists (occupational therapists, physical therapists, nurse practitioners, speech therapists), school teacher, medical doctors, social affiliations, autism spectrum disorder (ASD) support group, siblings of the children, daycare worker, other children or friends of child with ASD, church group, other family (sisters of participants) and neighbors. Furthermore, participants were asked to indicate on the eco-map their level of perceived relationships using the following indicators: very strong support, strong support, very strong and stressful support, strong and stressful support and stressful support (See Tables 3/Figure 2 & Table 4/ Figures 3). This reporting does not indicate any level of intensity or interval relationships but rather, allows the participants to express their perception of relationship to their sources of support. Collectively, the participants identified parents as giving very strong support at 38.89% (7 out of 18 times) and 33.33% as giving strong and stressful support (6 out of 18). Twelve of the participants reported that their spouses were sources of very strong support at 50% (6 out of 12 times) with the other half reporting stressful perceptions at 25% (3 out of 12 times) for strong and stressful support.

Table 3: Participants' Responses on Sources of Supports Measured in Units based on Eco-Maps

	Parent	Friend	OT/PT Speech Service	School Teacher	Doctor	Affiliations	ASD Support Group	Sibling	Spouse	Day-care	Other Child	Church	Other Family	Neighbors
Strong Support	2	8	1	5	6	1	3	0	0	1	0	4	3	0
Very Strong Support	7	16	3	4	1	0	0	3	6	0	3	3	2	0
Stressful Support	2	1	0	3	2	0	0	2	0	0	0	1	5	3
Strong And Stressful	6	2	0	4	2	0	0	2	3	0	1	0	2	1
Very Strong And Stressful	1	0	0	1	0	0	0	0	3	0	0	0	0	0
TOTALS	18	27	4	17	11	1	3	7	12	1	4	8	12	4

Figure 2: Participants' Response on Sources of Supports Measured in Units based on Eco-Maps

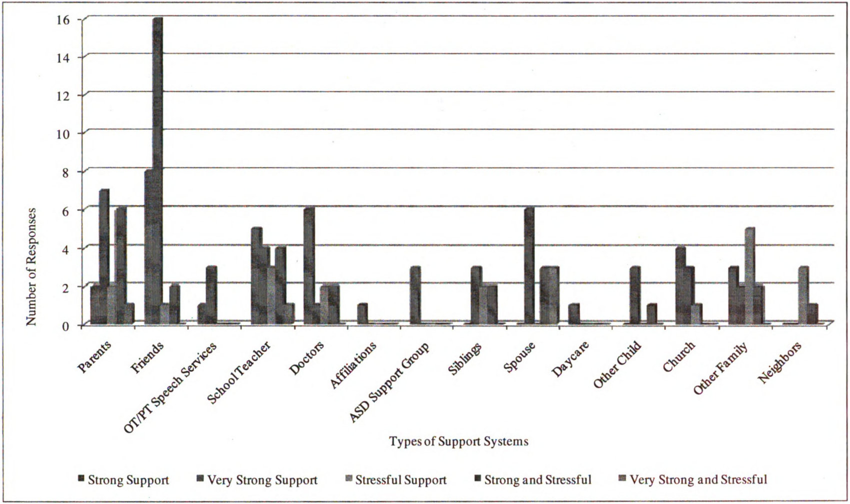
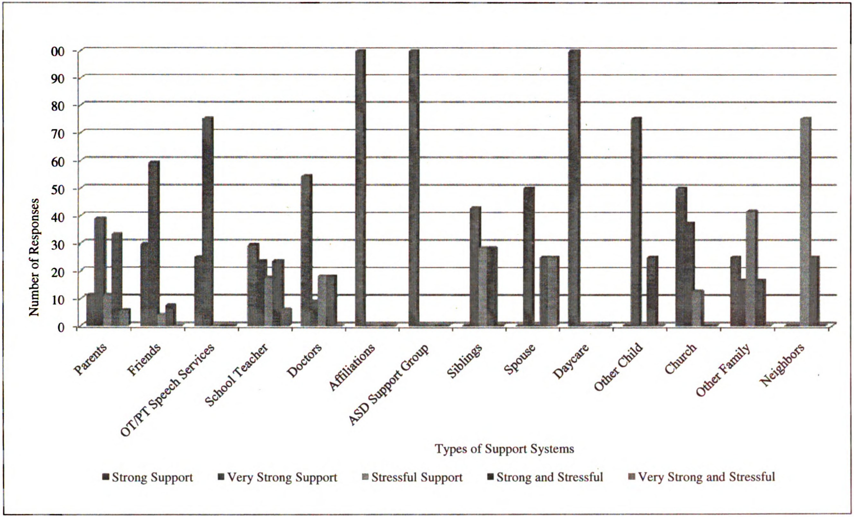


Table 4: Participants' Responses on Sources of Supports Measured in Percentages based on Eco-Maps

	Parent	Friend	OT/PT Speech Service	School Teacher	Doctor	Affiliations	ASD Support Group	Sibling	Spouse	Day-care	Other Child	Church	Other Family	Neighbors
Strong Support	11.11	29.63	25	29.41	54.55	100	100	0.00	0	100	0	50.00	25.00	0
Very Strong Support	38.89	59.26	75	23.53	9.09	0	0	42.86	50	0	75	37.50	16.67	0
Stressful Support	11.11	3.70	0	17.65	18.18	0	0	28.57	0	0	0	12.50	41.67	75
Strong And Stressful	33.33	7.41	0	23.53	18.18	0	0	28.57	25	0	25	0.00	16.66	25
Very Strong And Stressful	5.56	0.00	0	5.88	0.00	0	0	0.00	25	0	0	0.00	0.00	0
TOTALS	100	100	100	100	100	100	100	100	100	100	100	100	100	100

Figure 3: Participants Responses on Sources of Supports Measured in Percentages based on Eco-Maps



Participants perceived and reported their friends 27 times as strong sources of support and 59.26% (16 out of 27) of those friends were described as giving very strong support. Four specialists were indicated by participants with 75% (3 out of 4 specialists) giving very strong support. Meanwhile, participants perceived school teachers across the board with 29.41% (5 out of 17 times) reporting strong support, 23.53% (4 out of 17 times) reporting very strong support, and 23.53% (4 out of 17 times) reporting strong and stressful support. Doctors were reported by the participants as giving strong support 54.55% (6 out of 11 times) with perceived stress at 18.18% (2 out of 11 times) for stressful support and 18.88% (2 out of 11 times) for strong and stressful support. The participants reported stressful relationships with their medical practitioners.

Social affiliations through attending conferences were reported by one participant as a source of strong support. Autism spectrum disorder support groups in their school or community were considered by participants as sources of strong support at 100% (3 out of 3 times). Participants reported varying degrees of perceived support for the siblings of children with ASD with 42.86% as source of very strong support (3 out of 7 times), 28.57% as stressful support (2 out of 7 times) and 28.57% as strong and stressful support (2 out of 7 times). One participant reported a day care worker as giving strong support. The participants reported that other children or friends of participants' child with ASD gave them very strong support at 75% (3 out of 4 friends). The majority of church groups/members were perceived by participants as source of strong support at 50% (4 out of 8 times) and 37.5% (3 out of 8 times). Some participants reported about concerns over other family members like sisters perceived as sources of stressful support at 41.67% (5 out of 12) and neighbors at 75% (3 out of 4 times as sources of stressful support).

