# THE EMPLOYMENT STATUS AND MANAGERIAL CHALLENGES OF MOTHERS IN TWO-PARENT FAMILIES WITH CHILDREN DIAGNOSED WITH AUTISM SPECTRUM DISORDER

by

MELISSA ROBIN CASEY

(Under the Direction of Teresa Mauldin)

## ABSTRACT

This study sought to examine the managerial challenges and employment decisions of the mothers in two-parent families whose children have a diagnosis of Autism Spectrum Disorder (autism). Specifically, how does the presence of a child diagnosed with autism relate to a mothers choice to pursue employment outside the home in two-parent families and what factors are associated with making this decision? What are the managerial challenges brought about by having a child diagnosed with autism in two-parent families? Data were collected through semi-structured interviews with mothers of children diagnosed with autism in two-parent families in Georgia. Twelve interviews were conducted and through content analysis four themes were discovered: employment sacrifice, high time costs of therapies, lack of affordable or available services and insurance coverage, and the need for financial and legal services.

INDEX WORDS: Autism Spectrum Disorder, Maternal Employment

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# CHAPTER 1

## Introduction

Autism Spectrum Disorder (autism) is a developmental disability that affects a person's behavior, communication, and social interaction skills. This study seeks to examine the managerial challenges and employment decisions of the mothers in two-parent families whose children are diagnosed with autism. Specifically, in two-parent families, how does the presence of a child diagnosed with autism relate to a mother's choice to pursue employment outside the home and what factors are associated with making this decision? In two-parent families, what are the managerial challenges brought about by having a child diagnosed with autism? An overview of autism will be outlined including research about the financial and time costs the disorder places on a household. From the study implications for employers, financial planners, and families will be discussed.

As a developmental disability, autism affects a person's behavior, communication, and social interaction skills. Autism is reported to occur in all racial, ethnic, and socioeconomic groups. Diagnosing autism can be difficult and medical professionals must study a child's behavior and development to make a diagnosis. Common signs and symptoms include avoiding eye contact, unusual reactions to stimuli, delayed speech, and repetition of words or actions. Children diagnosed with autism will often have difficulty with communication and social interaction (Autism Speaks, 2010). The *Diagnostic and Statistical Manual of Mental Disorders Fourth Edition (DSM-IV)* criteria are used by medical professionals for diagnosing autism. Since there is no “medical” test to determine if a child has autism, diagnoses are done through observation by one or more medical professionals (Autism Speaks, 2010). The *DSM-IV* criteria look for the signs of autism in three distinct areas: impairment in social interaction, impairment in communication, and the repetition or development of patterns of behavior (Autism Speaks, 2010). Social interaction impairments include limited use of nonverbal communication techniques, the inability or unwillingness to develop relationships with peers, and a lack of awareness of one's surroundings. Communication impairments include slow or no speech and/or language development, an inability to start or continue conversation, repeated use of words or phrases, and a lack of creative and/or “make believe” ability. The repetition or development of patterns of behavior include signs such as a preoccupation with a specific word, pattern, or behavior, a need to adhere to strict ritual-like behavior, and repeated motor actions such as flapping or twisting of the limbs. The *DSM-IV* criteria indicate that delays or functioning impairment observed in these categories be first seen or developed prior to the age of three years (Autism Speaks, 2010).There is no known cure for autism and early intervention is essential for cognitive and social development despite which treatment option is chosen (Centers for Disease Control, 2010).

Because autism is a spectrum disorder, it affects people in different ways and is diagnosed in a variety of forms ranging from mild to severe. A person with autism could be diagnosed high on the spectrum and be regarded as mild. In this instance the person would experience very little complications from the disorder and need relatively few services. On the opposite end a person with autism could be diagnosed low on the spectrum and be regarded as severe. In this instance the person would experience extreme compilations from the disorder and possibly require full-time care services. The severity of the diagnoses has significant impacts on the types of interventions and services a person will require over the life course (Centers for Disease Contorl, 2010).

Treatment options can be clustered into three groups: behavioral and communication approaches, biomedical and dietary approaches, and complementary approaches (Autism Society of America, 2010). Behavioral and communication approaches seek to provide structure, direction, and organization for both child and family by changing negative behaviors and reinforcing positive behaviors (Centers for Disease Control, 2010). In conjunction with this type of treatment, speech therapy, occupational therapy, and sensory therapy are used to increase the child's ability to function independently (Centers for Disease Contorl, 2010). Biomedical treatments for autism include the use of medications and drug treatments to minimize symptoms and manage behaviors associated with autism (Autism Society of America, 2010). While dietary approaches as a treatment for autism have little research support, they do seem to help children in some instances, perhaps because of the routine established by monitoring and maintaining a diet (Centers for Disease Contorl, 2010). Lastly, complementary approaches, much like behavioral and communication approaches, use a variety of therapies such a music and art therapy or animal therapy to establish or change functioning behavior (Autism Society of America, 2010).

Because of the diverse range of treatment options, families must be aware of how each option will affect their household finances and daily functioning. Autism is an expensive medical condition and because of this researchers have attempted to estimate the costs associated with having a family member diagnosed with autism. Montes and Halterman (2008) estimated that parents of a child diagnosed with autism spent, on average, more than $5,272 in health care services a year compared to parents of a child without autism. Autism was also found to be associated with the loss of family income and significantly reduced the household income one would expect from a family based on parental educational attainment and other demographic variables. It was observed that significant out-of-pocket expenditures related to having a child with autism and the limited flexibility in the labor market leads to a decrease in household income relative to households of similar demographic characteristics (Montes & Halterman, 2008). On average a household with a child diagnosed with autism will have an expected loss of income totaling approximately 14%  when compared to a household without a child diagnosed with autism (Montes & Halterman, 2008). Sharpe and Baker (2007) found that the majority of medical intervention costs were not covered by parental health insurance and public education programs fall short of expectations leaving the parents no choice but to obtain outside services. The high cost of childcare was also cited as a major reason many parents must leave the labor force resulting in lower household income and putting the family at possible risk for bankruptcy or forfeited future savings (Sharpe & Baker, 2007).

The number of cases of autism diagnosed in the United States has been increasing rapidly. The Centers for Disease Control (2010) estimates that an average of 1 in 110 children in the U.S have a form of autism. It is now estimated that approximately 1.5 million Americans have a diagnoses of autism (Autism Speaks, 2010).  In Georgia, the prevalence of autism among children at age eight was 8 per 1,000 in 2002 (Centers for Disease Control, 2010). In 2006, the prevalence of autism among children at age eight had increased to 11 per 1,000 (Centers for Disease Control, 2010). The increase in autism was even greater in Arizona where the number of children with autism at age eight doubled from 6 per 1,000 to 12 per 1,000 between 2002 and 2006 (Centers for Disease Control, 2010). As the occurrence of autism continues to rise there is an increased probability that employers and financial planners will encounter a parent struggling to meet the increased demands, both in time and resources, brought about by having a child with autism (Sharpe & Baker, 2007)

## Problem Statement

Having a child with autism can place extreme financial and time demands on two-parent families. Children with autism often require additional medical and academic attention, speech and language therapies, and specialized childcare. These costs lead to an increase in normal household expenditures and can cause a drain on a household's finances. The financial constraints brought about by having a child diagnosed with autism can limit a family's ability to save for retirement. A recent study estimated that the lifetime cost to care for an individual with an autism was $3.2 million and on average, medical expenditures for individuals with autism were 4.1–6.2 times greater than for those without autism (Centers for Disease Control, 2010). Due to these expenses, the presence of a child diagnosed with autism can affect a mother's choice to pursue employment outside the home. A mother may find it financially beneficial to stay at home with their child because the costs of childcare services outweigh the benefits of labor force participation. Additionally, the time constraints in conjunction with having a child with autism may limit the employment opportunities available to mothers, forcing pursuit of part-time employment or forgoing employment entirely. Lack of employment by the mother and the associated reduction in potential household income because of the decision to be a caregiver can drastically affect the financial well-being of a household. Monte and Halterman (2008) implied that autism was associated with a loss of family income and speculated about the creation of barriers to entry into the labor market because of the difficulty of finding a work-family balance. Employers, financial planners, and families must be aware of these unique challenges faced by parents with a child diagnosed with autism. This research is especially pertinent to families who have a child that has recently been diagnosed with autism. Awareness about the struggles other families face can help parents with newly diagnosed children prepare for the future.

## Purpose of the Study

The purpose of this study was to examine the managerial challenges and employment decisions of the mothers in two-parent families whose children are diagnosed with autism. How does the presence of a child diagnosed with autism relate to a mother's choice to pursue or forgo employment outside the home and what factors are associated with making this decision? Does having a child diagnosed with autism limit a mother’s ability to obtain gainful employment? What factors are considered by mothers of children diagnosed with autism when making employment decisions? How has the presence of a child diagnosed with autism changed the future career plans and goals of the mother? How does having a child diagnosed with autism affect the daily work-family balance of the household? What are the managerial challenges brought about by having a child diagnosed with autism? Additionally, the impact on household finances and household expenditures as a result of the choice to pursue or forgo employment and as a result of having a child diagnosed with autism will be investigated. Employers and financial planners can benefit from this knowledge and learn how to work with parents who face these unique challenges. Families who have a child diagnosed with autism can benefit from this research by learning about the challenges faced by other families in a situation similar to their own.

### Research Questions

A number of specific research questions are investigated in the study. Among two-parent families:

1. How does having a child diagnosed with autism impact a mother's choice to pursue or forgo employment outside the home?
2. What factors and managerial demands are considered by mothers of children diagnosed with autism when making employment decisions?
3. What is the impact on the household finances and household expenditures as a result of having a child diagnosed with autism and the decisions of a mother to pursue or forgo employment?
4. How do mothers create a work-family balance in the home?
5. What kinds of financial and medical services are needed for mothers of children diagnosed with autism?

