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## EFFECTS OF AUTISM SPECTRUM DISORDER ON MOTHERS

Angelica Del Villar

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# EFFECTS OF AUTISM SPECTRUM DISORDER ON MOTHERS

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

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

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by  
Angelica Maria Del Villar

June 2018

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June 2018

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## ABSTRACT

As time keeps on passing, diagnosing a child with Autism keeps on expanding. The research study focuses on gathering data on the impact of mothers that have a child diagnosed on the Autism Spectrum Disorder (ASD). The members chose were from an online all mothers support group. The study was gathered utilizing the post positive approach. After fulfillment of the research the members will be able to view the results of this study by going to the California State University San Bernardino scholar works website. This research was conducted to share information to clinicians and any reader on the day by day battles and difficulties mothers face by caring for a child diagnosed with Autism.

## ACKNOWLEDGEMENTS

I would first like to thank my husband for having the unselfish love to allow me to go back to school while he provided ongoing patience and understanding to the sacrifices we had to make while I finished the program. I love you and appreciate it from the heart. I would also like to thank my advisor Dr. Carolyn McAllister for her guidance and support throughout my research. Lastly, my mentor Shyra Harris, in believing in me from the beginning and for her ongoing encouragement throughout the program.

## DEDICATION

I dedicate this study to my son Daniel who has shown me the beauty in the diagnosis of Autism. He is my motivation to want to be the best mom and social worker I can be to help other families going through the everyday struggles with ASD. Also to my older son Alejandro in hope that God may continue to bless his kind soul to see all the shades of grey as he walks beside his brother on his journey as well. Mom loves you both.

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# CHAPTER ONE

## INTRODUCTION

### Introduction

Chapter One of this research begins with a brief description of the reach focus, including the research question, and the purpose of the study. A literature review that provides findings is also included then concludes with the theoretical analysis section and the data implications. The theoretical analysis section specifics on the theory which this research is aligned with, and why. Then the data implications section explains how the findings of this study can contribute to the field of social work.

### Purpose

The purpose of this study is to gain an understanding of the impacts children diagnosed with Autism Spectrum Disorder (ASD) have on mothers. Autism Spectrum Disorders are a point of worry in the field. It is also a high concern in special education because of the high percentage of ASD in school settings (Matson & Kozlowski, 2011). The primary focus of this study, rather than a national study, is the individual experience of having a child with ASD. This study was conducted under the paradigm post-positivist approach in order to capture the true nature of a mother's experience in having child with ASD. The findings will provide readers with an understanding of various impacts of having

of having a child with ASD, which can help policy reform, develop programs, interventions, and resources for parents.

### Research Question

The research question is, what are the experiences of mothers that have a child with ASD? The intent of this study is gain a better understanding of the experience mothers who have children with ASD, and with that understanding inform and educate other parents, educators, and social workers that work with this population.

### Paradigm and Rationale for Chosen Paradigm

When conducting the study, the paradigm that was used is the post positivist approach. This approach allowed the researcher to build and practice theories that will help this population in capturing the most authentic experience from these mothers.

According to Morris (2013), post positivism allows the “data to be gathered in to a naturalistic manner, and data can be analyzed in the form of words rather than numbers” (p. 41). In taking this approach the study will allow social work professionals to gain a better understanding of mothers’ perspective in having a child diagnosed with ASD. With this knowledge, social workers can support mothers of children with ASD and can further help the community through support groups, workshops, and other resources.

## Literature Review

Autism Spectrum Disorder, or ASD, affects about 1 in 68 US children by the time they are 8 years old (Christensen et al., 2016). Due to the high incidence of the disorder in populations, researchers need to try and understand the impacts of a diagnosis on mothers and ways to best navigate care and support for families of the diagnosed. This literature review will review the history of Autism and Autism Spectrum Disorder, discuss the impacts of this diagnosis on the mother of the individual and his or her social environment, and review historical and current criteria for diagnosis in the Diagnostic and Statistical Manual, 5<sup>th</sup> Edition (DSM-5).

### History of Autism and Autism Spectrum Disorder

In 1911, psychiatrist Eugen Bleuler began to notice common behavioral traits in some of his patients. These patients were observed having trouble maintaining relationships, had an impaired ability to interact or socialize with others, and appeared to be irrational. These patients were unable to manage their external environment and often lived life according to their own internal world. Bleuler (1911) characterized this mental state as autismus, a spin-off of the Greek word, autos, meaning self (Kita & Hokosawa, 2011). Being that Bleuler's work was primarily focused on treating schizophrenia, it was believed that Bleuler's perspective of Autism was viewed as being a variation of a psychotic or psychosis diagnosis. Bleuler's definition of Autism would not be

considered ASD under today's criteria. It was not until 1943 that Autism was characterized as a pervasive developmental disorder.

In 1943, Kanner published what was known as the first publication focused on the lifestyle and symptoms of ASD. These patients were characterized as aloof and autistic (as coined by Bleuler), had language disorders, exceptional memory, and a preference for sameness and routine (Kanner, 1943; Kita & Hokosawa, 2011). Kanner (1943) determined extreme aloofness and having a strong preference for sameness and routine, as the main diagnostic criteria by which he would diagnose early infantile autism.

In 1944 pediatrician Hans Asperger conducted research on a very similar condition. Asperger observed patients that exhibited restricted interests, had exceptional memories, and appeared to more socially awkward--not understand conventional social rules (Asperger, 1944; Kita & Hokosawa, 2011). Asperger's patients had reasonably higher intellectual ability and milder developmental disabilities than Kanner's autistic patients. Historically, Autism and Asperger's syndrome have been used interchangeably as they share many similar symptoms. Both diagnoses include individuals who have: impaired social interaction with others, abnormal verbal communications, lack of or abnormal non-verbal communications, restricted interests, and repetitive or stereotypic behaviors (Kita & Hokosawa, 2011). The symptoms that make autism and Asperger's syndrome similar have been disputed. Some argue that there are more contrasts than similarities, however in 1988, Wing put forth the idea of ASD

(Autism Spectrum Disorder), suggesting that these two developmental disorders ought to belong in the same clinical group. Utilizing ASD has been the general consensus ever since and has been recognized and officially added into the Diagnostic and Statistical Manual of Mental Disorders: Third Edition or DSM-III. Since then, research has been conducted to further explore and differentiate ASD from other diagnosis.