Mothers' Types of and Levels of Supports based on Bronfenbrenner's Ecological Systems

Research question #3: "Using Bronfenbrenner's ecological systems theory, what are the mothers' levels of social support in the four systems: microsystem, mesosystem, and exosystem and macrosystem?

Research question #4: "What are the mothers' perspectives of the relationships and support systems that offered the highest degree of support to the mothers with children with autism spectrum disorder?"

The majority of participants reported strengths of social supports as coming from spouses, parents and friends. Fifty per cent of the 12 respondents reported very strong support from their spouses with the other 50% reporting varying strengths of stressful support. Participants perceived their parents as giving very strong support at 38.89% with an additional 33.33% as strong and stressful supports. The group collectively qualified their friends as strong sources of very strong support at 59.26%.

Parental support

All participants reported getting strong support from their parents, whether or not the parents were accepting of the diagnosis of the child or not. One participant shared about her parents' solid support after the child was diagnosed. She shared,

> *"My parents? They were completely supportive, they got books, they could read some more and learn some more and they shared books with me."*

One mother got teary-eyed when asked about the person who gives her the most support and she responded that her mother's support for her family and children remains on top of her list. She shared,

> *"She's still my hero, because she's been through a lot with my father. You know her own family thing. You know, she still makes time to say, "Okay, I'm going to the store and make me a list." It's not always, she will actually buy it. Like, I don't have to give her the money back. It is like, I know what she makes and I know her situation, you know, taking care of the kids for me and taking him to the doctor. I don't have to take off work. She does a lot. Her feeling has always been, "I can't give you money. I can't give you a million dollars. And this is my way of helping you in your life. And that's by supporting you with your family. "*

Spousal Support

Participants described the feeling of grief and inability to function in the midst of family support. They expressed that it helped that there were people around them who maintained optimism and remained proactive despite the challenges of parenting a child with ASD. When asked about family dynamics between her husband and her, one mother shared,

> *"Absolutely! He did. He is very -- he's not. I wouldn't say, not emotional. He is emotional. He's an emotional person, but he's more of a "let's just get it done. Let's fix it." So I think as soon as we knew for sure he was like, "All right. What do we do? Let's fix that," where I was more like, "Okay, let me grieve this for a while..." (Laughs) ...and he has literally just started researching immediately... and I was, I just started home-schooling (name of sibling of child with ASD) like it was a month into it. My life was perfect. I was thinking, "Oh*

> *this is great. I'm going to home-school," and then, I get the autism diagnosis and just totally overwhelmed (me), like I couldn't even function. I was in bed. I just like, couldn't get out of bed for a while, and I finally started seeing that there was hope, so then once I realized there was hope and that people were getting their kids better, then I'm like, "Okay. I can tackle this." Well then I would -- I kind of have my roller coaster moments, where it would be like, "Okay. I can do this. Oh, my gosh! I can't do this," and it was such a slow process of seeing progress. At least for me, it seems slow even though, we are like now going only to two years to get him to where he is. It's a long two years and it actually started before the two years...because it started when he was even over 15 months old, so to me, it's been almost four years because he'll be 5 in December - -- so about three, four -- three and a half years, I guess now."*

One participant expressed her appreciation about the level of support she gets from her husband. She said,

> *"I am grateful about it. We're team players!"*

Additionally, when this participant was asked who supported her the most, she indicated,

> *"That would be my husband, for sure! The most meaningful is the relationship with my husband. I mean we have really a solid relationship. We are definitely team players, we communicate, and we share our feelings honestly with each other. I think that probably is the most meaningful because just having the safe person that I can say and share anything and know that he is not going to judge me or look differently at me."*

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Support from friends

Participants reported having strong relationships with their friends who may have shared or not shared similar experiences with autism spectrum disorder. Most of them expressed gratitude over their friends' understanding of their children's special needs, support over a period of years and their kindness and assistance to their families and children as they navigate through their maternal journeys. One participant described her two significant friendships that helped her work through her own grief. She shared that,

> *"I have two who I consider my best friends and she, my other best friend, (name of friend), lost a child when she was 5 weeks old. She was 5 weeks old. Yeah, and she would have been (name of child's older sibling)'s age and so actually, we weren't friends before -- we weren't acquaintances before her daughter died and that situation, because I just started going to see her......made us really close friends and so when (name of child with ASD) was diagnosed, there's a lot of similarities between your feelings, and I've never lost a child and I will not say that this is the same because I know it's not, but (name of friend)'s emotions, and she still deals with those. You know, it has been seven years now, and my emotions with (name of child with ASD) because I felt like I lost, I felt like I lost my dreams for him at that time, and so she and I could really connect because her grief and my grief were very similar. Even though they weren't the same, we still went through the same emotions. Even though it was a totally different situation where she lost, she actually physically lost her daughter. I thought I physically lost my son."*

One mother described her friendships with both mothers with and without children with ASD. She shared,

> *"Yes, I have both. I'm definitely closer I think. It's hard to describe. I don't know because I have close relationships. (They are) different. I can relate to both. But I can relate more with my friend who two sons of the same age and difficulties so I can relate more to her. I think probably there is just a stronger bond because you go through with things that other people don t have children that have those difficulties that would help them understand."*

Institutional support

The educational institution was a source of social and service support for the mother and the child. One mother reported that,

> *"The staff that I have worked with the school, is wonderful, like, take for instance like last year when they were evaluating him because they thought they were going to re-certify him last year they change their mind, she was saying when he was five that if he would qualify in anything, they would make sure that he would stay. Very proactive. Because they see something there but they just don't know what it is . . . even if he doesn't qualify in any (of) them they (are) still gonna give him this that he will be able to get the services. "*

One institution called Judevine Center for Autism was considered to be a lifesaver for one of the participants when she learned of her son's diagnosis. When asked about supports for autism from infancy to adulthood, she enthusiastically shared,

> *"Pretty much! They have tons of programs and this actually, this center as referred to us by the gentleman that my husband work with because they had done it and they said that was kind of our first introduction to ABA (behavioral support program) because they kind of did it, it like a trial. Its where they introduced that and after that, we already had our people in place ready to go because by the time we did the summary meeting at the end of it all, I had my ABA consultant, I had my OT(occupational therapist), I had my PT(physical therapist)), everybody was there (to help us)."*

ASD parent support groups

One participant, who was a certified elementary school teacher, expressed her enthusiasm about being a part of a network of parents with children with special needs. She said that,

> *"I was one of the parents that could share . . . (other parents) they've seen through with this and most of them have children who are older so I could learn a lot. And from them, they could share their experiences during those meetings about things that they have done with the school, things that they have done with the other parents, and getting their kids together, and just the resources are shared places you can go, different tools they have used that have been helpful. I think it has been an immense help."*

In another situation, a participant got connected to a mothers' network, met a friend of her husband who was going through a similar experience with their child and the friend then shared his networks with them. She said,

> *"(I got notice) through the state, I would say, just through the initial program. Those people that I was directing with, they were the ones who say, "Okay I know this person. " And then Molly and then the other mom were okay. She had lived in Missouri her whole life, and had learned to get to know other people. (She said), "You need to talk to this person, find out who this person, what he is doing, I've heard that this gal is the one that is doing ABA and she's the consultant to have that's kind a help. It was all network and parents. (My husband's friend), he's the one who recommended Judevine and so all or a lot of our support and information came from other parents. We didn't get anything from the doctors; it was all from the parents."*

The results showed similar experiences of emotional, physical and social challenges of mothers during early detection and period of diagnosis. The microsystems parents, spouses, friends, social affiliations/networks, and medical and school service providers provided reciprocal supports with the microsystems of mothers and children in the mesosytem. The ecological systems theory provided an excellent theoretical framework in discussing the mothers' social support systems.