## Significance

The study of the managerial demands and employment status of mothers in two-parent families with a child diagnosed with autism is important for a variety of reasons. In addition to providing insight and knowledge for employers and financial planners, as the number of households affected by this disorder continue to rise there will be a need for applied research to inform polices that aid families. Mothers of children diagnosed with developmental disabilities often cite the high costs of childcare and the limited amount of flexibility in the work place as barriers to their ability to obtain and keep employment (Brennan & Brannan, 2005; Brennan, Rosenzweig, Ogilvie, Wuest, & Shindo, 2007; Kagan, Lewis, Heaton, & Cranshaw, 1999; Lewis, Kagan, & Heaton, 2000a, 2000b; Rosenzweig, Brennan, Huffstutter, & Bradley, 2008; Rosenzweig, Brennan, & Ogilvie, 2002). Work place polices can be developed to raise awareness and provide assistance to these families from the results of this study and others like it. This research can also shed light on the issue for governmental agencies and public policy makers who have the ability to provide funding to community support organizations and research entities. As, previously stated there is an increased probability that employers and financial planners will encounter a parent who has a child diagnosed with autism (Sharpe & Baker, 2007). Additionally, as the number of children diagnosed with autism increases, more families will need to be provided knowledge about financial and managerial challenges brought about having a child diagnosed with autism in the home.

Maternal employment in two-parent families has a drastic impact on the overall financial well-being for a family and the ability for a mother to pursue participation in the labor force can impact both the standards of living and the socioeconomic status of the household (Sharpe & Baker, 2007). Lack of employment opportunities coupled with the financial burden of caring for a child with a disability, such as autism, puts families at a greater risk for income related issues (Sharpe & Baker, 2007). Results can bring awareness and insight for financial planners to help families make decisions about how to allocate scarce resources and make sound decisions in relation to financing therapies, education services, and medical expenditures.

While no study has directly looked at the presence of having a child diagnosed with autism in the household in relation to a mother's employment status, several researchers have addressed the issue on a broader scope focusing on mothers of children with disabilities or chronic illnesses (Baydar, Joesch, Kieckhefer, Kim, & Greek, 2007; Gould, 2004; Porterfield, 2002; Powers, 2001). Further research focusing solely on the relationship between having a child diagnosed with autism and maternal employment is warranted because of the prevalence of the disorder and its potential implications for the household and the labor market.

## Assumptions

A traditional view of the household in two-parent families is taken by the researcher in this study, one in which mothers will exchange market work for household production given the presence of children. The main assumption in this study is that having a child diagnosed with autism in the household will have a greater impact on the employment status of the mother, rather than the father. A similar assumption was made in a 2007 study documenting the effects of asthma on maternal employment implying that a male spouse is unlikely to equally share in the care for a chronically ill child (Baydar, et al., 2007). Bayder (2007) indicated that while a male spouse in a two-parent family does lower the cost of a mother staying at home by providing income, The mother will be burdened by high demands on her household production time. Using this assumption, only mothers will be interview candidates in the study. The father’s role in the trade-off between market work and household production will be examined as well as their involvement related to the managerial and financial demands brought about by having a child with autism.

## Limitations of the Study

The general population of interest in this study is two-parent families where a child diagnosed with autism is present. This study is limited because results are applicable only for two-parent families and in those households where the mother was previously employed in the labor force before having a child diagnosed with autism. However, the implications for financial planners should be applicable for all families with children diagnosed with autism. Due to the nature of qualitative data, the study will be unable to determine causation in relationship to having a child diagnosed with autism and maternal employment status. Additionally, the qualitative data in this study do not allow for the generalization of results across the spectrum of the population. The recruitment of participants from community support groups suggests that participants might be of higher economic status than the average. Based on previous literature using families with a child diagnosed with a special need, a similar limitation was noted. This suggests that the majority of research participants in studies conducted with families of children with special needs are above the average socio-economic status (Baydar, et al., 2007; Brennan & Brannan, 2005; Gould, 2004; Heck & Makuc, 2000; Leiter, Krauss, Anderson, & Wells, 2004; Porterfield, 2002; Powers, 2001). Thus, results will only apply to those individuals who are participating in the study and those in similar situations.

# CHAPTER 2

## Review of Literature

This study sought to examine the managerial challenges and employment decisions of the mothers in two-parent families whose children are diagnosed with autism. The main purpose of the research was to gain insight and knowledge about the unique situations faced by mothers with children diagnosed with autism. To gain a full understanding of the importance of the relationship between maternal employment and having a child diagnosed with autism, a history of women in the labor force was reviewed. More specifically, the associations between maternal employment and children's health were explored. Given the limited amount of research on maternal employment and having a child diagnosed with autism, literature containing research on women's employment, maternal employment, and maternal employment for women whose children have special health care needs are outlined below to gain a breath of understanding for how having a child diagnosed with autism could potentially affect a household.

## Women in the Labor Force

The role of women in the labor force has drastically changed over time, in turn affecting not only the economy but the social structure of the United States. By 1850 almost 24% of the paid labor force was comprised of women (Brown, 1977). Made up of mostly young, unmarried females, this group of laborers filled textile mills and manufacturing plants. As the role of the women in society changed with increased access to education and political actions, so did the professional outlets offered to women as occupations (Kwoler-Folland, 1999). The dramatic increase of women working outside the household was due in part to the development of non-agricultural occupations for females and the resulting change of the household from a unit of production to a unit of consumption (Rotella, 1981). From 1976 to 1998 the average weekly hours worked by women increased approximately 42% (Herman, 1999). Full-time employment for women between the ages of 25 and 54 increased from 27% in 1969 to 50% in 1997 (Herman, 1999). Additionally, the number of women who worked more than forty hours a week rose from 14.1% to 19.9% between 1983 and 1993. Education also has had a dramatic effect on the employment status of women. At all levels of education between 1983 and 1993, women worked more weekly hours (Herman, 1999). Shorter work weeks, changes in household technologies, and the creation of new industry with less gender bias helped women combine household duties with labor force participation (Kwoler-Folland, 1999). Societal changes such as decreased family size, increased age at marriage, and higher divorce rates also helped make women's presence in the labor market acceptable (Kwoler-Folland, 1999).

### Mothers in the Labor Force

While women's presence has become an integral part of the United States labor force, the labor force participation of women with children has accounted for most of the increases in women's overall labor force participation (Hayghe, 1997). In 1969 only 23% of mothers with children under the age of three were participating in the labor force as compared to 63% of mothers with children under the age of three in 1999 (Herman, 1999). There has been a similar effect in the percentage of mothers with children under the age of three in regards to full-time employment. In 1998, 32% of these mothers were working full-time, up from 7% in 1969 (Herman, 1999).

In 1996, 77% of women with children who were of “school age” were in the labor force and 62% of mothers with “pre-school aged” children were working (Hayghe, 1997). Recently, slight drops in labor force participation for women with young children have been detected suggesting that younger children have a negative effect on labor force participation (Cohany & Sok, 2007). One notable change is the dramatic increase in single mother’s labor force participation. Between 1993 and 2000 the labor force participation rate for single mothers in the age range of 25 to 44 rose 14%, which suggests that single mothers encounter different circumstances than married mother in regards to their household production and thus their labor force participation (Hoffman, 2009).

The changes in American culture, making it acceptable for women with children to be in the workforce have led to many women already having established careers at the time of their first child 's birth and returning to those careers after a brief stint of maternity leave or time off (Hayghe, 1997). Earlier literature posing hypotheses that suggest maternal employment would result in household and marital discord and lower the developmental achievement and success rates for children have not been supported in additional research (Nieva, 1985). Additionally, literature suggests that maternal employment gives women a sense of empowerment, a greater role in the household decision making, and feelings of financial independence (Nieva, 1985).

## Mother’s Employment and Children’s Health

Salkever (1982) was one of the first researchers to examine the relationship between maternal labor force employment and children’s health. Through his research, Salkever explored the extent that a mother’s participation in the labor force was influenced by having a child with health problems. Data from the 1972 Health Interview Survey found that having a child with a health problem had a negative impact on maternal employment. This impact was increased by the severity of the health condition and had a larger impact for low income, two-parent families.

## Mother’s Employment and Children with Special Needs

Two unique avenues have been used to explore the relationship between employment and having a child with special needs. On the one hand, studies have attempted to show a statistically significant link between having a child with special needs and the employment status of the mother. These studies attempt to quantify the relationship and estimate the potential causation and relationship to other variables. On the other hand, some studies have taken a more relational approach and interviewed families about their personal experiences finding a work-family fit while having a child with special needs.

Consistently found in the literature was the negative relationship between maternal labor force participation and having a child with special needs (Baydar, et al., 2007; Brennan & Brannan, 2005; Gould, 2004; Heck & Makuc, 2000; Leiter, Krauss, Anderson, & Wells, 2004; Porterfield, 2002; Powers, 2001). While the presence of a young child with and without a disability was found to have a negative impact on maternal employment, Porterfield (2002) utilizing the Panel Study of Income Dynamic found that once children reach school age mothers both single and married with nondisabled children were likely to enter the workforce whereas married mothers of children with a disability were more likely to remain at home. Additionally, a relationship between labor force participation and education attainment level was found which suggested that those women whose education attainment level indicates potential higher earnings that would enable them to obtain qualified childcare will do so and remain in the labor force (Porterfield, 2002). A later study also using the Panel Study of Income Dynamics found that single and married mothers were less likely to be employed if their child's illness was severe or unpredictable (Gould, 2004). One troubling revelation from the literature was that children with special health care needs were less likely to have employer sponsored health insurance coverage which puts the household at financial risk given the increased medical expenditures often required for children with special needs (Heck & Makuc, 2000). More than half of mothers, in two studies of caregivers for children diagnosed with special needs, reported leaving the labor force due to disruptions brought about by their child's illness (Brennan & Brannan, 2005; Leiter, et al., 2004). Mothers of children with asthma reported decreased employment both full-time and part-time because of the unpredictability of their child's illness (Baydar, et al., 2007).