#### Current Diagnostic Criteria

Research allowed for a better understanding of ASD and its related disorders and helped cultivate the criteria for diagnosing autism. As a result, the rate of incidence in our population has decreased due to these more defined criteria. Published in 2013, DSM 5 presents ASD under a new classification system (eliminated subcategories: Asperger syndrome, PDD, -NOS, childhood disintegrative disorder, and autistic disorder). DSM 5 sets forth the following diagnostic criteria for Autism Spectrum Disorder:

A. Persistent deficits in social communication and social interaction across multiple contexts, as manifested by the following, currently or by history (examples are illustrative, not exhaustive; see text):

1. Deficits in social-emotional reciprocity, ranging, for example, from abnormal social approach and failure of normal back-and-forth conversation; to reduced sharing of interests, emotions, or affect; to failure to initiate or respond to social interactions.

2. Deficits in nonverbal communicative behaviors used for social interaction, ranging, for example, from poorly integrated verbal and nonverbal communication; to abnormalities in eye contact and body language or deficits in understanding and use of gestures; to a total lack of facial expressions and nonverbal communication.

3. Deficits in developing, maintaining, and understand relationships, ranging, for example, from difficulties adjusting behavior to suit various social contexts; to difficulties in sharing imaginative play or in making friends; to absence of interest in peers.

B. Restricted, repetitive patterns of behavior, interests, or activities, as manifested by at least two of the following, currently or by history (examples are illustrative, not exhaustive; see text):

1. Stereotyped or repetitive motor movements, use of objects, or speech (e.g., simple motor stereotypes, lining up toys or flipping objects, echolalia, idiosyncratic phrases).

2. Insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or nonverbal behavior (e.g., extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greeting rituals, need to take same route or eat same food every day).



3. Highly restricted, fixated interests that are abnormal in intensity or focus (e.g., strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interests).
4. Hyper- or hypo-reactivity to sensory input or unusual interest in sensory aspects of the environment (e.g. apparent indifference to pain/temperature, adverse response to specific sounds or textures, excessive smelling or touching of objects, visual fascination with lights or movement).

C. Symptoms must be present in the early developmental period (but may not become fully manifest until social demands exceed limited capacities, or may be masked by learned strategies in later life).

D. Symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning.

E. These disturbances are not better explained by intellectual disability (intellectual developmental disorder) or global developmental delay.

Intellectual disability and autism spectrum disorder frequently co-occur; to make comorbid diagnoses of autism spectrum disorder and intellectual disability, social communication should be below that expected for general developmental level.

(American Psychiatric Association, 2013, pp.50-51)

As mentioned, Christensen and colleagues (2016) found that 1 of 68 children will have been diagnosed with ASD by the time they are eight. Generally, ASD

diagnoses are made after the age of five, but early diagnosis is becoming increasingly important. Recent studies have been geared towards the feasibility, effectiveness, and benefits of early diagnosis and intervention of infants at risk of autism (Olliac et al., 2017). The PREAUT grid can help to detect Autism and ASD in children under the age of 3. It measures an infant's ability to engage in synchronous and joyous activities (Olliac et al., 2017).

### Impact of Autism Spectrum Disorder Diagnosis on Mothers

When a child is diagnosed with ASD, parents may initially experience a loss. They may mourn no longer having what they believed was a "normal" child, and may lack knowledge or understanding of how to cope with this new diagnosis (Norton & Drew, 1994). Some families may have similar emotional and psychological grief experiences when a child is given a disability diagnosis as they might if they lost the child to death. When a child dies, society provides social mechanisms and symbolic rituals to aid the family with the loss, but when a child has a disability, there is no societal mechanism to cope with the loss.

In her long research on grief and loss, Kubler-Ross identified and outlined five stages that a person who is dying or their loved ones might experience, which includes denial, anger, bargaining, depression, and acceptance (Kübler-Ross & Kessler, 2005). Later research demonstrates that these stages are not linear, and that people may experience none to all of these stages. An ASD diagnosis in a child may lead to similar experiences of loss as a child death (Penzo & Harvey, 2008).

A longitudinal study examining 155 parents of children with autism compared to 220 parents of children with no diagnosis was conducted for 33 years. The results demonstrated that parents of children with ASD experience more stress than other parents (Mouridsen, Rich, Isager, & Nedergaard, 2007).

At times outrage may take place after the diagnosis of a child. The parent's feelings of dread are affirmed, and the reality of the diagnosis starts. Some of this anger that parents feel can be fixed on others that do not have a child with autism or can decrease in occurrence and severity as the family learns how to work with the child with ASD (Benson & Karlof, 2009). Depression, anger, and sadness can come back as the child with ASD ages and does not meet typical developmental milestones (Featherstone, 1980; Hughes, 2003; Naseef, 2001; Penzo & Harvey, 2008).

#### The Impact on Nurturing a Child with Autism Spectrum Disorder

After the diagnosis, the burden in most families to raise the child lies with the mother. In many families, the mother is the primary caregiver, and this role is more common when there is a child with ASD in the home. (Heller & Hsier, 1997; Marks, 1998) This may lead the mother with ASD to feel more worried than typical about their parenting skills, and increase feelings of guilt and stress (Harris, 1984). Mothers are at a high risk for stress and psychological distress, which manifests in increased parenting stress, anxiety, and depressive symptoms (Estes et al., 2009).

As with parents of children without disabilities, parents of children with ASD need information and assistance in raising their children. As is more the case with ASD, they need access to information about managing behaviors and attitudes, and may need additional support (Boyd, 2002; Floyd & Gallagher, 1997). Attempting to raise children with ASD without any support on a professional level can lead to social withdrawal and fear (Smith, Oliver, & Innocenti, 2001). Mothers of children with impaired living skills, like getting dressed, eating, going to the bathroom, etc. face increased child-rearing responsibilities (Estes et al., 2009). Children with ASD often struggle with areas such as social exchanges, communication, and social behaviors (Baker, Lane, Angley, & Young, 2008; Hoffman et al., 2009). People working with a mother who have a child with ASD need to have an understanding of the stressors these mothers face and know what resources are available for support. Being able to support the entire family, particularly the mother, is important when working with individuals with ASD (Meadan, Halle, Ebota, 2010; Neely-Barnes & Dia, 2008). Knowing how ASD impacts all members of the family is the first step in providing comprehensive and useful assistance for them (Oprea & Stan, 2012).

Autism in comparison to other developmental disabilities impairs the mother's social relatedness, thereby causing emotional stress, pain, and disconnectedness. (Estes et al., 2009) This impacts mothers in public situations, especially when surrounding people do not understand autism and the particular challenges it presents. Lack of understanding, acceptance, and being

marginalized and criticized can complicate an already complicated situation (Oprea & Stan, 2012). Help from professionals, choosing the right school, having plenty of community support and familial support are just a few means by which a mother can vastly improve both her mental state and that of her child with ASD.