CHAPTER 5

SUMMARY, DISCUSSION, CONCLUSION AND RECOMMENDATIONS

As stated by Bendell, Stone, Field and Golstein (1989) and Weisberger (1991), the quality of life of family members who take care of children with developmental disabilities is affected. In this study, the mothers are and continue to be, the primary caregivers of the children with autism spectrum disorder (ASD). This chapter covers the following topics: 1) Summary of Findings; 2)Discussion of the Ecological Systems Theory and Mother's Support Systems; 3) Recommendations for Practice and Future Research.

Summary of Findings

The sample participants are characterized as follows: The majority of the participants are over 36 years of age and married. They are all Christians. The mothers all have post-high school degrees with the exception of one participant. In fact, there are two mothers with advanced degrees. Eight out of 13 are unemployed. Nevertheless, the majority have yearly household incomes of over $75,000.00.

The majority of the mothers have two parent- households. In one case of a single mother, a grandmother serves as the other parent. All in all, there is a perception of stability in the households. Majority of the children with ASD have siblings with the exception of two families. There is a balanced geographic representation of the group with rural, suburban and city dwellers.

The children diagnosed with autism spectrum disorder in the study are mostly boys (11 out of 13) and have diverse age ranges from 4 years to 11 years old. Majority of the children with ASD have sibling with the exception of two families. The majority of the children were diagnosed with Classic Autism.

According to interviews and complementing eco-map, and field notes reporting, strong sources of support come from parents, spouses, friends, other parents, other children, service providers and person from social affiliations and networks with varying degrees of perceived strength of support and stress. The linkages of relationships and experiences lie in the microsystems of the persons in contact with the mothers in our study. The linking of these microsystems forms the mesosystem. The mothers' microsystems linked in the mesosystem are characterized by the different sources of support in varying perceived intensities of strength and stress. Sources of support originate from the microsystems of parents, spouses, friends, other parents and children, people from social affiliations, networks and institutional providers (medical practitioners and school professionals). The majority of participants reported that strong social supports primarily come from their parents, spouses, and friends. Fifty per cent of the 12 respondents reported very strong support from their spouses with the other 50% reporting varying strengths of stressful support. Participants perceived their parents as giving very strong support at 38.89% with an additional 33.33% as strong and stressful supports. The group collectively qualified their friends as strong sources of very strong support at 59.26%.

Discussion of the Ecological Systems Theory and Mothers' Support Systems

According to Bronbenbrenner's (1989) ecological systems theory of human development, "contexts are described from the perspective of the developing person." In this case, the mothers' microsystems are described according to their perceptions and experiences of primarily being a mother with child with ASD. The use of phenomenological method was the best way to describe the mothers' supports and interrelationships in the systems. Their experiences uncover the complexity of relationships and activities in their settings of being a mother with a child with ASD. The mothers' microsystems consist of the "pattern of activities, roles, and interpersonal relations experienced by the developing person in a given face to face setting with particular physical and material features containing other persons with distinctive characteristics of temperament, personality and systems of personal belief (Bronfenbrenner, 1989)." The mothers experience their roles as parents with children with autism spectrum disorder in the microsystem. They establish interpersonal relationships with other microsystems (parents, spouses, friends and others) as they exchange information and engage in activities. The mothers' microsystems link with other microsystems forming the mesosystem characterized by linkages of relationships, activities and experiences. The mesosystem is characterized by the interpersonal relationships between mothers and children, mothers and their parents, mothers and spouse, mothers and their friends, service providers and others (See Figure1).

According to Bronfenbrenner (1979), the mesosystem is "a system of microsystem formed by interconnections inclusive of links in formal and informal communications and knowledge and attitudes in the phenomenological domain." The mothers' interconnections with the microsystems of parents, spouses, friends and others provide strong sources of support as they navigate their journeys of parenting children with autism spectrum disorder.

Inge Bretherton (1993) indicated that the originality of Bronfrenbrenner's work lies in "its emphasis on studying interrelationships among subsystems during periods of transition ... and attending to the communicative processes between two settings with its supportive links of shared goals, mutual trust, positive orientation and consensus." The mothers who participated in this study were primarily linked to the parents' microsystems, spousal microsystems and friends' microsystems. Additionally, the mothers' microsystems were also linked to the service providers' microsystems, persons from social affiliations and networks, other parents' microsystems and other children's microsystems. Their perceptions of the "communicative processes" between these microsystems provide linkages and sources of support and are best explained by Bronfenbrenner's ecological systems theory. This study revealed that the maternal microsystems' links with these other microsystems made up the mesosystem which continues to be a strong source of support for the mothers. This mesosystem provide the mothers with strong, emotional support and an inordinate source of resources, referral and information in order to, in turn, support their children's microsystems. The mothers' relationships and links which serve as strong sources of support occur in the mesosystem.

The mothers' responsibilities cover the spectrum of daily care and establishing routines for their children with ASD inclusive of the scheduling medical and hospital appointments and working with medical professionals and specialists to obtain care for the diagnosis. The mothers also attend school conferences, plan and implement daily activities for the children, and research information, resource and referrals to assist the children in obtaining appropriate care. They attend workshops and conferences about the disability, network with parents, church or institutional groups coordinate playgroups and socialization opportunities for the children and link with family members and friends in creating a web of support for the children. Concurrently, the mothers still attend to household chores and continue to be the primary caregivers to all their children.

Spouses, partners, parents, friends and significant others provide secondary support in the daily care of the children such as providing respite for the mothers, providing comfort through active listening and assurance of their presence when necessary. They are also available as emergency contacts for the mothers and their children. They bring the children to medical and hospital appointments, attend school conferences, assist with household chores, and care for the other children in cases where the mother had to attend to the child with ASD. The spouses, parents, friends and significant others assist the mothers in researching and obtaining additional information, resource and referrals. They link the mothers to networks and affiliations that would help the mothers obtain appropriate care and support for their children and themselves.

The mothers learn to advocate for their children and develop relationships outside of the family in order to create opportunities and socialization activities for their children with ASD. The primary role of the mother is a key factor in the advocacy of services and appropriate care for the child. There were mothers in the study who, in their perspective, successfully advocated for their children by developing the courage to ask questions, providing alternative solutions to medical and school professionals, and finding new information to challenges by referencing the web. There were mothers who embarked on finding experts in the field of autism, reading books, articles, and journals about autism, attending conferences/workshops, and locating networks of parents and professionals who have gone through similar experiences and challenges with their children.

Wolfe (1992), in his research, was accurate in stating that mothers had taken on the roles of "educator, decision maker, advocate, teacher, case manager, and program evaluator." In their quest to find appropriate care for their children with ASD, these mothers have courageously assumed these roles despite their feelings, at times, of denial, grief, loneliness, and sadness.

