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### Factors Influencing Father Involvement With Children Diagnosed With Autism Spectrum Disorder

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**FACTORS INFLUENCING FATHER INVOLVEMENT WITH CHILDREN  
DIAGNOSED WITH AUTISM SPECTRUM DISORDER**

A dissertation submitted

by

Kayleigh E. Hay, MS

To

ANTIOCH UNIVERSITY SANTA BARBARA

in partial fulfillment of  
the requirements for the  
degree of

DOCTOR OF PSYCHOLOGY  
in  
CLINICAL PSYCHOLOGY

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FACTORS INFLUENCING  
FATHER INVOLVEMENT WITH CHILDREN  
DIAGNOSED WITH AUTISM SPECTRUM DISORDER

This dissertation, by Kayleigh E. Hay, MS, has been approved by the committee members signed below who recommend that it be accepted by the faculty of Antioch University Santa Barbara in partial fulfillment of requirements for the degree of

DOCTOR OF PSYCHOLOGY

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## Abstract

Children in America are being diagnosed with Autism Spectrum Disorder (ASD) at rates that are much greater than in previous decades. There is an abundance of research that is being conducted to try and discover the cause of this neurodevelopmental disorder and the interventions that are useful in treating it. It is classified as a *spectrum* disorder because there is such a large range of severity levels. Similarly, there is a large range of involvement levels by fathers of children with autism. Much research has been done on maternal experiences, leaving a lack of knowledge regarding fathers and how and why they may or may not be involved in the life of their child with autism. This qualitative, phenomenological study sought to understand the lived experience of a father with a child who has autism and how coping skills, parenting styles, and cultural backgrounds may impact how much time a father chooses to be involved with that child. The data was collected through an interview process, The Brief COPE Inventory, and The Parental Authority Questionnaire-Revised. As a result of the analysis of this data, themes emerged; active coping styles and authoritative/flexible parenting styles seemed to allow for a father to be more actively involved in their child's daily life. In addition, cultural backgrounds may or may not effect involvement levels, but they do likely impact how a father perceives Autism Spectrum Disorder and the symptoms that accompany it. The results of this study contribute the current research in the field of autism and how fathers can be assisted in being involved more in the lives and intervention processes of their children with autism. *The electronic version of the dissertation is accessible at the Ohiolink ETD center <http://www.ohiolink.edu/etd>.*

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## Factors Influencing Father Involvement with Children Diagnosed with Autism Spectrum Disorder

### Chapter I: Introduction

When people find out they are expecting a child, it is typical for a flood of happy thoughts to run through their minds. What will the child look like? In what things will she excel? What interests will he have? All of these and many others are questions that expectant parents often ask with anticipation. However, there is one very specific question that parents do not tend to explore: “Will my child have a developmental disability?” Many consider this a question taboo, something improper or unacceptable to entertain prior to a child’s birth. This aversion is an indicator of how people truly feel about disorders that may make their child anything less than the society’s definition of *perfect* or *typical*. Although the possibility of developmental disability may not be a question that is explored regularly, it is very relevant.

One of the most common developmental disabilities of the current time is autism. According to the Center for Disease Control (CDC), about one in every 68 children are diagnosed with Autism Spectrum Disorder in the United States (Public Health Genomics, n.d.). As it is described within the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-5; American Psychiatric Association, 2013), autism falls under the formal diagnosis of Autism Spectrum Disorder (ASD), which requires that the individual meet the following criteria: a) persistent deficits in social communication and social interaction across multiple contexts; b) restrictive, repetitive patterns of behavior, interests, or activities; c) symptoms must be present in the early developmental period; and d) symptoms must cause clinically significant impairment in social, occupational or other

important areas of current functioning (DSM-5; American Psychiatric Association, 2013). Autism is categorized as a spectrum disorder because the severity of functioning varies among children who receive the formal diagnosis. For example, some children are able to speak while others are not. Autism affects many important areas of a child's development, but the symptoms are manifested in a wide variety of ways, ranging from mild behaviors to much more severe symptoms (Fischer et al., 1999). However, children with Autism Spectrum Disorder (ASD) demonstrate many of the same core deficits, including impairments in processing both social and emotional information, language problems, and ritualistic, restricted, repetitive, or stereotyped patterns of behavior (DSM-5; American Psychiatric Association, 2013). Some children are considered to be higher functioning on the autism scale (such as exhibiting typical language development and an increased social awareness), whereas others are considered to be very low functioning (showing severe deficits in language and high rates of stereotyped behavior).