Other studies have used interviews to explore the experiences of families with children that have special needs and have sought to gain insight into the personal matters that were behind employment decisions (Brennan, et al., 2007; Kagan, et al., 1999; Lewis, et al., 2000b; Rosenzweig, et al., 2008; Rosenzweig, et al., 2002; Shearn & Todd, 2000). Interview subjects cited insufficient community supports in educational programs, unfit childcare facilities, and the lack of flexibility and understanding in the workplace as the primary reasons for exiting or limiting participation in the labor force (Brennan, et al., 2007; Lewis, et al., 2000b). One common theme also found throughout the content analysis of the qualitative literature was the tendency of parents to pursue avenues of employment that contradict their education attainment level or skills acquired prior to having children. Interviewees stated that these jobs, which fell well below where one would have expected them to be employed, allowed greater amounts of flexibility and required less concentration thus helping parents to focus on the health care needs of their child (Brennan, et al., 2007; Kagan, et al., 1999; Lewis, et al., 2000b; Rosenzweig, et al., 2002; Shearn & Todd, 2000). Additionally, mothers expressed a personal desire to enter the workplace and feelings of discontent and isolation due to their limitations as mothers with children who have special needs (Lewis, et al., 2000b; Shearn & Todd, 2000). The statements from these mothers suggest that the ability to obtain gainful employment was not only essential to the financial well-being of their household but the psychological well-being of the mother.

In summary, a review of the literature found no single study that focused specifically on the needs of families that have a child diagnosed with autism. However, there has been research undertaken that shows the limitations experience by mothers of a child with special needs and the financial impact having a child with special needs places on the household. This suggests the need for research in the area of specific special needs diagnoses such as autism. This study contributes to the literature by focusing on the relationship between having a child diagnosed with autism and maternal employment and the potential effects having a child with autism has on household finances and expenditures, a mother's ability to obtain employment, and creation of a work-family balance within the household.

## Conceptual Framework

The Family Resource Management Model (Deacon and Firebaugh,1988) has been used as a conceptual framework in previous studies to assess the financial costs associated with having a child with autism (Sharpe & Baker, 2007). This model was utilized as the framework in the previous study to understand the trade-off between mothers and fathers in household and market work and to examine the relationship between having a child diagnosed with autism and maternal employment status. As discussed below, several concepts from the Family Resource Management Model can help frame the hypothesis that mothers of children diagnosed with autism in two-parent families will have a lower full-time labor force participation rate when compared with mothers in households without a child diagnosed with autism (Sharpe & Baker, 2007).

It is assumed under the model that a family's main responsibility is for the procreation, socialization, support, and development of children (Deacon & Firebaugh, 1988). Under this assumption, the family is viewed as a system unit with two subsystems consisting of the personal subsystem and the managerial subsystem. As a system unit, the family seeks to acquire and manage the resources needed to meet demands and accomplish goals through the collective work of the individual members. The Family Resource Management Model develops an input-throughput-output framework to organize how family systems use resources and make decisions under scarcity. Inputs are viewed as demands and resources that feed into the personal and managerial subsystems which are subsystems within throughput. Demands and resources can be both internal and external. Demands include family values, goals, claims, social norms, events, and personal goal orientation. Resources include family supports, social supports, income, net worth, personal capabilities, personal qualities, life experiences and relationships. Demands and resources move into the throughput where they are categorized under the personal subsystem or the managerial subsystem. In the personal subsystem values and capacities are developing and evolving before moving into the managerial subsystem which consists of planning and implementation. Through the managerial subsystem, the output response is generated leading to demand responses and resource changes. Demand responses include goal orientations, goal achievements, and personality development. Resource changes include personal capacities and qualities, income, and net worth. Demand responses and resource changes are influenced by environmental factors that are possibly beyond the family systems control. The input-throughput-output framework is circular in that feedback is flowing from the output stage to the input stage before the cycle begins again.

Recalling the assumption of the societal responsibility of the family, the input-throughput-output framework implies families will utilize resources and address demands to cater to the physical care and social development of children (Deacon & Firebaugh, 1988). Deacon and Firebaugh apply the Family Resource Management Model to families with handicapped members, which would include families with special needs children having a diagnosis of autism (Deacon & Firebaugh, 1988). Handicaps and/or chronic illness are presumed to make a difference in the managerial demands and responses of the family system in virtually all cases regardless of the family life cycle. Families will respond to the handicap in two distinct phases, the adjustment phase and the adaptation phase. It is assumed that the family system was functioning in a stable manner prior to the introduction of the handicapped member thus resulting in entrance of the family into the adjustment phase. The adjustment phase is characterized by a disequilibrium caused from an imbalance in demands and resources that forces changes within the family system.

Entrance into the adaptation phase occurs when changes within the family system have clearly been implemented (Deacon & Firebaugh, 1988). For families with children diagnosed with autism, adjustments followed by adaptations must be made in order to provide the kinds of health care and educational services required for the child's optimal development. Given the constructs of the Family Resource Management Model, the model supports the hypotheses of the current research. It is presumed that changes in employment status of the mother and the reallocation of her time from labor force participation to childcare would fall into the above categories. Using the model to support the hypothesized relationship between having a child with autism and maternal employment, the study assumes that families enter the adjustment phase upon the diagnosis of the child resulting in the need for the family to make changes to care for the new and unique needs of the child. Given these new and unique needs, a family will move into the adaptation phase when the mother leaves the labor market to care for the child with autism. Based on the assumption of the study, that a mother will be primarily responsible for the care of the child, it is assumed that the mother will specialize in household production during the movement from the adjustment phase to the adaptation phase. A trade-off between mother and father will occur here as the father will now specialize solely in market work.

# CHAPTER 3

## Research Method

The purpose of this study was to examine the managerial challenges and employment decisions of the mothers in two-parent families whose children are diagnosed with autism and determine how the presence of a child diagnosed with autism relates to a mother's choice to pursue employment outside the home. What factors and managerial demands are related to the decision to pursue employment outside the home and what is the resulting impact on the household as a result of having a child diagnosed with autism?

## Research Plan

A qualitative research approach was chosen for this study. The researcher determined a qualitative approach was the best method for the study after exploring data sets and talking with other researchers in the areas of childhood disability. A qualitative approach allowed for the appearance and development of themes through content analysis (Babbie, 1995, 2001; Bentz & Shapiro, 1998; Demarrais & Lapan, 2004; Wolcott, 2001). During content analysis, themes are shaped through patterns in the form of frequencies, magnitudes, structures, processes, and causes (Babbie, 2001). A qualitative approach also allowed the researcher to obtain more personal answers to the research questions since interviews were conducted with human subjects. Semi-structured interviews with mothers in two-parent families who have children diagnosed with autism in Georgia were preformed. A guided interview schedule was developed using interview construction guidelines that encouraged detailed, narrative responses from the interview subject (Demarrais & Lapan, 2004). The guided interview schedule can be found in Appendix A. Prior to beginning the interviews, a pilot study consisting of two interviews was conducted to refine and revise the interview questionnaire. Those interviewed in the pilot study were not included in the final sample used in data analysis.

## Sample Selection and Interview Procedures

Interview subjects were recruited from various autism community support organizations located within Georgia. Participants were required to be the mother of a child diagnosed with autism living in a two-parent household. Single mothers were excluded from the study because of the complexities surrounding governmental assistance programs available to them. The researcher contacted the directors of the various autism community support organizations and reached out to potential participants through social media outlets such as Facebook and website message boards. An explanation of the research and sample questions was given by the researcher to the directors of the organizations and potential participants along with a copy of the consent form. All University Board of Regents IRB procedures for conducting research with human subjects were followed. The consent form and a sample recruitment letter can be found in Appendices B and C. Contact information for the researcher was also provided so that potential participants had the chance to ask questions or gather further information. The community support organizations that were contacted regarding participation are described in Table 1.

After initial contact with the organization director, interested mothers were put in contact with the researcher and a phone interview was scheduled at a time of the interview participants choosing. Interviews were planned to last approximately 1 ½ hours, per literature guidelines to obtain enough relevant information from the interview subject (Demarrais & Lapan, 2004). The researcher planned to conduct interviews until “theoretical saturation” was reached. This occurs once the interviewer is no longer learning new information from the interviews. At this point it is best practice to conclude the interview process (Strauss, 1994). Interviews were taped using a tape recorder and cassette tape and were transcribed by the researcher upon completion. The interview protocol can be found in Appendix D.

## Data Coding and Analysis

Once all interviews had been conducted and transcribed, coding and content analysis was performed by the researcher to establish themes within the data. NVivo, a type of qualitative research software, was also used to establish validity of the themes the researcher developed from the transcriptions (QRS, 2010). From the themes, conclusions and implications were drawn based on the research questions established for the study. The research questions included: How does having a child diagnosed with autism impact a mother's choice to pursue or forgo employment outside the home? What factors and managerial demands are considered by mothers of children diagnosed with autism when making employment decisions? What is the impact on the household finances and household expenditures as a result of having a child diagnosed with autism and the decisions of a mother to pursue or forgo employment? How do mothers create a work-family balance in their home? What kinds of financial and medical services are needed for mothers of children diagnosed with autism?