The mothers in this study continue to move forward to explore, learn, and maintain tenacious support to improve services for their children with ASD. Most of the mothers in the study believed that they can improve their children's lives by servicing their needs as early as possible in their growing years. For those whose realization and acceptance of their children's disability came later, they continue to help their children by networking and linking with like-minded parents in order to get the services that their children need as soon as realistically possible. The mothers whose children are younger definitely take the role of advocacy in order to get critical services for them. This responsibility grows as the child gets older. This is supported by Weisberger (1991) and Traustadottir (1991) in their study that the parent "acts as an advocate by looking for unusual, developmental delays in early infancy" and the "role of mothers continue to grow in importance as the child matures."

The mothers' perspectives on their support systems are critical in their survival as caregivers for their children with autism spectrum disorder (ASD). From the time of pre-diagnosis and their challenging journeys towards acceptance of the diagnosis, the mothers' microsystems links to the other microsystems (spouse, parents, friends, siblings and affiliations) continue to play critical roles in the mothers' journeys of parenting. There are complexities to the interplay of relationships which can prove beneficial or detrimental to the mothers. The support is beneficial in the form of emotional, instrumental, information and appraisal supports (House, 1981). The support can be detrimental when help is extended to the children but is not in compliance to how the children with ASD need to be serviced based on best practice or specialists' advice.

The results show high support for mothers linked with their parents, spouses, friends, social affiliations, and networks. House's (1981) study on the four types of social support confirms the quality of support the mothers receive from their parents, spouses and friends, especially on the emotional and informational categories of support. Institutional support from medical practitioners and school professionals come in the form of instrumental and information support. Additionally, all the mothers know how to access information and knowledge online and consistently uses the web as a practical resource for inquiries.

Recommendations for Practice and Future Research

Claire Tregaskis (2006) ongoing research on "fundamental inequalities, structural and attitudinal barriers that prevents access to health and social care by families" is a critical starting point of discussion for these mothers of children with ASD. By discussing the barriers to access for appropriate services, there is a plethora of opportunity to offer solutions to these challenges and problems. The study disclosed critical areas that need to be addressed in order to improve services for families of children with ASD.

Implications for Practice

Recommendations regarding financial, insurance, or medical supports for children's health condition

Based on the findings in the study, the mothers reported the lack of financial, insurance or medical supports for the child's health condition. The majority of the families take care of the children's special dietary needs, intervention programs, supportive activities, and medical expenses out of their own pockets. Three participants reported the lack of medical supports for specialized care for their children with ASD.

One participant reported spending thousands of dollars in order to get appropriate care for her son's diagnosis. She believed in the detoxification program supported by the organization, Defeat Autism Now or DAN and really wished for intervention care and financial assistance for children with ASD. A majority of the participants reported the difficulty of accessing insurance coverage for neurological and behavioral assessments for young children with suspected developmental delays.

There is a need to explore preventive and wraparound care for children with ASD. Developmental assessments and clinical tools for evaluation are not as prevalent as with other childhood diseases or ailments. Parents may wish to initiate and conduct discussions with their government officials/ legislators and insurance providers to explore the ongoing problems and challenges of insurance coverage for assessments, intervention programs and medical care for children with autism spectrum disorders and other developmental disabilities.

There is a need and opportunity to train medical practitioners, especially, pediatricians, in offering assessments for children with ASD and linking them to neurologists, psychologists, and/or nurse practitioners who are specialists in the area of autism spectrum disorder.

Recommendations to address lack of support services for second language speakers

One participant, who is a second language speaker, really struggled with understanding medical professionals. She had a challenging pregnancy and her child had suffered complications after birth. She shared her story, thus:

> *"In (name of hospital), and I say, "Ok. I wait for (name of child)." I arrived in the hospital 3o'clock in the morning and (name of child) 11:45 am and*

> *I say ok and the doctor take care of the baby, cleaned, all of the baby. I look the baby and I say, "Oh, oh, you are here!" And I give a kiss. (The) doctor says, "I need to take the baby because she needs shots," and I said, "Ok." (Doctor said), "I (will) be back, maybe in three minutes."And I say, "Ok." And after three minutes, nobody came with the baby. Nobody tell me nothing. I say, "What happened because he had the baby?" In my mind, I don't know, she having a mark or something. I say, "Maybe somebody is stealing the baby go and see." (My aunt says), "Ok." My aunt is with me, translation me with the doctor. He said, "Okay," and she goes. In the past two hours, nobody coming, I am alone in the room."*

Two other bilingual mothers had varying challenges understanding and resolving the service providers' explanation of the diagnoses of their children, rationale, and procedure of care for their children with ASD. There is a need for parents and medical/school service providers to come together and collaboratively work towards finding solutions towards improved working relationships for the benefit of the children.

The Individual with Disabilities Education Act (IDEA) has federally mandated parental involvement in servicing families with children with disabilities or special needs. In order to effectively engage and involve the parents in educating their children, there is a need to develop, distribute and maintain supportive and assistive services, devices, information and collateral materials that serve multiple and diverse populations of families. Emerging from this study is the need for translated service documents and translators for mothers with children with special needs. The translators need to be adept with the nuances of the disability, medical and legal terminologies and familiar with documents and service delivery procedures. The translators' expertise is significant in order to clarify, review and confirm diagnoses, instructions and services for the families with children with ASD.

Servicing procedures need to have mandatory evaluations or outtake processes to make sure parents and families understand the diagnosis, rationale for the diagnosis, medical and health condition, process and service delivery for the children.

Mothers, especially women of color and/or second language speakers, need to network and work together to articulate their needs, disclose challenges and difficulties in effective service delivery. They need to contribute, gather, and share information and resources with each other. Mothers should communicate their children's needs to their families and networks. It is very important that they establish a working relationship with service providers in order to access appropriate and timely care for their children with ASD.

Recommendations to address compassion and understanding from service delivery providers

Service providers need to understand that the time of detection and period of early diagnosis are especially sensitive and emotionally difficult time for parents of children with ASD. It is a "first time experience to have a child with ASD" for ten out of the thirteen mothers. The weight of responsibility and emotional challenges for the other three mothers with other children with developmental disabilities are not any lighter or less.

Some of the mothers reported lack of compassion from service delivery providers. In one case, a mother reported, *"I don't feel better because these papers, the people who are here know nothing about my feelings, they tell you all about (name of child) mental number, she's a number, it's a number, sometimes their diagnostic, I don't understand. "*

This participant shared that she would bring her relative to translate for her in the medical clinic, hospital, or the school but they ended up waiting a long time anyway to obtain services for her child. She expressed frustration over matters that were not clearly explained to her by service professionals. There was even a situation that she asked for her child's hospital records and the medical professional did not give it to her until the mother threatened to talk to her lawyer about the matter.

One of the participants was a young, bright mother and she felt that the medical doctors were ignoring her concerns for her child just because of her youth. She was a student in the medical field and was very observant of her eldest, young, son's development. Her son stopped talking when he was about 12 months and preferred playing in isolation and away from other children.

> *"My pediatrician told me that he's fine. He's just probably not talking (because, according to her) "You had your kids so close together," - which insinuates because I was young mother who have 3 children . . . maybe this is why (he is) not talking. And so when she told me that, I left (her) Dr. (name of doctor). I left. So, you think there's anything wrong (with) the fact that he doesn't speak? I know he can hear me coz' when I call him, he looks, but he's not speaking. Mind you it didn't matter (that I) was (an) educated mother who knew a little about psychology. No, it didn't matter. I was a young mother (who) doesn't know what I was doing so I left her and went to another pediatrician. And, oh*

goodness, I can't remember these pediatricians' name. I literally went (through) 3 or 4 (pediatricians)."