### Theoretical Orientation

Since the study relates to a social impact on mothers' of a child with autism, a theoretical orientation positive approach of resilience theory would best fit. Resilience can be characterized as a multi-layer field that has been used by a variety of specialist such as educators, social workers, psychologist and others in the previous couple of decades. Resilience theory tends to empower individuals and systems to surpass adversity (Van Breda, 2001). The mothers to the individual with autism have day to day challenges that can affect their well-being and lead to burnout. This study supports that factors into accessing support for these mothers are providing appropriate social support that they are lacking in. In doing so this can help out to prevent burnout, have additional time for their child, and assist the family as a whole to be resilient. Positive viewpoints are an essential component of resilience. Families develop resilience when they seek after answers for their issues, look past the hardships situations, and are able to make the best choices accessible to them. (Walsh, 2003). According to Gray and Holden (1992), mothers that get larger amounts of formal or casual social interaction reported having less emotion of anger, depression and anxiety.

Additionally, some researcher found depression and anxiety in parents of children with ASD was linked with low levels of social support.

### Potential Contribution to Social Work Practice

The information found in the study can be used as a contribution in the micro as well in the macro work of social work. The data from the mothers of children with ASD, shows that there is a need for assistance. After receiving their child diagnosis they are left in a vulnerable state of mind along with the distress that comes from raising a child with Autism. The caregiver is overlooked when it comes to providing the family support because the child with ASD is the primary focus and services are added to assist. According to the National Association of Social Workers (2018), one of their core values include respecting the inherent dignity and worth of the person. Social workers should work on mothers on empowering them and should provide social support to this population. Helping these mothers who have children with ASD in connecting them services that provide support to help them adjust to their child's diagnosis is essential.

As social workers, they value the importance of human relationships and having strong social support is essential for this population. Social workers need to develop skills and competencies in working with children with ASD and their families (Preece & Jordan, 2006). Helping parents by empowering them to advocate for their children is an important part of social change.

Macro-level. Social workers play a role in the macro level of intervention and it can be done so by educating the community members about what it means

to have autism and the characteristics. In educating the members of the community it would benefit both the professionals and the community in understanding what it means to have autism and how to appropriately respond. Another way a social worker can help in a macro setting is to help in advocating for daycare centers for this population. Addition to this the mothers should have access of attending support groups that allows them to feel more connected with others. This can help by providing them a sense of feeling reassurance that they are accepted by the community.

Micro-level. At the micro-level social workers can help the mothers in the therapeutic process in coping with the challenging diagnosis. They are also able to assist with providing case management to ensure the continuity of care other service providers to better assist the family as a whole. During the process of case management there can be meetings taking place in order to ensure that the needs are being met with not only the child but also the mother.

### Summary

Chapter One discussed the research topic, research questions, and a detailed implication of how the research can help in the social work field and practice. A theoretical orientation was chosen for the study and explained why. The literature review provided a short history of Autism and the current diagnosis criteria using the DSM-5. The literature states how the diagnosis can impact the mother as well as the family as a whole and the challenges they face.

## CHAPTER TWO

### ENGAGEMENT

#### Introduction

Chapter Two summarizes the engagement phase and discusses the ways in which researchers include the gatekeeper in order to access to the study participants as well as the study site. Additionally, this chapter explains how this researcher overcame issues challenges in the study related to diversity, ethics, and politics.

#### Study Site

In the engagement for post positivism, the research focus is developed by the researcher, and then it is reviewed with the management on site which in this case study was the administrators. The study site took place at the location of the participant via internet or phone. Since the participants are involved in an online support group the location was determined by them.

#### Engagement Strategies for Gatekeepers at Research

In this engagement portion for post positivism, the research focus is developed by the researcher, and then it is reviewed with the gatekeeper, which was the person in charge of the support group. The study site was the support group. A flyer was approved by the gatekeeper and then posted in the group to gather participants. The researcher met with the gatekeeper (administrator) just



to continue gathering participants for the study. After gathering a large sample, the researcher utilized the website Fuze or Zoom for conducting the interviews with individual participants.

### Self-Preparation

In the process of self-preparation, there are some things that have to be considered. One thought that can be crucial is the approach taken when working with the participants. A foundation of trust and safety must be established to allow the participants to be able to open up. One way of doing this is to open and honest with the participant and provide the confidentiality information. The researcher reviewed confidentiality and had informed consent signed. Visual data, audio videos and worksheet were carried out with the participants identifying presenting problem and incidents that follow due to the amount of change in the home.

In the post positivism research process there may be other biases that can influence the research such as underlined mental health issues or a problem that the individuals will bring up. The researcher journaled events being shared that have to do with the outcome of the child and how it is affecting the mother and impacting the home environment.

### Diversity Issues

During the research there may emerge some possible diversity issues. A possible diversity issue that can come up is in post positivist studies is the applicants' own view of the issue. One that I have seen in the discussion topics is

when a mother is having a rough time coping and others have taken it as a view that the mother isn't accepting of the situation so there can be some judgments among the group. This can cause the person to hold back and not want to participate. This is why that the interviews were done individually confidentially.

### Ethical Issues

This study was submitted to and approved by the IRB board prior to its execution. The researcher was connected with participants through an online Facebook group called, "Autism Moms In It Together." Participants were not asked to reveal any information regarding their personal identity including, name, address, phone numbers, emails, or any other information that might reveal their identities. This researcher has destroyed any information containing any content revealing the identities of participants, and has coded the participants to provide further security. The study was broadcast to the online group, through which participants were asked to reply directly to the researcher in private messages. These messages have all been deleted and the researcher's participation in this group has been suspended dependent upon final publishing of this study. All participants signed consent forms, informing them that the study was voluntary and confidential, with concise descriptions of the nature of the study and usage of the data resulting.

### Political Issues

Programs to support children diagnosed with ASD and their families must be made accessible and affordable. It follows that if this is to be successfully

funded, it needs to become a policy priority. Funding in the form of block grants, health insurance coverage, and other benefits should be expanded to reach as many families in need as possible. The current federal administration is looking to cut funding for government funded social services, if cuts are made to essential funding for programs serving children with ASD and their families, the results could be drastic. This study shows that while most participants are already taking advantage of support programs and services, more is needed.