## Table 1: Community Support Organizations

| Community Support Organization | Description |
|---|---|
| Extra Special People (Extra Special People, 2010) | A 501(c) (3) non-profit organization based out of Watkinsville, Georgia. The organization serves children with development disabilities and their families through support clubs and summer camp programs. |
| Albany Autism Center (Albany Autism Center, 2010) | A not for profit organization located in Albany, Georgia. The organization provides speech, occupational, and behavioral therapy to children with Autism in the community. |
| Autism Society of America Northeast Georgia Chapter (Autism Society of America Northeast Georgia, 2010) | A local chapter of the Autism Society of America. The organization seeks to provide access to resources and create opportunities for individuals and families coping with autism. |
| Autism Society of America Greater Georgia Chapter (Autism Society of America Greater Georgia, 2010) | A local chapter of the Autism Society of America. The organization seeks to provide access to resources and create opportunities for individuals and families coping with autism. |
| Easter Seals North Georgia (Easter Seals North Georgia, 2010). | Provides a variety of therapy and support group services to individuals with disabilities and their families in numerous locations across Georgia. |
| Emory Autism Center (Emory Autism Center, 2010) | A division of Emory University School of Medicine. In addition to providing diagnoses and treatment services, the center conducts research and hold support groups for families in the metro Atlanta area. |
| North Georgia Autism Center (North Georgia Autism Center, 2010) | Provides behavioral therapy to children with autism. Additionally, the center holds play groups, family counseling sessions, summer camps, and parent support clubs. |
| Talk About Curing Autism Georgia Chapter (Talk About Curing Autism, 2010) | A support group for parents and families in the metro Atlanta area that holds monthly meetings to help parents learn about autism and create a network of support. |

# CHAPTER 4

## Results

This study sought to examine the managerial challenges and employment decisions of the mothers in two-parent families whose children are diagnosed with autism. Specifically, how does the presence of a child diagnosed with autism relate to a mother's choice to pursue employment outside the home and what factors and managerial demands are associated with making this decision. Data were collected through semi-structured, interviews with mothers of children diagnosed with autism in two-parent families located in the state of Georgia. This chapter will discuss how the interview process unfolded and what was learned about the relationship about having a child diagnosed with autism Spectrum Disorder and maternal employment status.

### Pilot Study

A pilot study containing two participants was conducted prior to the beginning of the study in order to refine and revise the interview questions. Those interviewed in the pilot research were not included in the final sample. The pilot interviews were conducted exactly like an interview in the study would be conducted. Families were contacted through the previously mentioned organizations and asked to participate in an interview. Because of the complexities revolving around their roles as mothers and wives, both subjects opted for phone interviews. A time was chosen, in these specific cases both mothers found it most suitable to speak in the morning hours when their child was at school. The mothers were e-mailed consent forms and a brief overview of the study including the research question and interview protocol. An e-mail was sent to the mothers 24 hours in advance of the interview to clarify any confusion or answer any questions. At the time of the interview on the scheduled day, the researcher called the participant. The first interview was conducted using the speaker phone device of a cell phone. The second interview was conducted using Skype on a desk top computer.  In both interviews a tape recording device was turned on to tape the interview. The researcher introduced herself and gave a brief introduction of the study. The interview protocols were explained and the participant was given a chance to ask any questions. The researcher then began the interview with the first question from the interview question guide. The document can be found in Appendix A. Once the interview reached a stopping point the researcher thanked the participant for her time and the call was ended, and the tape recorder was stopped. Following the phone call, the tape recording was transcribed by the researcher.

In the first interview, the interviewer attempted to use the speaker phone device of a cell phone to play the phone conversation loud enough for the tape recorder to pick up the voices and record the conversation. The result was less than perfect and the recording quality was poor. The interviewee also had a difficult time understanding some of the questions when asked. In response to this problem and in anticipation of having to conduct future interviews over the telephone, a subscription to the computer software Skype was purchased. Skype is an internet based voice and video conferencing system which allows a person to call cell phones, landlines, or other computers. The second interview was conducted using Skype and problems related to voice recording and audibility were resolved.

The interviews lasted, on average, an hour each and both participants seemed very willing and excited to share their experiences. It was important to introduce the study in a way that the subject understood the goals of the researcher in conducting the interview. An introduction was developed for the second interview which helped the researcher feel more comfortable and the interview start smoothly.

Through conducting the interviews, several fundamental problems with the interview question guide were identified.  The interview did not possess a flow and the order and wording of the questions were jumbled. It was important that the researcher be able to follow up and ask questions based upon the responses of the interviewee. Many of the answers to other questions were given during the discussion of another subject, in that case the researcher would ask the subject to elaborate on the specific topic and skip the question later on. Because of the nature of the interviews, the questions were just a guide and the researcher allowed the conversation to flow in the direction the subject went. After listening and transcribing the interviews, the interview questions were revised. The revised interview questions can be found in Appendix A. It is again important to note the interviews were being conducted in the form of a phone conversation. It was not simply asking the questions one by one and receiving the answer. In the second interview of the pilot study very few questions were asked aside from the initial question and the needed material was gathered through follow up questions in response to comments made by the subject.

### Limitations of the Pilot Study

Two major limitations were observed while conducting the pilot study. The first was the difficulty in scheduling and keeping interview appointments. Initially, four interviews were set up in the timeframe of the pilot study. Two of the four mothers were unable to be reached at the time of scheduled contact and were later reached via e-mail when another interview time was scheduled. The researcher decided to reassign those two mothers from the original plan of four mothers in the pilot study to the final sample of the study based on their date of availability and the appearance of themes emerging from the previous interviews already conducted in the pilot study.

The second major limitation observed in the pilot study was the inability of the researcher to conduct in-person interviews. Because of the preference of the interview subjects the interviews were conducted over the phone and as a result lack a certain-personal touch. The inability of the researcher to see and interrupt the facial expressions of the mother being interviewed was in fact a major drawback to the technology used. While Skype does have video conferencing technology that would have allowed the researcher to see the person during the interview, this technology was not used because it would require the participant to own and be knowledgeable about the operations of a web cam. In this study Skype was used as a means to place phone calls to cell phones and land lines only, and to obtain a reliable voice recording.

## Study

After the completion of the pilot study, 12 interviews were conducted with mothers in two-parent families with a child diagnosed with autism living in Georgia. Only 12 interviews were conducted because once the researcher reached 12 participants a pattern of common responses was developing. This practice is known as "theoretical saturation" and is an accepted practice in qualitative research. According to Strauss (1994), once is interviewer is no longer learning new information from conducting interviews it is best practice to conclude the interview process.

The interview subjects were contacted through the directors of local community organizations and through social media. Many of the community organizations had Facebook pages and organization message boards on websites. Directors encouraged the researcher to reach out to perspective participants in this manner by posting a message. After the pilot study it was determined that all interviews would be conducted via Skype due to the inability of many mothers to commit to an in-person interview.

The interview process was conducted in the manner determined best in the pilot study. Participants were put into contact with the researcher via phone or e-mail and a time and date was selected for the interview. The mothers were e-mailed consent forms and a brief overview of the study including the research question and interview protocol. The consent forms were sent back to the researcher via e-mail prior the interview. An e-mail was sent to the mothers 24 hours in advance of the interview to clarify any confusion or answer any questions. At the time of the interview on the scheduled day, the researcher called the participants using Skype on a desk top computer. Next to the computer was a tape recording device that was turned on the tape the interview. The researcher introduced herself and gave a brief introduction of the study. The interview protocols were explained and the participant was given a chance to ask any questions. The researcher then began the interview with the first question from the guided interview schedule. Once the interview reached a stopping point the researcher thanked the participant for her time and the call was ended and tape recorder was stopped. Following the phone call, the tape recording was transcribed.

## Participant Demographics

The 12 women in the study ranged from 32 to 48 years of age. They resided in six different counties throughout the state of Georgia. Eleven of the 12 mothers had at least one other child and were still in their first marriage. The education level of the mothers ranged from high school or some college to the completion of a college bachelor's degree with eight of the 12 mothers possessing a college bachelor's degree. In 11 of the 12 households the husbands held full-time jobs and were the primary contributor to the household's income. Three of the 12 mothers were employed part-time and estimated that they contributed less than 20% to their household's incomes.

## Interview Themes

Upon the competition of the interviews, each interview was transcribed and content analysis was conducted by the researcher. The transcripts were printed out and put into a notebook. While reading the study, the researcher highlighted common words, phrases, and themes. To obtain validity and reaffirm the themes identified by the researcher, qualitative research software was used. The researcher acquired a version of NVivo, software produced by QRS International. NVivo allowed the researcher to import the transcribed interviews and sort the data into classifications (QRS, 2010). NVivo allowed the researcher to use the imported transcribed interviews to do content analysis and to perform queries of the data to find patterns and themes. After the interviews were uploaded into the NVivo software, the researcher went through the process of coding the transcripts. Through the use of “nodes”, the researcher highlighted common words and phrases. "Nodes" are defined as common key words in relation to the research questions that are seen in the interview transcripts. This process was nearly identical to the content analysis process that was previously done through the researcher thematic analysis.

After the transcripts were coded, two types of queries were run: word frequency queries and text search queries. The first query (word frequency) gave the researcher the 100 most frequently used words in the interview transcripts. The top words, as to be expected, were nouns such as "we," “you,” and “I.” Other than nouns, there were a number of top words that were consistent with the researcher’s analysis of the interviews. "Money," "financial," "time," "work," "hard," "family," "employment," "insurance," "retirement," "support," "employed," "job," "life," "hours," "expensive," "finances," "challenges," "future," "paid," "private," "needs," "forgo," "afford," and “medical" were among the top most frequently used words. The second type of query (text search) located words in common phrases throughout the interview transcripts. The researcher preformed a number of queries with different words in the search for column and the relevance of the word in the documents was generated. When the word "employment" or "job" or "sacrifice" was queried as a text search it generated an average relevance of 15.12%. When the word "financial" or "finance" was queried as a text search it generated an average relevance of 15.3%. When the word "time" or "cost" was queried as a text search it generated an average relevance of 14.7%. Overall the NVivo qualitative research software was helpful to confirm that the researcher was on the right target with the themes identified in the interviews, furthermore, it help the researcher establish validity.

Four distinct themes appeared: employment sacrifice, high time costs of therapies, lack of affordable or available services and insurance coverage, and the need for financial and legal services. Only one theme directly stated employment but the three subsequent themes had major implications for a mother's ability to pursue employment, create a work-family balance, and the financial impact on the household. The four themes are discussed in details in the following section. Quotes from the mothers extracted from the interview transcripts have been integrated into the discussion of themes to give a clearer picture of the managerial constraints faced by the families. The quotes help to illustrate the trade-offs made by mothers and fathers in regards to the adjustment and adaptation phases of the Family Resource Management Model.