In one situation, a medical professional disclosed the diagnosis to the mother without prior explanations or preparations. The participant was caught unaware by the diagnosis. She shared,

> *"She (the doctor) was like, "You know, yes, I do believe your son has a lot if sensory issues but it's more sensory than autism but there may be still a chance that there is an autism there..." and of course, so I was just like, "Oh, my gosh, my husband was right, there was something wrong with my son."And she's like, "You know, nobody has told you."And I completely broke down in the office. She said, "Oh, my gosh, I thought someone had said something to you and you (were) just going to get confirmation." And (I said), "You're the first one to officially say that my son (has autism).*
>
> *She didn't know but that was kind at the end of the appointment and she said, "Don't worry. We'll take care of you." But that was that. And so, then it was through the neurologist that they asked lots of questions, (did) observations, and he was like, "Yeah, (he has autism), but he (neurologist) wasn't very nice about it."*

Service providers need to recognize that there are gender differences in responding and providing programs for parents with children with ASD. Although both parties go through the stages of grief and emotional cycles, service providers need to be trained in how parents cope with challenging situations. The service providers need to assist mothers and fathers/significant others to be positive and proactive in providing care for their children with ASD.

The educational plans of children with ASD should clearly detail the category for parental engagement and with this document, address family concerns such as translation services, therapy, and information about supportive and assistive networks and agencies. Mothers and families need information about networks and agencies that could support and assist them, in case their immediate families, especially spouses, partners, or parents, are not available or prepared to help them.

Intake and outtake program of services for families of children with ASD need to include training on compassion and understanding of the experiences that primary and secondary caregivers of children with ASD go through in parenting and assisting the children. By guiding parents with understanding, kindness and compassion, service providers would be able to transition parents into accepting this unexpected and new situation. This is especially crucial for first time parents who may have differing expectations of their first child.

Mothers, through their networks, can share names of doctors who are giving compassionate, positive, professional help to other parents with children with special needs. Participants have expressed that other parents' referrals have been very valuable as they access information and services for their children. Mothers who joined a network of other parents felt empowered about advocating and supporting their children with ASD.

Recommendations regarding effective communication and relationships between families and service providers

One mother expressed her satisfaction with her children's pediatrician. Her family has been with this pediatrician for 12 years and she is very pleased with her. She shares, *"My eldest child has cerebral palsy, my third has attention deficit disorder and my fourth one has autism spectrum disorder. Dr. (name of doctor) has always been very good to us. She makes sure that the children are well taken care of. She refers us to other specialists so we could obtain the proper assessments for our children. She always follows up on the health conditions of the kids and keeps us informed."*

On the other hand, one participant expressed her difficulty and frustration with medical professionals and her struggle of being referred from one medical professional to another without being given a thorough explanation of the diagnosis.

"She said, "Dr. (name of doctor), you bring the report (name of child) is autistic and you never tell me, why never tell me? He say, "Oh yes, I tell you (name of child) is autistic but were using different names with autistic." And I say, "I am confused now. I wanna know tell me what happen." (Doctor says) "Oh, yes she is autistic." And, she explain(ed) to me what is autistic. I say, "I feel very bad because I say autistic is a new word for me and I don't know."

"Nobody tell me and I go to the library and the computer and I check autistic and I say (name of child) have the symptoms but I say I'm not a doctor. I see the report, I see the truth. Now I tell you that (name of child) is autistic, that's the truth. He (the doctor) tell (told) me, "Don't believe me." He tell (told) me, "You go to Children's hospital and get a second opinion." (Second doctor) tell me, "Yes, (name of child) is autistic because (other doctor) tell me but I can tell you the truth if you go to the psychiatric and have assessment for the truth. . . but

my inference is not for this time, it is for autistic." Now I have this special child that needs health care."

For most of the mothers, there were initial challenges with communicating with their medical practitioners. The majority of the mothers have multiple medical practitioners for their children due to varying insurance coverage, dissatisfaction in care and lack of perceived appropriate service for their children.

Service providers need to provide parents with available, clear, concise, and detailed information about the assessment tools, diagnosis, rationale for the diagnosis, and medical/ health conditions of children with ASD. There is a great opportunity for service providers to inform parents about institutional support services that are available to families. Information, resources, and referrals about content, duration and costs of medical care or intervention programs after diagnosis would be helpful to parents figure out their next steps to helping their children. This way, parents can make the appropriate decision for their children's welfare.

Parents are advised to clarify and ask questions if there is anything in the conversation or delivery of services that they could not understand. Service providers can be more resilient and flexible in taking the time to explain rationale, methods and procedures of care for the families.

Recommendations regarding access to services and medical, educational, institutional support

There were research participants who were concerned about the lack of access to services and medical, educational and institutional support to families of children with autism. The factors ranged from the school's uncertainty about diagnosis, lack of process or navigation system for families so they could access appropriate assistance, and lack of resource, and referral information so the children can be helped promptly with appropriate intervention. One participant expressed her concerns about the school's uncertainty over the child's diagnosis which is affecting his services. She said,

> *"I guess it would just be the uncertain diagnosis. The school doesn't want to recognize that diagnosis. They're not going to provide some service for children that would be on that spectrum . . . he could benefit from that a little bit."*

Participants are concerned about the appropriate services for their children. One mother had asked the school to follow up on updating her child's educational program but the school was not responsive. The mother shared,

> *"I think (name of child's father) thinks that the (school) need our son in ASD class because they're sure that if he was in there, they can have the class. If I take my son out to move out of that class, they won't have an ASD class. They won't have a special education class. No, I think, I don't get as much support from teachers and no, I am not satisfied."*

Families need to informed and aware of their rights and privileges as parents of children with ASD. Service providers could provide a list of agencies, non- profit institutions, schools, hospitals, medical clinics or specialists' offices that provide care for children with ASD. By law, schools provide parents with legal documents explaining their rights to services for their children. Individual education plans could include line items for parental (intended for parents and legal guardians) intake and outtake procedures for care of the children and the families to address parental engagement.

Key Recommendation to improve practice

A strong family based support approach needs to be applied in servicing the needs of families and children with autism spectrum disorders, with consideration and attention to the ecological support systems that are linked to the mothers and children.

Recommendations for Future Research

This study will contribute to family research of children with ASD. Future research should cover involvement of a more diverse pool of human subjects (more Asian- Americans, Arab-Americans, African- Americans, Native-Americans, and Hispanic/Latino). A larger sample of participants would increase the generalizability of the study. Research could also be conducted with fathers as the focus of the research using the same set of questions for qualitative and, comparative analysis. Study on gender differences and resiliency could be integrated into future research for families with children with ASD. Research could also use variables of socio-economic status and location of domicile for human subjects and its effects on experience and perspectives of parents and receipt of services for the children. It would be interesting to conduct a comparative and in-depth study of service provider sites that would utilize and apply the recommendations stated in this study as intervention procedures for servicing families and compare it with sites that do not use these recommended procedures. These studies could contribute towards improving practice and service delivery to families with children with ASD.

These recommendations were formulated based on mothers' perceptions and experiences of parenting children with ASD. Recommendations from the mothers and professionals could be integrated into a balanced service delivery program for the children.