### The Role of Technology in Engagement

The study used social media technology to gather participants for the research. Using technology was how I engaged the participants. Many people in this population are busy with their children, jobs and going to use the social media technology to gather participants for the research. Therefore, the role of technology played a significant part in the study. One big factor when using technology is the risk of confidentiality. I addressed this issue in a form discussing what confidentiality is and how this research will be conducted carefully so that confidentiality is not broken.

### Summary

In this chapter, the engagement stage was discussed. The site where the research was going to take place was also included. Participants involved in the research were also included in the chapter. The participants that were going to be targeted and how technology played a big role in the study were also included. The role of the gatekeeper was also brought up and how they play a

unique role for this study. How to self-prepare and issues that could arise in the research with a plan were also provided within this chapter.

## CHAPTER THREE

### IMPLEMENTATION

#### Introduction

Chapter Three examines the methodology and strategies used to finish this study. Furthermore, this section focuses on the sample and instruments used. It also examines the process how the instrument was utilized, the information gathered from the study, and obstacles to the investigation. This chapter also discusses the participants in the study and the approach that was utilized in the research and why this approach is best appropriate.

#### Participants

This study focused on mothers that have a child with ASD. The participants are all mothers in a support group online. The study examined how the mothers reacted to their child's diagnosis of ASD. The mothers are from different ages, ethnicities and have different demographics.

A flyer was posted on the online support group to gather a large sample of participants. The mothers that were willing to participate in the interview was provided direction to email or call the researcher. An electronic message was sent out to members in the support group. The mothers/participants that were interested were contacted and provided with a consent form and demographic sheet prior to setting up a time to conduct the interview. After receiving the consent and demographic forms the researcher provided a date and time to

conduct the interview using Zoom or Fuze. In conducting the post-positive research the method that was used was qualitative research, which allows the research to be done in a naturalistic setting.

### Data Gathering

The data in this research was collected through interviews with participants. Some of inquiries questions incorporate things, for example, general data about the youngster, the mom's response in the initially knowing the diagnosis, if/how ASD has changed their lives and the stress experienced after the diagnosis. Prior to the verbal interview, the researcher sent an informed consent by email for the participant to review, sign electronically, and send to the researcher. The phases of data collection consisted of observation, interviews, and qualitative data collection. All data was recorded.

### Data Recording

Data was kept in a confidential memory drive, and then transcribed onto a spreadsheet to have it available after the study is done for graphing purposes. The data was used through audio recording devices with consent of participant. According to the text (Morris, 2013) there should be a journal to track ongoing data and notes on experiences. After the recording was completed the researcher transcribed the information onto a document.

## Data Analysis

The research data will be used through qualitative analysis using the “bottom up” approach. This approach has four different phases: open coding, axial coding, selective coding and conditional matrix. Selective coding will be used where the core theme is being identified. The last stage is the conditional matrix, where the data will be mostly completed (Morris, 2013).

### Open Coding

According to Morris (2013), “open coding is an inclusive process of gathering data from several key players” (p. 257). In this portion of this study, the researcher read the data from the interviews a couple of times and began to gather common themes. Some of the themes gathered were: experience of child’s diagnosis, impact on family, the experience of raising children diagnosed, needed resources and lessons, reflections, and advice.

### Axial Coding

In this segment of the study the researcher analyzed the similar responses of the members and compared them with other answers to check for similar responses. The response was not repeated if it was similar to the others. To avoid repetition only a phrase of the research was used.

### Selective Coding

Selective coding is where the core theme was identified by the similarities that the mothers reported. The stage in this process is to identify the patterns the

caregivers created by expressing their feelings and statements from the diagnosis of their child to then be analyzed.

### Conditional Matrix

The last stage in this post positivist study is contingent grid. This portion is when the researcher indicates how the study is used in a micro and macro social work practice. Mothers in this examination are lacking with regards to social and emotional support to work through their child's diagnosis on a daily basis. This matrix connects the discoveries of this study to human experiences. This study will help future clinicians to recognize resources to mothers and link them with the proper resources to help them meet their social and emotional needs.

### Summary

In summary, this chapter discussed the population of the participants and the steps taken to gather these voluntary members. It also provided how the research would be conducted and the steps followed towards the interview. Furthermore, it delivered details for the recorded method, data collection method, and the plan for data analysis. Again, the data was gathered through interviews, recorded and stored through confidential journals.



## CHAPTER FOUR

### RESULTS

#### Introduction

This chapter provides results of the qualitative survey regarding the experiences of mothers of children diagnosed with Autism Spectrum Disorder (ASD) in hopes of improving future experiences by means of planning, information, resources, and support for mothers of children diagnosed with ASD.

#### Participants

Mother's responded to a flyer posted in a Facebook group called, "Autism Moms In It Together." Eight participants were assigned a number from one to eight. The participants are mothers from ages twenty-three to forty-five and have one or more children diagnosed with ASD. The majority, or five out of eight, of the participants have more than one child. One mother has vocational training, three mothers have an associate's degree, one mother has a bachelor's degree, two mothers have master's degrees, and one mother has a doctorate degree. As far as marital status, three are separated, three are married, one is divorced, and one is in a relationship. Three mothers are Caucasian, two are Latino, one is biracial, one is Hispanic, and one is African American. Their annual incomes range from less than \$16,000 to more than \$40,000. One works full-time, two work part-time, one is self-employed, and four are unemployed, with one of those four attending college. It should be noted that Participant 8 only responded to

sixteen of twenty-five questions as they became emotionally overwhelmed and requested to stop the survey.

## Results

Questions of the survey are divided into the following five categories: 1) the mother's experience of the diagnosis, 2) the effects of the diagnosis on the family, 3) the experience of raising children diagnosed with ASD, 4) needed resources and support, and 5) lessons, reflections, and advice.