**Employment sacrifice.** Nine of the 12 mothers in the study were not in the labor force and labeled themselves as "stay at home moms." The remaining three were employed on a part-time basis. Of the stay-at-home mothers, five of the 12 said they had planned to stay at home while their children were young then return to the workforce, but they felt unable to regain employment after their child was diagnosed. Four of the 12 mothers quit their jobs to manage the demands of their child's therapies. While the decision of the eight mothers to exit the workforce did cause a decrease in household income, the benefits of the mother's household production may outweigh the benefits of market work due to the cost of services for children with autism. Mother A is a 32 year old women with a daughter diagnosed with autism.

> *Mother A: We also do academic tutoring and Applied Behavior Analysis for two hours a week with a therapist and we pay for that privately. Then I work with her every afternoon when she comes home from school, I follow the program written by the therapist. It would be so difficult for me to get a job because right now I am the one providing the afternoon therapy but if I am not there to do it's going to be a lot more expensive to pay a therapist to watch my daughter do that than what I would be making, so it's not as cost effective to do so.*

Mother G is a 40 year old woman with two children diagnosed with autism.

> *Mother G: I worked until halfway through my pregnancy and I always thought that I would go back and do something but with their school schedules and the therapies it's just hard to manage and you can't find a nanny who will want to take care of them.*

The nine mothers who were not in the labor force believed that unless they were in an extreme situation they would not be returning to the workforce. The mothers described an extreme situation as the loss of the husband's income or a drastic change in their financial needs. Three of the nine mothers who were not in the labor force stated that they missed their careers. Unable to find a part-time job to fit their needs, two of the nine mothers who were not in the labor force volunteer with various autism community support groups to fill the void left by losing their career. Volunteering is positive adaptation made by mothers in response to the constraints that discourage employment. Mother C is a 40 year old women with a daughter diagnosed with autism.

> *Mother C: I really miss the working part of my life, but like I said before, I knew with her schedule and the fact that I wanted to be involved with school and I needed to be home after school, it was going to be hard to find a job that would allow me the flexibility to be home every afternoon participating in school stuff, so I went the volunteer route instead.*

Three of the 12 mothers worked on a part-time basis. All three of the mothers in the labor force stated that financial reasons related to autism were the main reason that they were still employed. Additionally, all three of the mothers held part-time jobs. Two mothers worked for a family member or spouse and one mother stated she worked a less demanding career than she originally anticipated when entering the workforce. Because of their children's demanding schedules it was necessary for these mothers to have flexibility in employment. Mother F is a 35 year old women with a son diagnosed with autism.

> *Mother F: I work for my sister-in-law and she helps me a lot in the raising of this special child. I have a very flexible boss when it comes to my son. She even took him to therapy for me one hour drive so I could stay and work.*

The three mothers in the workforce complained that the needs of their child had limited their upward mobility in their career. They were limited in that they could not travel, work long hours or irregular hours, and often found it hard to focus on work because of the demands of their child. Giving up or limiting a career is an example of the trade-off made when a mother specialized in household production as opposed to market work. The difficulties faced by mothers in the workplace are a major factor related to the decision of mothers in two-parent families to forgo or seek employment. Mother H is a 41 year old women with a son diagnosed with autism.

> *Mother H: The research and the therapy is a full-time job, I think it limits your ability to be successful and advance in your [paid] job.*

According to seven of the 12 mothers, the fathers of children diagnosed with autism also felt they had made sacrifices in their employment. While the impact of having a child diagnosed with autism on a father's employment was not one of the original research questions in the study, a number of mothers mentioned an impact on the father's employment in regards to having a child diagnosed with autism. Driven by the pressure to provide for their family, fathers worked long hours and even weekends at jobs that were not necessarily ideal. Additionally, two mothers stated that their husbands were unable to take promotions because it would keep them away from home for extended periods of time or would require moving the family to an area without the necessary resources for their child. Mother G, 40, shared her husband's experience in the interview.

> *Mother G: He has been a major part of his life but it was not without sacrifice and he lies in bed and worries how in the world I am going to provide for these kids. He has to keep his job and make enough [money].*

Fathers were not the main focus of the study but their employment allowed the trade-offs made by the mothers from market work to household production.

**High time costs of therapies.** All 12 mothers in the study indicated that the therapies require a large time commitment. One mother even compared it to taking as much time as a full-time job. The therapies require travel, organization, monitoring, continuous evaluation, and research. Five of the 12 mothers said that they must travel long distances because of a lack of affordable or appropriate services in their local area. Three of the 12 families had moved out of state for periods of time to obtain services provided at hospitals, boarding schools, and summer camps. Moving to acquire services reflects an adaptation made in response to the impact that having a child diagnosed with autism has on the household finances. Children diagnosed with autism often participate in three to four different therapies during a weekly or monthly period in addition to schooling. Mothers must develop a routine to manage and keep a consistent schedule. Additionally, most Applied Behavior Analysis therapies and various other types of occupational therapies and speech therapies take place inside the home. Mothers must be present to monitor and support the therapist in working with their children. The need for a mother to manage and to be present in therapies reflects an adjustment that must be made by the families. Mothers leaving or limiting their time in the workforce to focus on household production is the resulting adaptation. Mother C, 40, reflected on the changes that occurred in her household as a result of the therapies.

> *Mother C: Basically we went from living a fairly normal life, whatever that means, to I mean we had forty hours a week of Applied Behavior Analysis. You have therapists coming in and out of your home forty hours a week. You know they are college age people and they are all different so I sat in on all of my daughter's therapy so I could make sure they were doing it the same way and make sure it was the best.*

Under the Americans with Disabilities Act, the public school system in Georgia is required to provide special education to children requiring accommodation but many parents cited the system as inadequate for their child’s particular needs. Homeschooling, tutoring, and private schools were popular choices among families in this study. Each option, however, requires not only a financial obligation but a time obligation for mothers who must teach her child herself or provide transportation to a specialized facility. Mother A, 32, expresses her concerns about the financial obligations her family faces related to autism.

> *Mother A: That's the hard thing I think that we face and we hear all the time from others it's so hard to be saving as much as you should be because you have so many extra financial needs now. Like I was talking about sending her to private school. We were spending as much on her kindergarten as most people spend on college*

Three of the 12 mothers kept their children on specific diets where daily monitoring and special shopping was required. Foods were said to be hard to find and meals often much harder to prepare with many mothers having to cook two separate meals for their families at each meal. Constant evaluation of the current therapies a child receives was necessary for the mothers because their children's needs were constantly changing. When therapies began to lose their effectiveness, mothers said they spent hours researching new techniques or options for their children.

**Lack of affordable or available services and insurance coverage.** All 12 participants encountered some sort of difficulty in getting their children diagnosed with autism and getting the services that they felt their child needed. Families had to go from doctor to doctor and often received a variety of different diagnoses prior to getting an autism diagnosis. This process was not only time consuming and emotional for the mothers but also placed a large financial toll on the household. Ten of the 12 mothers said they spent hours researching autism on the internet and in the library. Two of the 12 mothers suggested autism to their doctors as a possible diagnosis based on the symptoms they were observing in their child. Mother H, 41, shared her experiences researching autism.

> *Mother H: Our pediatrician did not even say the word autism. It was really me finding out on my own. Really our regular doctor was not much help. Everything I did, even finding out about Babies Can't Wait it was basically me using word of mouth, the internet.*

Once the families received an autism diagnosis, many had difficulty finding the services and getting access to those services. Two of the 12 families in the study had to hire lawyers and file suit against the school system to get their children special education services.

The therapies associated with autism were almost never covered by the insurance held by the participants in the study. Only two of the 12 mothers in the study stated that any of their child's therapies were covered by insurance. Mother G, 40, had difficulty getting coverage for her two children diagnosed with autism.

> *Mother G: They were diagnosed at 27 months and I remember calling the insurance company and being told, well we are not going to cover this. And when you leave the doctor's office they tell you how much therapy you're going to need and you know if you take the Applied Behavior Analysis route which most people feel is the most successful, that's 40 hours a week usually at $50 an hour. Anything to do with developmental delay or autism they are not going to pay for. And I remember just being devastated.*

When therapies such as Applied Behavior Analysis and occupational therapies were covered by insurance the amount of coverage was very limited. Most therapists recommend around forty hours a week of Applied Behavior Analysis and for the two families who did have insurance coverage, it only covered between 4 and 12 hours a month. Occupational therapies, speech therapy, and cognitive-behavioral therapies were not covered by insurance companies, but seven of the 12 mothers did have some access to these services on a limited basis through the public school system during the school year. Additionally, experimental treatments like a specialized diet or a hyperbaric chamber must be paid for out-of-pocket. The 12 mothers in the study estimated they spent between $20,000 and $50,000 a year in out-of-pocket medical expenses for their child diagnosed with autism. The therapies required by a child diagnosed with autism that are not covered place an extreme financial toll on the household, as parents are forced to cover the expenses out-of-pocket. Additionally, the therapies place a burden on the caregiver, in most cases the mother, because of the length and number of therapies obtained by the children. The high time costs of the therapies are directly linked to the inability of the mothers to remain in the workforce on a full-time basis.

Four of the 12 mothers said that they wanted their child to have similar experiences to typical children their age and paid for specialized social skills class, camps, and sports programs. Mother B is a 39 year old women with a son diagnosed with autism.

> *Mother B: We are spending more money on tutoring and social skills class, you would not believe how much that costs. I'm just trying to get him caught up socially.*

In addition to therapies, childcare was also cited as being expensive and difficult to obtain. Unable to hire normal babysitters, nine of the 12 mothers said they were forced to seek trained staff or family members to care for their children and found it difficult to do things that parents often enjoy. Mother B, 39, talked about the struggles she has faced dealing with her child's autism.

> *Mother B: This is hard, emotionally, physically, and financially. We can't do the things that normal people do. We cannot go to people's houses or take vacations. Other people just don't understand. This is very, very hard.*

**Need for financial and legal services.** Eight of the 12 mothers had seen a financial planner or a lawyer. Two of the 12 mothers said they has thought about or considered seeing a financial planner or a lawyer but it was not the right time. Two of the 12 mothers said her husband acted as the financial planner and she felt confident in her husband's ability to manage money.