This is one of the parental research studies that address the mothers' perspectives regarding parenting children with autism spectrum disorder with the goal of providing insights and information about experiences, supports and perspectives. The research study has solid objectives of providing suggestions and recommendations for service providers as they assist mothers, parents, grandparents, families and children. A key recommendation is the formulation, utilization, and implementation of strong family-centered support programs in addressing the needs of primary and secondary caregivers of children with ASD. Parents, especially mothers, need to be empowered and have proximal positions of input, perspective, authority, engagement and involvement in the access and delivery of services to their children and families. Medical, school, and institutional systems need to promote authentic intake and outtake procedures for families, compassionate interaction and clear instruction of procedures, and diverse and culturally-sensitive tools and programs in order to promote nurturing relationships with parents with children with autism spectrum disorder.

APPENDICES

APPENDIX A

Introductory Letter

Agency/School Recruitment of Participants to the Study

APPENDIX A

Introductory Letter
Agency/School Recruitment of Participants to the Study
The ecology of experiences and supports of mothers with children with autism spectrum disorder during the children's early years

Dear Administrator/Head of School:

My name is Victoria Martinez and I am a doctoral student at Michigan State University, College of Social Sciences & Department of Family and Child Ecology. I would like to request your assistance in the recruitment of mothers to participate in a study exploring the experiences and supports regarding being a parent with a child with autism, especially during the child's early years. I would like to disclose that I am a parent with a child with autism. Participation in this study is voluntary and the participants can withdraw anytime without penalty.

If the mothers agree to participate, they will be asked to fill out a demographic questionnaire, complete an eco-map, and be asked to participate in interviews consisting of a series of open-ended questions regarding her experiences and support systems being a mother of child with autism. They will be asked to participate in interview sessions which will last 1.5 to 2 hours with an option for a follow up interview lasting no more than 1 hour if necessary for clarity of responses. The participants will be asked by the interviewer whether they will allow the interview to be audio-taped or digitally voice recorded. They have the right to stop the recording at any time during the interview. This study is for academic purposes only. All interviews are strictly confidential and are conducted under the strict policies of the Institutional Review Board Human Protection Program of Michigan State University.

Aside from filling out the demographic questionnaire and participating in qualitative interviews, there will not be any additional requirements. If you have any questions regarding this research project, you may call me at (248) 390-1861 or email me at marti464@msu.edu. If you have any questions or concerns regarding the rights of the study participants or are dissatisfied at any time with any aspect of this study, you may contact, anonymously or otherwise, my Dissertation Chair, Dr. Julia Miller, Ph.D., of the College of Social Sciences –Family and Child Ecology, by phone (517) 432-3818, by email at jrmiller@msu.edu or by regular mail 10 Human Ecology, East Lansing, MI 48824 and/or Dr. Daniel Ilgen, Ph.D., Chair of the Social Science, Behavioral, Education Institutional Review Board by phone (517) 355-2180; fax (517) 432-4503; email at irb@msu.edu or by regular mail at 202 Olds Hall, East Lansing, MI.

Your help in this matter is greatly appreciated.

Thank you.

Victoria Martinez-Doctoral Student
Michigan State University
College of Social Sciences

Department of Family & Child Ecology

Mailing Address:
7235 North Village Drive
Clarkston, Michigan 48346

(248) 390-1861 marti464@msu.edu

APPENDIX B

Introductory Letter

Parent Consent for Participation in Study

APPENDIX B

Introductory Letter
Parent Consent for Participation in Study
The ecology of experiences and supports of mothers with young children with autism spectrum disorder

Dear Parent:

My name is Victoria Martinez and I am a doctoral student at Michigan State University, College of Social Sciences & Department of Family and Child Ecology. I would like to invite you to participate in a study exploring your experiences and supports regarding being a parent with a child with autism spectrum disorder, especially during your child's early years. I would like to disclose that I am a parent with a child with autism spectrum disorder. Participation in this study is voluntary and you can withdraw anytime without penalty.

If you agree to participate, you will be asked to fill out a demographic questionnaire, complete an eco-map, and be asked to participate in interviews consisting of a series of open-ended questions regarding your experiences and support systems being a mother of child with developmental disabilities. You will be asked to participate in an interview session that will last 1.5 to 2 hours with an option for a follow up interview lasting no more than 1 hour if necessary for clarity of responses. You will be asked by the interviewer whether you will allow the interview to be audio-taped or digitally voice recorded. You may stop the recording at any time during the interview. This study is for academic purposes only. All interviews are strictly confidential and are conducted under the strict policies of the Institutional Review Board Human Protection Program of Michigan State University.

Aside from filling out the demographic questionnaire and participating in qualitative interviews, there will not be any additional requirements. If you have any questions regarding this research project, you may call me at (248) 390-1861 or email me at marti464@msu.edu. If you have any questions or concerns regarding your rights as a study participant or are dissatisfied at any time with any aspect of this study, you may contact, anonymously or otherwise, my Dissertation Chair, Dr. Julia Miller, Ph.D., of the College of Social Sciences – Family and Child Ecology, by phone (517) 432-3818, by email at jrmiller@msu.edu or by regular mail 10 Human Ecology, East Lansing, MI 48824 and/or Dr. Daniel Ilgen, Ph.D., Chair of the Social Science, Behavioral, Education Institutional Review Board by phone (517) 355-2180; fax (517) 432-4503; email at irb@msu.edu or by regular mail at 202 Olds Hall, East Lansing, MI 48824.

Thank you.

Victoria Martinez-Doctoral Student	Mailing Address:
Michigan State University	7235 North Village Drive
College of Social Sciences	Clarkston, Michigan 48346
Department of Family & Child Ecology	(248) 390-1861
marti464@msu.edu	

APPENDIX C

Informed Consent Form

Parent Consent for Participation in Research Study

APPENDIX C

Informed Consent Form

Parent Consent for Participation in Research Study
The ecology of experiences and supports of mothers with children with autism spectrum disorder during the children's early years

Investigators:	Julia Miller, Ph.D. College of Social Sciences Department of Family and Child Ecology (517) 432-3818
	Victoria R. Martinez, M.A. College of Social Sciences Department of Family and Child Ecology (248) 390-1861

Purpose

We would like to invite you to participate in a research study exploring your experiences and supports regarding being a mother with a child with autism spectrum disorder during the child's early years. The secondary investigator is a parent with a child with autism. Participation in this study is voluntary and you can withdraw at anytime without penalty. This study is being undertaken as part of a doctoral dissertation research project. Your participation in this study will consist of an interview of 1.5- 2 hours with an option for a follow up interview lasting no more than 1 hour if necessary for clarification of your interview responses. You have been selected as a possible participant in this study because of the following: a) you are a mother over the age of 18 years old with a child with autism spectrum disorder (ASD) as diagnosed by a medical professional, school official, or special education specialist; b) your child's age range is within 2-11 years of age. If you are under 18 years of age, you cannot be in this study without parental permission.

The population trends indicate a marked increase in the prevalence of autism spectrum disorder in our country and state. These trends are significant enough that we need to provide research that will study the families who are directly involved with caring for children with autism spectrum disorders (ASD). There is a need to study the role of families, especially mothers, in assisting their children with autism spectrum disorder, and to identify the social support systems that will assist the families in accessing early intervention services and family supports. This research study highlights the primary and significant role of mothers in caring for children with ASD.