### The Mother's Experience of the Diagnosis

The children diagnosed with ASD ranged in age from two years and nine months to seven years of age. They received their diagnoses between one year and eight months and four years and six months. The mothers suspected ASD in their children when they either were not meeting the usual developmental benchmarks or had a sharp regression in their development. Participant 1 said:

My son always hit his milestones early. However, at 6 months he stopped for a while until he started talking at 9 months. He had been saying Dada, Mama, Gigi, please, and thank you for 3 weeks. Then one day he woke up and it was like he had never said a word. He looked so confused when we tried to get him to speak. (October, 2017)

Upon receiving the diagnosis, mothers experienced a range of emotions: validation, relief, determination, guilt, sadness, and heartbrokenness. Participant 7 said:

Why didn't I see it earlier. Why didn't I stop it? Why didn't I get her help sooner? However, I also felt that she needed help therefore I wanted just to know so I can go on with the steps to do so" (July, 2017)

All participants were familiar with the stages of grief. In regards to their child being diagnosed with ASD, three were in the acceptance stage and the other five cycle through the stages over and over again. As Participant 8 said:

I am familiar with the stages of grief. I am still currently going through them due to her diagnosis, my divorce, and many other life-altering situations occurring at the same time. Referring to her diagnosis 7 months ago, I feel like I go up and down with emotions, especially with the unknown future for her and me. (January, 2018)

Six of eight participants did not fully understand the ASD diagnosis and were in need of more information regarding the diagnosis, while two understood and had intimate knowledge of ASD upon receiving the diagnosis. Participant 3 said:

Honestly I knew very little.... I had experience as a teenager working in a fast food restaurant with a gentleman who you could not touch but was amazed at his knowledge of baseball.... I also had experience with a young man who was part of a baseball team I managed and loved his enthusiasm and him as an individual (I now know he was very high functioning) but other than those two experiences I knew nothing and have felt lost as to what to do with my son. (November, 2017)

In evaluation of the pros and cons of receiving a diagnosis for their children, all participants listed access to therapies and other necessary programs as a pro. The list of cons was more diverse. Six of eight participants said that the diagnosis stigmatized their child and/or their family. One participant said they did not experience any cons in conjunction with the diagnosis, and one cited the inability to communicate effectively as a con of the diagnosis. Participant 1 responded, "Pros: he can receive the help he needs, there was a name for why he is the way he is, and it gave me closure. Cons: daycares were hesitant to accept him, people refuse to be around him, and the diagnosis will follow him for the rest of his school life and possibly into adulthood" (October, 2017).

Four out of eight participants had a positive experience with the clinician/doctor when they were given the results of the assessment. Three out of eight participants had a negative experience with the clinician/doctor when they were given the results of the assessment. One participant did not cite either a negative or a positive experience. Participant 2 had a negative experience:

Very 'clinical.' They used a lot of acronyms and didn't try to explain. If I didn't have any prior special education experience I would have been lost. They didn't know I had that experience so I imagine that's how they were with most parents. There were 5 specialists sitting around the table spitting out numbers and acronyms. They didn't even try to answer my questions or give any useful real life information. (January, 2018)

When asked to describe the ride home after their child had been diagnosed with ASD, mothers had a variety of unique experiences with emotions ranging from gratefulness, clarity, and relief, to overwhelm, fear, and the worst experience in their lives. Describing their experience, Participant 6 said:

[It was] a nightmare... like living another person's life. I couldn't stop crying all the way back home. And more specifically, I remember having a lot of issues having to deal with my son like nothing has happened, because for him nothing did happen. One of the worst experiences in my life. I'm usually in control of my emotions, my actions and behaviors, but there I was without any control on the situation. I was unable to speak with family or friends, I felt bad for myself, I just wanted to stay in bed crying.

(February, 2018)

Participant 4 had to give up their professional life.

I used to be the General Manager at a franchised Massage Envy in Florida. It was a typical 9-5 job with Sundays and Wednesdays off. The only problem was, I was on call every day, all day. This interrupted my kid's time with me, my son's appointments and therapies. My significant other became very aggravated that I was not able to give the kid's the time that they deserved so I have decided to take some time off of work.

(December, 2017)

## The Effects of the Diagnosis on the Family

Eight of eight participants claimed that the diagnosis had affected other members of the family. However, the responses of the family members were very diverse. Describing the impact on her other older child, Participant 8 said:

My son also felt relief when she was diagnosed- we had an answer as to why her world seemed so difficult. It still has been hard for him to understand her ASD moments versus her normal toddler moments, and he struggles when she is in her overwhelmed sensory modes. (January, 2018)

Similarly, Participant 5 noted,

My older son goes to counseling. Around the times my child with autism regressed my older son began to have 'accidents' in his pants. I think it impacted him so much that we have now caught on and he is having therapy. I don't know about my additional family. I think they feel sorry for my son and our family. I do know that socially it is mostly us and my in-laws. My family loves us but I don't think they get it and I don't expect them to. (December, 2017)

All participants' families have been financially impacted by their child's ASD. Citing increased financial burden for copays, unexpected expenses, not being able to work a normal job, less money for family outings, and increased spending on resources for their child. Participant 3 said:

The fact we have so many things like diapers still at almost the age of 4, we are trying to find funding for a weighted blanket, funding for a tablet as he's non-verbal and who knows what else is going to come up is difficult on my financial situation. (November, 2017)

Five of eight participant's spouses work full-time, with two of those five participants' spouses working full-time with another part-time job. One participant works part-time, one has no spouse and does not work, and one participant is a student and does not work. Participant 5, speaking of their spouse said, "My spouse works a full time and part time job. Monday-Friday 7:30-4:00 and Wednesday 5-9pm. He carries this family and support us" (December, 2017).

#### The Experience of Raising Children Diagnosed with Autism Spectrum Disorder

Seven of eight participants agreed that their parenting style changed after learning that their child had ASD. Among those whose parenting styles changed, they claimed that they became more lenient, patient, flexible, and gracious.

Participant 3 said, "We are following routine more and I am even more patient with him than I was before (others believe I make excuses but they don't understand and hand over hand is a big thing for us now)" (November, 2017).

Participant 1 said, "I have had to learn to pick my battles, let go of some of my expectations, and give lots of grace" (October, 2017).

Four of eight participants noticed that the diagnosis has affected them positively on a personal level, three of eight participants noticed that the diagnosis has affected them negatively, and one participant had noticed both

positive and negative effects. Responding to how ASD had affected them personally, Participant 5 said:

Wow... I am a different person. I have always been emotionally connected with people and felt that I understood their pain, which is have empathy, however, I was wrong. No one truly understands until they are in those shoes. I have grown claws and fangs. When I say this I mean I am my sons voice and protector which I have grown a back bone. It has always made me weak where I become overly sad and sentimental. I guess I am still going through the grieving stages. (December, 2017)

Seven out of eight participants agreed that mothers of children with ASD lead more stressful lives than mothers who do not have children with ASD, citing the children constantly need attention, need to go to a lot of different appointments, the expense associated with their care, and lack of understanding from the outside world as sources for their stress. Participant 2 said:

Yes, definitely. There's just that much more to juggle and therapists don't care if you have a job or more kids. I'm frequently told that 'if he's a priority, I'd make it work.' Which is an unbelievably horrible thing to say to a mom. Of course he's my priority. Being able to eat every day is a priority too. It doesn't mean he's less of a priority. (January, 2018)

When asked how they manage or cope with the stress, four participants responded with self-time activities such as taking a bath, watching television, taking a walk, massages, and seeing a counselor. One participant uses



affirmations to decompress, two participants use perseverance to keep their morale high, and one participant cannot escape her stress. Participant 4 said. “It can certainly be challenging and stressful. I tend to hold myself together by just reminding myself to be strong and that I’m all he has. I also think of the happiness he brings me” (December, 2017). Participant 8 said:

I am not managing my stress very well. I have dropped half time in school, I have made financial sacrifices and sold items of value to keep afloat. I don’t go out, I don’t travel...TRUTH?!?! Even this interview has brought me to tears and raised my level of stress so high with the reality of things, I have to stop, I can’t finish the rest. I am so sorry. (January, 2018)

Participant 8 requested to end the interview at this point.