Of those who did see a financial planner or lawyer they did so in order to secure their children's financial future in the event of an unforeseen tragedy or death of one or both parents. They feared that in the event of one or both or their deaths their child would end up in the care of the state, most likely living in an institution or a group home, or that their other children would have to bear the financial burden of supporting the sibling. Money placed into a special needs trust listing another individual as the beneficiary secured that the child would have money upon the death of the parents. Additional requests and instructions were written in wills prepared by a lawyer or an estate planner. The eight families who had seen a financial planner or lawyer also sought out advice on how to accurately plan for retirement given their child would remain in the home through adulthood and how to appropriately spend their money in order to continue to pay for non-insurance covered therapies. Preparing for the future is an adaptation the families made in response to the need to adjust their future orientation. Mother G, 40, shared how her family is preparing for the future.

> *Mother G: Now we are looking at special needs trusts and life insurance and we met with a financial planner this summer because not only do we need to make sure we provide for ourselves in retirement but he is going to be retiring with us and then we have to make sure that after the fact [of our death] there is enough money. We have three other kids we have to provide for, we really have not saved for retirement since they got diagnosed, and we have a lot of catching up to do.*

Six of the eight families that had sought advice from financial planners indicated that the services were poor. They felt like the planners were uneducated in the area of childhood disability and lacked empathy for the family. One of the parents felt judged by the planner because of the family's current spending. Mother F, 35, talked about the negative experience she had when seeking financial services.

> *Mother F: The person we went too, it was hard for them to look at what all we were spending on our child and not look at us like we were crazy. And all I told them was what would you do if it was your child. You know? I know from a financial perspective it does not look like the smartest plan, but it's your child. I mean what parent isn't going to want*

> *to do everything they possibly can to help their child. I think the judgment issue was hard for me, because it was like you felt like you were being judged as to what you were doing*.

In two cases the parents were encouraged to take financial steps they did not approve of, like saving for a college education they believed their child would not obtain. When asked how financial planners could assist families with children diagnosed with autism, one mother thought it would be helpful if the planner put him or herself in their shoes, asking them to think about what parent would not want to do the very best they could to treat and support their child.

## Conclusions

The interviews conducted with mothers of children diagnosed with autism resulted in the development of four distinct themes: employment sacrifice, high time costs of therapies, lack of affordable or available services and insurance coverage, and the need for financial and legal services. The purpose of the study was to examine the managerial challenges and employment decisions of the mothers in two-parent families whose children are diagnosed with autism. The interview findings suggest that the having a child diagnosed with autism creates a more complex situation then research questions in the study are able to capture. While only one of the themes directly states employment, other themes have direct ties to the managerial demands related to having a child diagnosed with autism. The finding also provides examples of the adaptations the families made in response to the adjustment brought about by having a child diagnosed with autism. It was clear from the interview findings that mothers had difficulty working and also struggled to keep up with the time and financial demands brought about by having a child diagnosed with autism. The high time costs of therapies required an increased time commitment from the mothers which directly impacted their ability to remain or enter a situation of employment. The time cost of therapies was a major factor that mothers considered when making employment decisions. The therapies created a number of managerial demands and problems. The financial hardships created by the lack of affordable or available services and insurance coverage resulted in the possible need for a mother to work to financially support their household but burdened by the time commitment and unavailable or inadequate services, employment was not an option. Having a child diagnosed with autism had a drastic affect on the household finances, but a mother's choice to forgo employment was viewed for the most part as a financial savings given the lack of affordable services. While not mentioned in the original research questions in the study, fathers employment was also impacted by the time and financial constraints brought about by having a child diagnosed with autism. These finding suggest that fathers are also adversely affected by the managerial constraints that having a child with autism imposes and that impact of having a child diagnosed with autism on the employment status of the fathers should be addressed in the future. Mothers in the study created a work-family balance in the home by limiting their employment and through the help of family members and when available, specialized services. Due to the financial hardships created by having a child diagnosed with autism, there was a need for families to have specialized financial and legal services.

# CHAPTER 5

## Discussion and Implications

This study sought to examine the managerial challenges and employment decisions of the mothers in two-parent families whose children are diagnosed with autism. Specifically, how does the presence of a child diagnosed with autism relate to a mother's choice to pursue employment outside the home and what factors and managerial demands are associated with making this decision. Data was collected through semi-structured interviews with mothers in two-parent families who have a child diagnosed with autism in Georgia. A pilot study was conducted and following the pilot study, Skype interviews with 12 mothers were conducted. Four major themes appeared in the interviews: employment sacrifice, high time costs of therapies, lack of affordable or available services and insurance coverage, and the need for financial and legal services. Themes found in the interviews were consistent with the findings in the review of literature for mothers of children with special needs. The interview findings had direct and indirect links to employment and validated that mothers faced difficulty managing the time and financial demands of having a child diagnosed with autism. The interview findings also suggest that the having a child diagnosed with autism creates a more complex situation than the research questions in the study are able to capture. For example, there were many internal and external factors that went into the employment decisions of the mothers such as the complexity of the treatment for autism which created a variety of factors that increased the managerial demands for the family.

## The Family Resource Management Model

The Family Resource Management Model (Deacon and Firebaugh, 1988) was utilized as the framework for determining the relationship between having a child diagnosed with autism and maternal employment status as well as evaluate the trade-offs made in response to managerial demands. It is assumed under the model that a family's main responsibility is for the procreation, socialization, support, and development of children (Deacon & Firebaugh, 1988). The Family Resource Management Model develops an input-throughput-output framework to organize how family systems use resources and make decisions under scarcity. Recalling the assumption of the responsibility of the family, the input-throughput-output framework implies families will utilize resources and address demands to meet the physical care and social development needs of their children (Deacon & Firebaugh, 1988). Handicaps and/or chronic illness are presumed to make a difference in the managerial demands and responses of the family system in virtually all cases regardless of the family life cycle. Families will respond to the handicap in two distinct phases, the adjustment phase and the adaptation phase. It is assumed that the family system was functioning in a stable manner prior to the introduction of the handicapped member thus resulting in movement of the family into the adjustment phase. The adjustment phase is characterized by a disequilibrium caused from an imbalance in demands and resources that forces changes within the family system. Entrance into the adaptation phase occurs when changes within the family system have clearly been implemented (Deacon & Firebaugh, 1988). The themes found in the interviews clearly reflect elements and dynamic relationships in the Family Resource Management Model.

**Employment sacrifice.** Nearly all of the mothers in the study were not in the labor force. Adjustments followed by adaptations were made in order to provide the kinds of health care and educational services required by their children. Changes in employment status of the mother and the reallocation of her time from labor force participation to childcare would fall into the above categories. Families entered the adjustment phase upon the diagnoses of their child resulting in the need for the family to make changes to care for the new needs of their child. Given these new and unique needs, the family moved into the adaptation phase when the mother left the labor market to care for their child. Volunteering for community organizations was another adaptation made by mother to fill the void left by losing their career following the adjustment phase. Adjustments followed by adaptations in regards to the father's employment also follow the model. Families enter the adjustment phase in the same manner, upon the diagnoses of the child with autism. Because of the increased financial demands and the movement from a dual-income household to a single income household, fathers moved into the adaptation phase by increasing work hours, forgoing promotions, or changing work roles. The basis assumption of this study is that mothers trade market work to specialize in household production. This assumption is based on previous research and follows the traditional economic view of the family. Future research that focuses on the trade-offs fathers make in regards to market work and household production is warranted from the appearance of the fathers in the interview themes.

**High time costs of therapies.** The mothers in the study cited that the time the therapies took required as much time as a full-time job. After receiving an autism diagnosis the families are thought to be in adjustment phase as they work to create equilibrium. In this instance the time commitment required mothers to make changes in their daily routines to accommodate the new demands brought about by autism. Mothers in the study cited the need to be present at their children's therapies as well as the travel time required for many therapies. Once the families developed a routine and made schedule changes they are considered in the adaptation phase. In the majority of cases, mothers left the workforce to accommodate the newly established routine.

**Lack of affordable or available services and insurance coverage.** All participants encountered some sort of difficulty in getting their child diagnosed. In regards to the input-throughput-output framework developed by the model, the difficulty obtaining the diagnoses is the input. In response to this difficulty parents cited visiting other doctors and doing personal research about autism. The parent's actions, such as researching autism or seeking out a medical specialist, represent the throughput. The output or outcome is the resulting diagnoses of autism in their child. Once an autism diagnoses had been determined the parents would be considered in the adjustment phase as they sought initial services for their child. The therapies associated with autism were almost never covered by the insurance held by the participants in the study. Much like the previous themes, families must work to create equilibrium. In this instance the lack of affordable service and insurance coverage is the input requiring some type of change in the throughput. Changes in spending behavior were necessary to accommodate the financial demands brought about by autism. Due to the lack of available service, four families in the study adapted by moving out of state for a period of time to receive the services their children needed.

**Need for financial and legal services.** Many of the participants sought out a financial planner or a lawyer in order to secure their children's financial future in the event of an unforeseen tragedy or to seek advice on how to plan for their financial futures or manage resources. The lack of financial security and an unknown future would be the input in this situation creating a need to establish financial soundness and a plan for the future. Actions developed by the financial planners or lawyers would result in an output where the families would be secure financially moving forward and have an established legal plan for their child's care. Families in the study were seeking these services because of the disequilibrium created by their uncertain futures. The development of these services for families with children diagnosed with autism would create the necessary output in terms of the model. The Family Resource Management Model is limited in this study because it does not help explain why the mother is the parent who specializes in household production while the father specializes in market work, as assumed in this study. The model is useful, however, to help frame the changes occurring in the family from the adjustment phase to the adaptation phase using the input-throughput-output model.