Procedure

If you agree to participate, you will be asked to fill out a demographic questionnaire, complete an eco-map, and be asked to participate in interviews consisting of a series of open-ended questions regarding your experiences and support systems being a mother of child with autism spectrum disorder. The interview session will last 1.5 to 2 hours with an option for a follow up interview lasting no more than 1 hour if necessary for clarity of responses. <u>Your participation is completely voluntary</u>. The interviewer will ask whether you will allow the interview to be audio-taped or digitally voice recorded. You may refuse to answer questions, request that the recording be stopped at any time during the interview, or withdraw your participation at any time. This study is for academic purposes only. You may request the results of the research from the investigators upon completion of the study.

All interviews are strictly confidential and are conducted under the strict policies of the Institutional Review Board Human Protection Program of Michigan State University. Aside from filling out the demographic questionnaire, completing an eco-map and participating in qualitative interviews, there will not be any additional requirements.

Benefits and Risks

There are no implied benefits in your participation to the study. However, the study will generate valuable knowledge to mothers and families who have children with autism spectrum disorder (ASD) in exploring beneficial social support systems as they access services for their children. This study will contribute towards the understanding of more effective support systems for families with children with ASD. The results of this study will only be used for academic purposes and the researcher can provide you with the findings of the research upon your written request.

There are minimal risks associated with this research study associated with feeling a sense of discomfort about answering questions relating to your experiences and perspectives. However, if you become tired or feel uncomfortable revealing personal information to the researcher, you may take a break at any time or refuse to answer any question. Always remember that your participation is completely voluntary and you may withdraw from participating at any time.

Privacy and Confidentiality

Your privacy will be protected to the maximum extent permitted by law. All completed forms, interviews, and conversations are strictly confidential and are conducted under the strict policies of the Institutional Review Board Human Protection Program of Michigan State University. If you consent to this research study, your interview will be audio-taped or digitally recorded to assure correct transcription of participant information. However, you may stop the recording at any time. All participant data will be identified by a code number and a list of code number linked to the participant name will be kept in a locked file in the primary investigator faculty's office along with the audio-tapes and transcriptions for three years. Only the researcher, dissertation committee members and the Institutional Review Board have access to the data. After the period of three years, all data connected to this research study will be destroyed.

Your Rights to Participate or Not Participate

Your participation in this research study is complete voluntary. You maintain the right to withdraw at anytime. For your protection, you will also be told of any significant findings that may develop during the research process that may affect your willingness to continue. There will be no money or material compensation for your participation. If you have consented to the study and later on decide to discontinue, you may tell the investigators/researchers, withdraw your consent and immediately stop your participation in the study. There will be no penalty for your withdrawal or refusal to participate at any time.

Conflict of Interest and Disclosure

The Principal investigator and the Dissertation committee members have no significant financial interests connected to this study.

The secondary researcher is a parent with a child with autism. As the secondary researcher, the role will be taken to acquire knowledge for research purposes and not contribute personal perspectives to the study. You may withdraw from the study without penalty if this poses a possible conflict or problem with your participation in the study.

Contact Persons for the Research Study

If you have any questions regarding this research project or the nature of your participation, please contact:

Julia Miller, Ph.D. College of Social Sciences Department of Family & Child Ecology 10 Human Ecology East Lansing, MI 48824 (517) 353-9467 jrmiller@msu.edu	OR	Victoria Martinez, M.A. College of Social Sciences Dept. of Family & Child Ecology (248) 390-1861 marti464@msu.edu

If you have questions or concerns about your role and rights as a research participant, would like to obtain information or offer input, or would like to register a complaint about this study, you may contact, anonymously if you wish, the Michigan State University's Human Research Protection Program at 517-355-2180, Fax at 517-432-4503, or email irb@msu.edu or regular mail at 202 Olds Hall, MSU, East Lansing, MI 48824.

FOR THE PARTICIPANT:

My signature below indicates my permission and voluntary agreement to participate in this research study.

____

Print Name of the Participant / Subject

____

Signature of the Participant / Subject

I agree for this interview to be audio-taped.

Yes_____ No_____

____

Signature of the Participant/ Subject

____

Date

____

Signature of the Person Obtaining Consent

____

Date

APPENDIX D

Demographic Data

APPENDIX D

Demographic Data

Date of Interview: **Code____**

Site Location:

PARTICIPANT INFORMATION

Age

___ Less than 18

___ 18 – 25

___ 26 – 35

___ 36- 45

___ 46- 55

___ Over 55

Race/Ethnicity

___ White/Caucasian

___ African-American

___ Asian-American

___ Native American

___ Hispanic-American/Latino

___ Other _________

Highest Level of Education

____ High School

____ Associate Degree

____Bachelors Degree

____ Masters Degree

____ Doctoral Degree

____ Other

Religion (not mandatory)

___ Protestant

___Catholic

___ Jewish

___ Islamic

___ Hindu _____

___ Other ______

___ None

Marital Status

___ Single

___ Married

___ Divorced/Separated

Employment Status

____ Employed

If employed, nature of work ____________

____ not employed

____ In between jobs

____ Spouse' Occupation

____ Spouse Not Employed

Household Income

______ $200,000.00 and up

______ $150,000.00 - $199,999.00

______ $100,000.00 – 149,999.00

______ $75,000.00 - $99,999.00

______ $35,000.00 - $74,999.00

______ $34,999.00 and lower

Family Composition At Home

______ Spouse

______ Partner

______ Mother/Father of Participant

______ Grandmother/Grandfather

______ Other Relatives

______ Friend

CHILD INFORMATION

Code____

Age of Child at time of interview ____

Sex of Child _____ Male ____ Female

Does the child have siblings? ___ Yes ____ No

Indicate number, ages and sex.

When was the child diagnosed? Indicate Month/Year ________

Who or what institution did the diagnosis? ________

What instrument or tools were used for the diagnosis?

What is the diagnosis of the child?

____ Classic Autism

____ Asperger Syndrome

____ Pervasive Developmental Disability Not Otherwise Specified

____ Rett Syndrome

____ Child Disintegrative Disorder

Is the child currently receiving help for the diagnosis? ___ Yes ___ No

Indicate and please specify:

___ Public School

___ Private School

___ Early On

___ Private Professional

___ Public Agency/Non Profit

Is the child currently enrolled in an educational/service program?

Indicate and please specify:

____ Public School

____ Private School

____ Head Start Program

____ Agency Program

____ Other

Would you like to share any other information that would be pertinent to this research study?

Thank you for completing this questionnaire.

All information will remain confidential.

APPENDIX E

Interview Questions

APPENDIX E

Interview Questions

Code _____

RESEARCH QUESTIONS	*INTERVIEW QUESTIONS*
1. What are the mothers' experiences and perspectives during the period of early detection and period of diagnosis of the child's autism spectrum disorder?	1. Describe your experience with your child and your first memories of your child's development. PROBE: Cite a situation wherein you were interacting with your child and how he/she behaved with you. 2. Describe your perspectives when your child plays/interacts with your spouse/partner, siblings, family members or especially, with other children. How did you feel about these interactions? PROBE: When did you suspect that something was "different" with your child? How old was the child at that time? 3. Who did you approach with this suspicion? How did they react?