### Needed Resources and Support for Mothers of Children with Autism Spectrum Disorder

The resources participants cited are as follows: ABA therapy should be more accessible, housekeeping, self-time, daycare, emotional support, case management, IEP for schools, financial support, resources and information, hope, adult interaction, speech therapy, occupational therapy, and increased accessibility of all available programs. Participant 6 said,

I have read about support groups, but have not find one in my area. I wish I could go and talk with other mothers about the challenges; I desperately need more adult interaction, more talking with other people. Life as a mother of a kid with ASD can be isolated. My son receives ABA at school,

as a mother, I would love to learn about ABA methodology so I could be more useful from home. I want to learn how is that my son learns, so I can help him in all areas in his life, not only academic. I also believe the resources for people Spanish speaking in this country are quite limited, I wish there would be a way to create groups, blogs or more information for the people who speaks Spanish and do not know how to navigate the diagnosis. In addition, I think there should be more data on the best school districts or even States, cities, for people with autism. There are many places without the proper services, I wish people would know what to do or where to move when the diagnosis come. (February, 2018)

When asked about what resources they currently use to help take care of their children, participants listed Early Steps, SSI, ABA, OT, PT, speech therapy, daycare, preschool, support groups, and family members. Participant 7 responded, "I don't have much resource other than ABA, speech and OT. She also gets some through school, which is a help as well" (July, 2017). Participant 5 said, "My in-laws. Sad, but true. I think they need a break too sometimes. They have been a huge support but I know that they are getting older and I cannot rely on them for a long time" (December, 2017).

The participants' opinions of support groups were mixed. Two of seven participants asked found support groups to be very helpful, three of seven participants found them to be useful, one participant found them to be okay, and one participant was not a fan. Participant 1 had a negative outlook on support

groups saying, “I do not think support groups help much more than giving parents a space where they can complain about their child” (October, 2017). Whereas Participant 2 said, “They can be very helpful. Sometimes it turns in to a ‘you’re kid isn’t severe enough so you don’t belong’ situation which stinks. Every kid is different. Every mom could use support” (January, 2018).

When asked what would be an ideal way to cope with stress experienced because of their child’s ASD, participants listed exercise, learning, leisure time, and communication as possible ways for coping. Participant 6 said:

I would say time for myself without having to worry about how my son is being treated. I haven’t found a babysitter, so it’s me all the time. I wish I could go for a coffee and read a book, I wish I could have a night to sleep without interruptions, and I think I would benefit from therapy and ABA education. (February, 2018)

### Lessons, Reflections, and Advice

Five of seven participants said that their clinician/doctor/staff could have had a more personal approach when assessing and diagnosing their child with ASD in order for future parents to have a more positive experience, while two would not have changed anything. Participant 2 would prefer that the medical staff, “Be compassionate and kind. Not so clinical” (January, 2018). Participant 4 recommends staff, “Be more encouraging, listen instead of talking” (December, 2017). Participant 5 said:

I think that having the staff understand that this time is difficult and providing a friendly and welcoming environment is important. I wish I would have had a sheet stating what next and some steps on what to do and resources available and phone numbers to have in case a parent or person needed to talk to someone for support. I walked in nervous and scared and walked out like I was in the dark and it was scary. At times I feel that I am still in this dark tunnel and having to just follow my gut to guide me when I feel that there are many professionals that can help alleviate some of that stress. (December, 2017)

When asked what ASD has taught them as parents, participants said it has taught them to go with the flow, different parenting tactics from children without ASD, to see through their child's eyes, be humble, celebrate achievements, be patient, and be understanding. Participant 6 said:

My son's ASD diagnosis has taught me to be more humble, understand that there is a whole different world of special needs that I do not know and that people are suffering and being affected by it. I learnt that my actions can affect profusely somebody's day, and that I have to be really careful for what I say or how I behave in public, because there is a lot of sensitivity and ignorance out there. I learnt that there is nobody else that could be a better advocate for my son's needs, and that I have to prepare myself for every possible scenario. And most importantly, the ASD has taught me to enjoy and celebrate my son's everyday accomplishments, for

little or insignificant that they could appear to the neuro-typical eye.

(February, 2018)

As far as preparing their children with ASD for adulthood, three out of seven participants preferred to live in the present and not worry about the future, two participants said it depended on their level of independence and their siblings might have to help in the future, one participant said they might still be living at home, and one participant liked to have continual conversations about the topic with no particular plan in mind. Participant 4 said:

I am working with him just as much as the therapists and I also want to purchase a house with a little apartment on the garage or a mother in law suite in the future just in case. I want him to have his personal space but still in the same household when he gets older if need be. (December, 2017)

Participant 5 said:

My son is just about to turn 7 and I am thinking of 1st grade so I cannot think that far. It is bad... I know but I will have to put thought into it as the years come closer. Right now I just want him to be 6 and not see him as an adult yet. (December, 2017)

All participants asked would like to dispel misconceptions about ASD. It is not a disease/illness, it cannot be controlled, every ASD case is unique, and remind others that ASD people are people too. Participant 2 said, "There is no cookie cutter mold. Every person with autism is very unique" (January, 2018).

Participant 3 said, "It's not a disease and it's not like the movie Rainman.... These are people who have feelings and should be treated with the same respect as everyone else."