## Implications

### Employment sacrifice

Nearly all of the mothers in the study were not in the labor force and felt unable to regain employment after their child was diagnosed with autism because of the necessity to manage the demands of their child's therapies and the expense of specialized childcare. The reliance on one income with the financial demands of autism caused stress for the employed father. Mothers in the workforce complained that the needs of their child had limited their upward mobility in their career and left them unable to travel or work irregular and long hours. There are many implications for employers that can be drawn for this study. Mothers expressed a desire to work but an inability to do so because of the lack of flexibility in the workplace. Employers need to consider options for mothers who wish to remain or join the workforce. Options such as working from home or creating a customized schedule would help mothers who need to be available to transport their child to specific appointments or therapies. Companies could also consider hiring mothers on a contractual basis where they work on a specific project from home or part-time in the office Flexibility to take a reasonable amount of personal days to care for their child without facing employment repercussions could also increase opportunities for mothers to join the workforce. From a pure labor economics standpoint employers have little financial incentives to put these polices into place, but there are many reasons for an employer to consider family friendly policies. When companies do not hire mothers, they may be losing an excellent employee. With the advancements in technology, telecommuting to work is becoming easier and more acceptable. Changes in work place policies may be forced to change due to the rise in the number of children diagnosed with autism and other special needs. In the future more employers will have employees who need these accommodations. Additionally, family friendly policies will help companies' public relations campaigns. For families who have a child that has recently been diagnosed with autism, parents must be aware of the challenges that exist in the workplace. The caregiver, male or female, may need to adjust their expectations regarding a career.

### High time costs of therapies

The therapies for autism required travel, organization, monitoring, continuous evaluation, and research by the caregiver. Lack of affordable or appropriate services in the local area and the frequency of therapies often increased the time burden for mothers. Homeschooling, tutoring, and private schools were popular choices among families but each option required a time obligation for mothers who took the time to teach their child themselves or provide transportation to a specialized facility. For those families who kept their children on specific diets, foods were said to be hard to find and difficult to prepare. Constant monitoring was necessary to maintain the diet. The creation of centralized centers that provide a variety of services for families would help ease the time costs of the therapies for mothers. While the actual hours of therapy would not be changed, the convenience of obtaining a variety of therapies and services in one location would help decrease travel and increase the ability to create and maintain a schedule. Parents with children who have recently received an autism diagnosis need to become familiar with the services offered in their area. It may be possible that the best services are located in an area far from their home and will require daily or weekly travel or possibly even a move.

### Lack of affordable or available services and insurance coverage

Difficulty in getting their child diagnosed and receiving the services they needed was a major problem encountered by mothers. In addition to seeing various doctors, most mothers resorted to internet-based research on autism. The therapies and research related to autism has a direct link to a mother employment decision based on the time demands brought about by each activity. Due to the increases in autism in recent years, awareness and education for doctors, parents, and educators on the signs and symptoms of autism is essential. Parents, doctors, and educators represent individuals who are highly involved in monitoring the development of a child after birth. If knowledge about autism can be distributed to the public there is a greater opportunity someone will recognize the beginning of autism and early intervention can begin as soon as possible. Options for increasing awareness for autism include television PR campaigns, information meetings held at schools for both parents and educators and periodic training in medical offices for doctors.

The therapies associated with autism, experimental treatments, special diets, and specialized childcare were cited as expensive and difficult to get covered by an insurance company. Mothers in the study estimated they spent between $20,000 and $50,000 a year in out-of-pocket medical expenses for their child diagnosed with autism. Experiences were said to be hard-emotionally, physically, and financially. In addition to seeking out the financial and legal services discussed later in the paper, families experiencing emotional distress should seek out counseling or support through a community group. This theme has huge implications for public policy. The creation or expansion of more social programs, both publicly and privately run, for families with children diagnosed with autism could help ease the financial burden faced by families and increase the quality of life for not only the child but the whole household. The large amount of out-of-pocket expenses spent by families each year related to therapies decreases the family’s ability to save for retirement or spend money on nonessential goods. Additionally, the enactment of laws or changes in the policies of insurance companies could help families get more therapy covered. Laws could require insurance companies to cover some of the therapies associated with autism. Within the insurance companies, changes in policy such as the coverage of experimental treatments or more options for specialized care would help parents find the appropriate therapy for their child. Families whose children are diagnosed with autism should research the social programs offered in their state as well as contact state and local organizations about grants for families with children diagnosed with special needs.

## Need for financial and legal services

It is important to many parents of children diagnosed with autism that their child will be taken care of in the event of their death, particularly in the event of an unexpected death and not left in the care of the state with the risk of being placed in a group home or institution. Financial planners who focus specifically on people with disabilities do exist in the financial planning community and it is important for these planners to connect with schools, therapists, and community groups in their service area so that families are aware of their services.  It is important for families whose children have an autism diagnoses to be informed and proactive about their financial future. For other planners who do not specialize in disability, knowledge about special needs trusts is essential for any planner working with a family whose child has a disability like autism. A special needs trust is a way of providing complementary income for individuals with a disability without interfering with government benefits (Special Needs Alliance, 2008a). The trust pays for the medical expenses or treatments not covered by Medicaid as well as any personally enriching activities seen fit for the individual. The special needs trust is managed by a named Trustee who holds the responsibility to appropriately manage the distribution of income for the individual with a disability (Special Needs Alliance, 2008a). A letter of intent is often written by the parents addressed to the Trustee of the special needs trust. The letter of intent describes the medical history and needs of the child as well as things like the daily routine, favorite foods or activities, and any other pertinent information (Special Needs Alliance, 2008b). How to fund the trust and how much money the trust will contain are important factors for financial planners to discuss with their clients. It is best practice for planners to help parents think about the long term care of their child and develop a “life care plan.” A “life care plan" is a document containing information about how parents want their child to be cared for through the life course. It would include information about goals and hopes the parents have for their child such as the desire for their child to live independently or the need for their child to have a constant companion. After developing a plan as to how parents wish for their child to be cared for, the "life care plan" can be used to make estimates as to how much money the trust should hold to finance the wants and needs of both parent and child. Life insurance is also one way to fund the trust (Special Needs Alliance, 2008b).

Retirement is also an important topic for families of children diagnosed with autism. When typical families plan for retirement, it is assumed they will not still be caring for a child. In the event that a child diagnosed with autism cannot live independently, parents must plan to support them throughout their life. The retirement plan must now change from saving to support two people to saving to support three.

When working with families who have a child diagnosed with autism, financial planners need to help these clients to develop spending plans that identify ways to decrease spending in other areas in order to pay for their child's medical necessities. Parents place the upmost importance on the care of their child and because of this will do and spend just about anything to help them thrive. In order to help them avoid getting into financial trouble such as credit card debt, planners can look for ways that their clients can decrease spending in other areas in order to pay for their child's medical expenses. Common ideas for cutting expenses include limiting food related purchases such as eating out or buying coffee, setting spending limits around holidays, or re-evaluating cell phone plans and transportation needs. Additionally, planners can help clients evaluate their homeowners insurance, private mortgage insurance, and look for real estate tax reductions (Loonin, 2008). Planners should also be knowledgeable about social service programs in the community to refer clients who may be struggling. Free or sliding scale services offered through social service programs may help clients find resources or obtain help for a reduced rate (Loonin, 2008).

Lastly, a planner can help families with children diagnosed with autism by developing a benefit-cost analysis pertaining to different therapies. A benefit-cost analysis is a way to establish and organize priorities under scarce resources (Marcus, Rubin, & Rubin, 2000). It would be impossible for families to afford every type of therapy offered for autism, but on average, a child will receive three to four different types of therapy a month. When experiencing financial distress, a family will have to decide which therapies are the most important to continue to pursue. As an unbiased party, a financial planner can help parents determine which therapies are financial feasible so as to help them make reasonable choices and not damage their financial standing.

## Study Limitations

There were limitations while conducting this research study. The first limitation came from the interview process. All interviews were conducted via Skype due to the inability of many mothers to commit to an in-person interview. While there were several limitations associated with this course of inquiry it allowed the sample size to be much larger than if in-person interviews were conducted. Interviews conducted via Skype lacked a certain personal element and eliminated the ability of the researcher to see the participant's body language and facial expression. While much could be gathered by the tone of voice of the participant, face-to-face communication would have been helpful. Skype does have video conferencing technology that would have allowed the researcher to see the person during the interview. This technology was not used because it would require the participant to own and be knowledgeable about the operations of a web cam. In this study Skype was used as a means to place phone calls to cell phones and land lines only.  Another limitation of conducting interviews via Skype was problems with the technology. Internet and phone connections were sometimes unclear or slow. Participants also needed to be informed they would be reached via Skype because the phone number that appeared on a cell phone was often listed as restricted. The mothers' busy schedules were also a limitation in setting up and keeping interview appointments. On more than one occasion the interview had to be moved or the mother did not answer the phone.

Using qualitative research as a method was a limitation in terms of the results. Due to the nature of qualitative data the study was unable to determine causation in relationship to having a child diagnosed with autism and maternal employment status. Additionally, the qualitative data do not allow for the generalization of results across the spectrum of the population. The sample population used in the study could be a limitation because only mothers in two-parent families were interviewed. Additionally, the interview participants were recruited from autism community support groups and communicated with the researcher over the internet. These factors suggest that the mothers in the study may have a higher socioeconomic status than other mothers of children diagnosed with autism.

The Family Resource Management Model allowed for the changes made by parents in the household in response to having a child diagnosed with autism, explained by the adjustment and adaptation phases of the model. At the same time it was limiting. The Family Resource Management Model does not explain why the mother, as opposed to the father, chooses to make the adaptation to specialize in household work, as assumed in the study. Additionally, the focus of the study on mothers, to the exclusion of the fathers, limits the study.

## Future Research

Future research on families with children diagnosed with autism is necessary because of the lack of applied research in the area and the increase in the incidence of autism. This study was a small scale research study conducted with participants in Georgia. Because of this the results are not nationally representative. A large scale qualitative study that can provide results for policymakers nationwide is needed. The lack of employment by mothers whose children are diagnosed with autism shows the needs for a research study to address what practices could be put in place in the workplace to help mothers gain the flexibility they need to manage the demands of both their child and a career. The financial hardships faced by households where a child is diagnosed with autism point to the need for future research in the area of financial planning for families with special needs children. Research findings specifically for financial planning practitioners about the best practices for working with families are necessary to help create knowledge and standards for the financial planning community. Additionally, this study only focused on mothers in two-parent families. Another study that focuses on single mothers is necessary because of the differences in the needs of single mothers. Fathers were largely left out of this study given the traditional view of the household and assumptions used as a framework. As the number of mothers entering the workforce increases and well as the growing number of stay-at-home fathers, there will be a need for research in this area.