	PROBE: How did the people react to your suspicion? Did they share the same suspicion as you have? How did they express it? Did you tell them right away or did it take time for you to open up about your suspicions? 4. Who did you first approach to ask for help? How did they react to you? Were they helpful? Were they indifferent? PROBE: If you are married, how did you tell your husband? Or did he initially approach you? Did you tell your husband right away or did it take time for you to ask for assistance or help? If your child has a sibling, did you tell him/her and how did you express it? How did you tell your family member? Or did the family member initially discuss it with you? Did you tell your family member right away or did it take time for you to ask for assistance or help?

	If you approached a friend, a significant person or professional, how did you open up with this person? Did you tell this person right away about your suspicion or did it take time for you to ask for assistance or help? 5. Describe how you were able to obtain assistance/help for your child. PROBE: What type of professional was initially referred to you? Did they refer you to someone else? Was the referral helpful? What type of referral did they provide to you and was the referral helpful? What type of professional was initially referred to you? 6. What was your experience at the time that you were searching for answers? How did you feel? PROBE: When you got some initial answers to your concerns, how did you feel? Did you explore the questions of

	possible causes for the diagnosis? 7. Who and what were the persons/institution/organization that finally provided you with the diagnoses? How did you feel when you learned about the diagnosis? PROBE: How hard/easy was it to for you to get an evaluation for your child? Did they provide you with any other kinds of support for your child and your family? 8. What was your reaction to the diagnoses? What was your husband or family member's reaction to the diagnoses? 9. How did you obtain help for your child in connection with the diagnosis? How long did it take from the time of the child's diagnosis to the time of obtaining the help that you needed? PROBE: Who (person) or what (organization) assisted you in order to get the help that you need for your child?

	10. Were there changes in your family role or lifestyle when the child was born and when he/she was finally diagnosed? How did you feel when they informed you about the diagnosis? PROBE: Describe differences/similarities in your role or lifestyle before and after the child's diagnosis. 11. Did the diagnosis of the child change the way you behaved with your child?
<u>RESEARCH QUESTIONS</u> **2. What are the mothers' experiences of social support systems that affect, influence, assist and challenge mothers in assisting their children during their early years (birth to early years)?**	12. Keeping in mind that persons or institutions that assisted you in obtaining your child's diagnoses, what were the kinds of supports that they provided for your child, your family and yourself? How did they help you? (information gathering, emotional support, social networking) PROBE: Were they helpful? Did you feel that they

	understood your situation? Did you feel alone? Did you feel supported?
3. Using Bronfenbrenner's ecological systems theory, what is the mother's level of social support in the four systems: microsystem, mesosystem, exosystem, and macrosystem?	13. Describe the levels of support from: immediate (husband) or partner, other children, family members, friends, school district (teachers, principals, Early on, special education teachers), and community and/or parent groups? PROBE:: Who/what do you feel helped and supported you the most during your challenging times? How about your friends? How about your social affiliations? Friends with children? Neighbors? People at the school bus stop? People at work? How about your personal beliefs? 14. What were the barriers that you encountered in the process of getting help for your child (second language, miscommunication, lack of medical/financial support, lack of family, school, or institutional support?

	15. Describe your relationships/experiences with mothers/families with children with autism spectrum disorders/developmental disabilities and your relationships/experiences with those mothers/families that do not have children with autism spectrum/developmental disabilities. 16. How did you feel during this whole journey? Did you feel sad, depressed, elated, empowered, and helpless?
RESEARCH QUESTIONS **4. What are the mothers' perspectives of the relationships and support systems that offered the highest degree of support to the mothers with children with autism spectrum disorder?**	17. Share a meaningful experience about how you were supported or helped. PROBE: Who was the most significant person or group of people or association/organization who helped you made sense of your child's challenges and your family's struggles? What are the ways that you feel you have been helped? 18. What have you learned that you need to do in order to get the help you need for

	your child and for your family?? PROBE: Who are the people that you need to get involved in order to get help? 19. Identify the "success" you feel you have accomplished while accessing the supports for your child. PROBE: What did you need to do and what kind of information do you need to successfully access the support? 20. Having these rich experiences of being a mother with a child with ASD, how do you feel about sharing this knowledge with other parents or professionals? PROBE: Did this experience changed the way you relate to other parents and professionals?
	Is there anything else you would like to share with regarding your experiences?

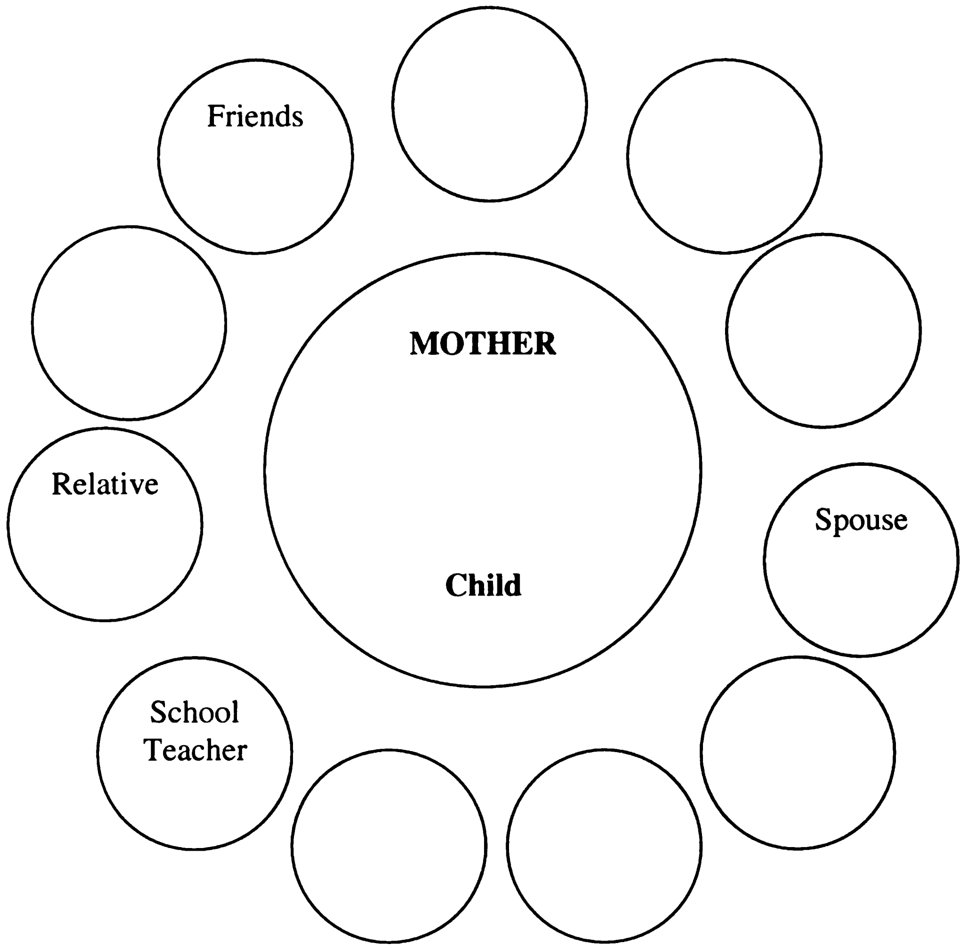
APPENDIX F

Participants' Eco-Map

APPENDIX E

Participants' Eco-Map

Code ________



Instructions: Identify significant people / institutions and fill in empty circles as applicable. Fill in connections where they exist. Indicate nature of connection by drawing lines. Identify strength of support / relationship by the following:

----------------	For strong
==========	For very strong
++++++++++	For stressful

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