The seven participants completing the interviews offered these words of encouragement for other mother's hearing news of their child's ASD diagnosis for the first time: don't give up, you can do this, it will be an adventure, be kind to yourself, take action as quickly as possible, and don't give up hope. Participant 3 said, "Take a deep breath! It's not the end of the world! They just think different and if you can take the time to observe you will see just how brilliant your child is!" (November, 2017). Participant 4 said:

It is going to be okay!! You are blessed with an amazing child and no matter how much therapy you put your child through, it is up to you to see your child blossom!! Work with them daily, never lose faith and keep your head up. (December, 2017)

Participant 5 said:

wow congratulations... you are going to have an adventure. There are going to be so many easy days and challenging ones. You will always be learning and never be bored. You will be an awesome mom and learn to advocate for them, be their voice and be stronger than you ever imagined. Be kind to yourself on the days that it hard and with every decision you make do it with kindness and for the benefit of your child. Our children are

blessings and God has a plan for each one of them and us as well.

(December, 2017)

### Conclusion

Within this chapter, the results of the post-positivist interviews focused on mother's experience of having children diagnosed with ASD are revealed in hopes of improving future experiences by means of planning, information, resources, and support for mothers of children diagnosed with ASD. The outcomes of this study were taken from a sample size of eight participants along with their demographic information. The interviewees answers were presented in five categories: 1) the mother's experience of the diagnosis, 2) the effects of the diagnosis on the family, 3) the experience of raising children diagnosed with ASD, 4) needed resources and support, and 5) lessons, reflections, and advice. The results will be talked about further in chapter five.

## CHAPTER FIVE

### TERMINATION AND FOLLOW UP

Chapter Five provides a summary of the termination of this study, communication of the findings, discussion of the findings, and implications for future research.

#### Termination of Study

This study was conducted during the fall of 2017 and terminated in the winter of 2018. Participants were recruited from the online Facebook support group, “Autism Moms in it Together.” Consents and demographic sheets were provided via email and collected prior to interview. The interviews were conducted virtually through Fuze or Zoom online meetings. One participant terminated the survey early at question sixteen, and all other participants were informed of the termination of the interview orally and by electronic communication.

#### Communication of Findings

The findings of this research will be disseminated via the ScholarWorks database at the Pfau Library, California State University, San Bernardino beginning July 2018. The researcher has notified participants of this availability and will continue to engage with participants in the online Facebook support group, “Autism Moms in it Together,” however, results of this study will not be



discussed until the official release. The researcher will communicate the results of this study in a written thesis and electronic presentation.

### Discussion of Findings

All participants of this study were familiar with the stages of grief, and confirming Penzo and Harvey (2008), five out of eight participants cycled through the stages of grief after receiving a diagnosis of ASD for their child, and eight out of eight participants have experienced all the stages of grief associated with loss. This means that when medical professionals are giving the diagnosis, they need be aware that the mothers are going to be going through a grieving period, similar to that of mother's losing a child. Going further, medical professionals need to provide support to mothers of children diagnosed with ASD similar to those they would provide to a mother who has recently lost her child. These resources may need to be available for the duration of the child living under the mother's care as many mothers cited that they continuously cycle through the stages of grief without termination.

Confirming Mouridsen and colleagues (2007), seven out of eight participants agreed that mothers of children with ASD live more stressful lives than mothers who do not have children with ASD. This stress was associated with increased caregiving responsibilities, thereby also confirming Heller and Hsier (1997) and Marks (1998). Resources should be made available that not only assist the mother in her caregiving responsibilities, but also aid the mother in processing her stress, providing her with resources and materials. As many of

the mothers cited that leisure time would assuage their stress, it is important to give the mothers a resource that temporarily relieves them of their parenting duties for a long enough time that they might decompress.

This study was unable to confirm or disprove Benson and Karlof (2009), Featherstone (1980), Hughes (2003), Naseef (2001), or Penzo and Harvey (2008) as participants recalled a variety of emotions after the diagnosis of their child, ranging from positive emotions such as validation to negative emotions such as depression and anger. This could be associated with the stages of grief formerly discussed. Some mothers may be completely surprised by the diagnosis, others anticipating or even hoping for the diagnosis. Medical professionals should be prepared for a wide range of emotions and necessary resources and programs to help the mothers cope with whatever their experience might be.

Confirming the need for access to information and professional support, Boyd (2002) and Floyd and Gallagher (1997), seven out of seven participants cited that they need additional resources for raising their children. Among the resources cited were: ABA therapy should be more accessible, housekeeping, self-time, daycare, emotional support, case management, IEP for schools, financial support, resources and information, hope, adult interaction, speech therapy, occupational therapy, and increased accessibility of all available programs. While many of these resources are available not all mothers have access due to prohibitive costs, waiting lists, and lack of necessary

transportation. These additional resources are necessary in improving both the health of the mother and the success of their child with ASD.

Six of eight participants said the diagnosis stigmatized their child and/or their family, thereby confirming Oprea and Stan (2012) that the ASD diagnosis contributes to lack of understanding, acceptance, and being marginalized, and confirming Estes and colleagues (2009) that the developmental disability impairs the mother's social relatedness. Support groups specifically engaged in providing a positive and supportive environment for mothers could help to improve the mother's sense of social relatedness and acceptance. Participants had mixed reviews of support groups, however this mix would be balanced through the use of a professional moderator in the group, which would help ensure the conversations were not geared towards shaming, complaining, and derailing others' statements of their experiences. This tactic could also carry over to online support groups, which consistently lack professional moderators and strength-based growth.

#### Implications for Future Research

This research adds to the body of research aimed at understanding how ASD diagnoses affect the mothers of children who are diagnosed. Which is the first step in providing useful and meaningful assistance to them (Oprea & Stan, 2012). Future research is necessary to determine the proficiency, accessibility, and usefulness of online support groups. As participants' reviews of support groups were highly mixed, it would be interesting to see if a professionally

moderated online support group was more or less effective. Additional research is also needed to determine the issues preventing mother's from taking advantage of available resources as well as specifically which programs prove to be most useful in easing the mother's parenting related stress.

#### Implications for Social Workers

Social workers should be treating mothers of children diagnosed with ASD similarly to mothers who have lost a child, helping them process their relapse in the stages of grief, while also providing them with resources and programs to help ease the burden of raising their child. This kind of support could be taken to online support groups. Social workers would be efficient and professional moderators, contributing to the content of the online support group, while guiding discussions and ensuring that any discussions therein are positive and productive.

APPENDIX A  
APPROVAL LETTER

**CALIFORNIA STATE UNIVERSITY, SAN BERNARDINO**  
**SCHOOL OF SOCIAL WORK**  
**Institutional Review Board Sub-Committee**

Researcher(s): Angelica Del Villar

Proposal Title: Affects Autism Spectrum Disorders has on Mothers

# SW1781

Your proposal has been reviewed by the School of Social Work Sub-Committee of the Institutional Review Board. The decisions and advice of those faculty are given below.