## Conclusion

This study sought to examine the managerial challenges and employment decisions of mothers in two-parent families whose children are diagnosed with autism. Through a process of semi-structured interviews with mothers of children diagnosed with autism in Georgia, the researcher found consistencies related to the general body of literature focusing on mothers of children with special needs. This study contributes to the literature by focusing only on autism, the relationship to maternal employment, and the potential effects having a child with autism has on household finances and expenditures, and the creation of a work-life balance within the household. During content analysis, four major themes appeared in the interviews: employment sacrifice, high time costs of therapies, lack of affordable or available services and insurance coverage, and the need for financial and legal services. The findings have direct and indirect links to employment and implied that mothers faced difficulty managing the time and financial demands of having a child diagnosed with autism.

Among the mothers in the two-parent families with a child diagnosed with autism in this study, most chose to leave the labor force due to the time constraints and managerial demands brought about by having a child diagnosed with autism. Many mothers cited the large time commitment required by the therapies coupled with the high cost of specialized childcare and educational services as the major factors in their decision to leave or limit their time in the labor force. Mothers identified the significant financial demands in relation to therapies and medical treatments for autism as having a major impact on the household finances and expenditures. To create a work-family balance in their home, mothers balanced their time spent in paid market work and in household production by specializing in household production. The special circumstances created by having a child diagnosed with autism created a need for financial and legal services provided by financial planners and lawyers specifically designed for families who have children with special needs. The main assumption in this study is that having a child diagnosed with autism in the household will have a greater impact on the employment status of the mother, rather than the father. Using this assumption, only mothers were interview candidates in the study.  The results of the study indicate that the circumstances surrounding having a child diagnosed with autism is more complex than the research questions were able to capture. Additionally, findings suggest that having a child diagnosed with autism is also related to the employment status of the father. The fathers in study made employment sacrifices based on the time constraints, managerial demands, and financial needs of their children. Future search including or solely focusing on fathers in two parent families who have a child diagnosed with autism is warranted.

Families who have a child diagnosed with autism can use the results of this study to become informed about the struggles families in similar circumstance face. Families who have a child that has recently received a diagnosis of autism can use this study as a tool to plan for their future in regards to employment, household management, and financial or legal planning.

This study has shed light on the difficulties faced by families with a child diagnosed with autism. It is the hope of the researcher that the information provided by the study can be used as general awareness to inform the public and encourage others to pursue more advanced research.

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# Appendix A

## Guided Interview Schedule

### Original Guided Interview Schedule

1. You have a child diagnosed with autism, correct? At what age was your child diagnosed?
2. How has your child's diagnoses affected your household in terms of functioning, work-family balance, finances etc? In other words what (if anything) changed after your child was diagnosed with autism?
3. (If household experienced changes after the child was diagnosed with autism) What steps do you and spouse take to manage the work life balance in your household?
4. Were you employed prior to your child's diagnoses?
5. Are you currently employed?
6. What went into your decision to pursue or forgo employment?
7. Did you have any challenges you faced in regards to employment?
8. (If Interviewee experiences challenges) What kinds of services would have helped you overcome these challenges?
9. Do you currently receive support from community organizations or family members?
10. ( If Interviewee receives support) Does the support you receive contribute to your decision to pursue or forgo employment?
11. What role do finances play in your decisions about employment?
12. What is the impact on the household finances and household expenditures as a result of having a child diagnosed with autism? How has your decision to pursue or forgo employment impacted household finances?

13. How do you view your future in regards to employment, retirement etc now that you have a child diagnosed with autism?
14. Have you considered using a financial planner or seeing a financial counselor?
15. (If does see or has considered seeing) In what ways does/do you think your financial planner or financial counselor has helped or does help your family? In what ways do you feel like you are unique as a client given your circumstances?
16. I need to ask about a few demographic details.

Current Age: ______________

County of Residence: ____________

Highest Level of Education Completed: ______________________

Marital Status: First Marriage____ Second Married____

Other Children? _______ Ages_____________ Medical Conditions____________

Significant Other Employed:_________________________

Number of People in the Household:___________________

17. Is there something I should have asked, and didn't? Please tell me about that.

Revised Guided Interview Schedule

1. Can you please tell me about your Son/Daughter's autism diagnoses and the process that you went through to find out your child had autism?

2. How has your child’s diagnosis change your household in terms of how you functioned, your job, and your finances? In other words what (if anything) changed after your child was diagnosed with autism?

3. Were you employed prior to your child’s diagnoses?

4. Are you currently employed?

5. Do you currently receive support from community organizations or family members?

6. ( If Interviewee receives support) How does the support you receive help your household?

7. What is the impact on the household finances and household expenditures as a result of having a child diagnosed with autism?

8. How do you view your future in regards to employment, retirement etc now that you have a child diagnosed with autism?

9. Have you considered using a financial planner or seeing a financial counselor?

10. (If does see or has considered seeing) In what ways does/do you think your financial planner or financial counselor has helped or does help your family? In what ways do you feel like you are unique as a client given your circumstances?

11. I need to ask about a few demographic details.

Current Age: ____________

County of Residence: ____________

Highest Level of Education Completed for both you and your spouse: ____

Income Range: ______

Your Contribution to the Household Income: _______

Marital Status: First Marriage____ Second Married____

Other Children? _______ Ages_____________ Medical Conditions____________

Significant Other Employed:_________________________

Number of People in the Household:___________________

12. Is there something I should have asked, and didn't? Please tell me about that.

# Appendix B

## Consent Form

THE EMPLOYMENT STATUS OF MOTHERS WITH CHILDREN DIAGNOSED WITH AUTISM SPECTRUM DISORDER: A QUALATATIVE STUDY

CONSENT FORM

I, ________________________________, agree to participate in a research study titled " THE EMPLOYMENT STATUS OF MOTHERS WITH CHILDREN DIAGNOSED WITH AUTISM SPECTRUM DISORDER: A QUALATATIVE STUDY " conducted by Melissa Robin Casey from the Department of Housing and Consumer Economics at the University of Georgia under the direction of Dr. Teresa Mauldin, Department of Housing and Consumer Economics, University of Georgia. I understand that my participation is voluntary. I can refuse to participate or stop taking part at anytime without giving any reason, and without penalty or loss of benefits to which I am otherwise entitled. I can ask to have all of the information about me returned to me, removed from the research records, or destroyed.

The purpose of this study is to examine the relationship between maternal employment status and having a child diagnosed with autism. Specifically, how does the presence of a child diagnosed with autism relate to a mothers choice to pursue or forgo employment outside the home and what factors are associated with making this decision. Additionally, the impact on the household as a result of the choice to pursue or forgo employment will be investigated. If I volunteer to take part in this study, I will be asked to do the following things:

1) Answer questions about my experiences having a child diagnosed with autism and how it has affected my ability to pursue employment, my household, my financial resources, and my ability to find a work-family balance. The interview will be no longer than two hours.
2) The information from my tape-recorded interview will be transcribed and used in the compilation of experiences of mothers with children diagnosed with autism. If direct quotations from my interview are used in the report, I will not be personally identified with those quotations.

No risk is expected from participation in this study: However, there may be moments of personal embarrassment or sadness in sharing difficult circumstances about my experiences having a child diagnosed with autism. I will be assigned an identifying number and this number will be used on all of the tapes and transcripts of my interview. No individually identifiable information about me or provided by be during the interview will be shared with others without my written permission

I will receive no monetary compensation for participation in the research study.

The investigator will answer any further questions about the research, now or during the course of the project. You may contact Melissa Robin Casey at (404) 735-7585 or mrobincasey@gmail.com if you have any further questions.

I understand that I am agreeing by my signature on this form to take part in this research project and understand that I will receive a signed copy of this consent form for my records.

| | | |
|---|---|---|
| ____________________________ | ________________________ | |
| Name of Researcher | Signature | Date |

Telephone: ________________

Email: ____________________________

| | | |
|---|---|---|
| __________________________ | ________________________ | |
| Name of Participant | Signature | Date |

Please sign both copies, keep one and return one to the researcher.

Additional questions or problems regarding your rights as a research participant should be addressed to The Chairperson, Institutional Review Board, University of Georgia, 612 Boyd Graduate Studies Research Center, Athens, Georgia 30602-7411; Telephone (706) 542-3199; E-Mail Address IRB@uga.edu

# Appendix C

## Recruitment Letter

Hello,

My name is Melissa Casey and I am graduate student at The University of Georgia. I am working towards a M.S in Consumer Economics. I am focusing my thesis research on families who have children with Autism Spectrum Disorder. I am planning on conducting phone or in-person interviews to learn about the struggles families have maintaining a work-family balance. Example questions are listed below.

1. You have a child diagnosed with autism, correct? At what age was your child diagnosed?
2. Do you have other children? Do they have any medical conditions?
3. Were you employed prior to your child's diagnoses?
4. Are you currently employed?
5. What went into your decision to pursue or forgo employment?
6. What are some of the challenges you face in regards to employment?
7. What kinds of services would help you overcome these challenges?
8. How does your decision to pursue or forgo employment affect your household?
9. What role do finances play in your decisions about employment?
10. How do you view your future in regards to employment, retirement etc now that you have a child diagnosed with autism?

I am currently looking for a group of families to interview and am hoping that your organization would be willing to help by sending out an e-mail or contacting those families that you think might be willing to participate. If you believe that you would be able/willing to help please contact me.

Thank you,
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# Appendix D

## Interview Protocol

1. Interviewer introduces self and briefly explains purpose of the research study.

2. Interviewer obtains signatures on consent form and asks if there are any questions regarding the form, interview, or research study.

3. Reassure interviewee that statements made in the interview will be clustered with other interview responses and remain confidential in the written report.

4. Begin recording devices and conduct interview in accordance to the interview guided questions.