-----  
Proposal is:

X approved

to be resubmitted with revisions listed below

to be forwarded to the campus IRB for review

Revisions that must be made before proposal can be approved:

faculty signature missing

missing informed consent  debriefing statement


revisions needed in informed consent  debriefing

data collection instruments revision

agency approval letter missing

CITI missing

revisions in design needed (specified below)

  
\_\_\_\_\_  
Committee Chair Signature

5/22/2017

\_\_\_\_\_  
Date

Distribution: White-Coordinator; Yellow-Supervisor; Pink-Student

APPENDIX B  
INFORMED CONSENT

## INFORMED CONSENT

The study in which you are asked to participate is designed to gather information on the Effects Autism Spectrum Disorders Has on Mothers. The study is being conducted by Angelica Del Villar under the supervision of Associate Professor Carolyn McAllister, School of Social Work, California State University, San Bernardino. The study has been approved by the Institutional Review Board Social Work Sub-committee, California State University, San Bernardino.

**PURPOSE:** The purpose of the study is to provide an insight to how a child with ASD affects the mother on all aspects of her life.

**DESCRIPTION:** Participants will be asked questions regarding their personal impact on how having a child with ASD have changed their lives.

**PARTICIPATION:** The participation in the study is voluntary and can refuse to participate in the study or discontinue at any time without any.

**CONFIDENTIALITY OR ANONYMITY:** Your responses will remain anonymous and data will be reported in group form only.

**DURATION:** It will take 30 to 45 minutes to complete the survey and interview.

**RISKS:** There are no foreseeable risks to the participants.

**BENEFITS:** There will not be any direct benefits to the participants.

**CONTACT:** If you have any questions about this study, please feel free to contact Angelica Del Villar at (559) 739-9170 (delva301@coyote.csusb.edu) or Dr. Carolyn McAllister at 909-537-5559.

**RESULTS:** Results of the study will be available at the Scholar Works (<http://scholarworks.lib.csusb.edu>) at the Pfau Library, California State University, San Bernardino after July 2018.

This is to certify that I read the above and I am 18 years or older.

Place an X mark here \_\_\_\_\_

Date \_\_\_\_\_

I agree to be tape recorded: Yes \_\_\_\_\_

No \_\_\_\_\_



APPENDIX C  
DEBRIEFING STATEMENT

## DEBRIEFING STATEMENT

### Study of Affects Autism Spectrum Disorders Has on Mother

This study was intended to explore the impact that a mother with a child with ASD has changed their lives. It also gives a glimpse into how mothers experience their relationships with their children diagnosed with an ASD. The study was to also help understand how mothers experience their relationships with their children diagnosed with an autism spectrum disorder (ASD). More research in this area is suggested to gain more of an understanding of the struggles and needs of this population. This would be useful for both the families of children with ASDs as well as the professionals who may be working with them.

Thank you for taking the time to participate in this study. If you have any concerns or questions regarding the study, please, contact Angelica Marie Del Villar ([delva301@coyote.csusb.edu](mailto:delva301@coyote.csusb.edu)), or Dr. Carolyn McAllister ([cmcallis@csusb.edu](mailto:cmcallis@csusb.edu)), School of Social Work, California State University, San Bernardino. Results of the study will be available at the Scholar Works (<http://scholarworks.lib.csusb.edu>) at the Pfau Library, California State University, San Bernardino after July 2018.

APPENDIX D  
DEMOGRAPHIC

## DEMOGRAPHIC INFORMATION FORM

Please do not write your name on this form. It will be stored separately from any other information that you complete during this study and will not be linked with your responses in any way. The information will allow us to provide an accurate description of the sample.

Instructions: Please provide a response for each of the following questions:

1. What is your age? \_\_\_\_\_

2. Highest Education Completed

GED	High School Diploma	Associate Degree
Bachelors	Masters	Vocational Training

3. What is your marital status?

Single	Married	Separated
Divorced	Widowed	In a Relationship

4. What is your annual income (or combined annual income if you have a spouse)?

Less than \$16,000	\$16,001 to \$20,000	\$20,001 to \$25,000
\$25,001 to \$30,000	\$30,001 to \$40,000	Greater than

5. With which racial or ethnic category do you identify?

African American	Asian/Pacific Islander	
Caucasian	Latino	Other: _____

6. How many children do you have? \_\_\_\_\_

How many of your children are diagnosed with ASD? \_\_\_\_\_

7. What is your current employment status?

Part-Time (30 hours or less)	Full Time (40 hours or more)
Unemployed	Other _____

APPENDIX E  
INTERVIEW QUESTIONS

## QUESTIONNAIRE INTERVIEW

1. How old is your child and at what age was he/she diagnosed with ASD?
2. Describe that moment(s) when you starting thinking to yourself, my child is not developing typically?
3. What was your first thought after hearing your child's diagnosis?
4. Are you familiar with the stages of grief and do you or are you still going through the stages of grief?
5. What did you know about ASD prior to your child's diagnosis?
6. What are the pros and cons in having your child assessed and diagnosed?
7. What was your experience like with the clinician/doctor when you were given the results of the assessment?
8. Describe to me the ride back home, after hearing your child has ASD.
9. Did your parenting style change after you learned your child had ASD? If so, how?
10. How are your other children or family members feeling about having a sibling/relative with ASD?
11. How has ASD affected your family financially?
12. Do you or your spouse work? How often?
13. How has your child's ASD affected your relationship with your spouse?
14. In what ways has ASD affected you personally?
15. Do you feel mothers who care for children with ASD lead more stressful lives then those who do not? Why or why not?
16. Parenting a child with ASD can be challenging and stressful, how do you cope or manage that stress?
17. What kinds of resources are needed to help mothers parent children with ASD?
18. What resources do you utilize to help care for your child?
19. What is your opinion on ASD support groups?
20. What would be the ideal way for you to cope with the stress you experienced because of your child's ASD?
21. If you can go back in time and re-experience the day you had your child assessed for ASD, what could the clinician/doctor/staff done to make experience a more positive one?
22. What has ASD taught you as a parent?
23. How do you plan on preparing your child for adulthood?
24. What is one thing you wished everyone knew about ASD?
25. Having gone through the experience of your child's diagnosis, what advice or words of encouragement would you give to another mother who is hearing the news for the first time.

Note: Some questions are adapted from Olson, 2010.

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