It is currently estimated that one in every 68 children in the United States are diagnosed with autism (Baio, 2014). The current prevalence rate for this disorder is estimated at about 14% (Baio, 2014), with boys about 4.5 times more likely to be diagnosed with ASD than girls (Baio, 2014). There has been a rise in the diagnosis of autism over the past few years but without a solid explanation for the increase. This seemingly sudden rise in diagnoses should make autism an instantaneously relevant issue for all people—even without children with autism of their own, most people are likely to know a family member or a friend who has a child with autism, or to encounter someone who has been diagnosed with autism. Autism not only affects the child who received the diagnosis, but it also has significant ramifications for the child's family. The prevalence

rate of autism spectrum disorder is currently at its highest since it was recognized as a developmental disorder. More and more children are being diagnosed along the autism spectrum, leaving multiple questions unanswered for many people.

Autism is a disorder that is gaining increased levels of research interest within the study of developmental disorders. The first to provide a clinical description of the disorder, Leo Kanner published a paper in 1943 entitled “Autistic Disturbance of Affective Contact,” in which he discussed 11 socially isolated children who all possessed high levels of intelligence, the need to be alone, and an obsession for things that are the same (Baker, 2013). Since then, how the symptoms and characteristics of autism are defined has continued to change and evolve. During the 1950s and 1960s, autism was known as a form of schizophrenia, and was then considered a biological disorder of brain development in the 1970s (Baker, 2013). Finally, in 1980, infantile autism was first introduced into the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-III) (Waller et al., 1999).

The fact that the defining aspects of this disorder are constantly evolving is one of the reasons that it is considered to be a *spectrum disorder*. Clinicians using the DSM-III found that the diagnostic criteria for autism were too restrictive and failed to address developmental changes, which led to the under diagnosis of autism (Denckla, 1987). However, as of late, there has been a substantial surge in the number of children diagnosed with Autism Spectrum Disorder. One of the more likely contributors to the increase in diagnoses is the lack of knowledge that people have had about the characteristics and diagnostic traits of the disorder. Each of these contributors is likely to add to the frustration that parents experience when seeking a diagnosis for their child.

When exploring the hardships that parents face in raising children with a developmental disability, much of the research has been conducted on mothers or couples. Very few researchers have focused on the experience of fathers of developmentally disabled children and their interactions with their children. With the scarcity of research studies that include fathers as the sole sample populations, fathers are underrepresented within the research regarding Autism Spectrum Disorder (ASD). There are many effects that a father's involvement with a child with a disability has on a family unit as a whole. At the news of a diagnosis of Autism Spectrum Disorder for their child, parents' lives are instantly changed. Not only are they faced with the possibility that their child's life may be vastly different from their previous expectation, they also now need to cope with the changes that are bound to take place in their parenting strategies and marital relationships. Mothers and fathers both experience stress when parenting a child with autism, although the type of stress experienced may be different. Irrespective of the type of stress, caring for a child with autism often puts a strain on a marital relationship.

Research has studied marital relationships of couples with children diagnosed along the autism spectrum and how these relationships are affected by the diagnosis. According to Freedman et al. (2011), who analyzed the divorce rate among parents of children with autism, marital relationships are negatively affected as a result of raising a child with ASD. Parents of children with autism experience much more intense feelings of stress compared to parents of typically developing children. When a father is not involved in the life of a child with autism, the mother experiences significantly more stress than in the case of an involved father. This added stress puts a direct strain on a marital relationship.

Factors influencing how much time a father chooses to spend being involved in the life of his child with autism include his coping skills, parenting style, and cultural background. Different cultures view behaviors differently (Freeth et al., 2013). Most of the research on ASD has been conducted in Western countries, but it is important to examine which behaviors are considered “typical” across various cultures (Freeth et al., 2013). Differences in cultural background can affect how readily a father accepts the diagnosis of a developmental disorder for his child.

As aforementioned, most research on the effect of ASD diagnosis on family dynamics has focused on mothers or couples rather than on fathers. Consequently, there is little knowledge about what leads to the wide variation in the time that fathers spend with their children with autism. As such, there is a need for more research studies that examine fathers’ relationships with their children with autism and explore the factors that contribute to variations in those relationships and levels of involvement. In addition, it is important to determine the effect of father involvement on the early intervention process for these children.

Since autism is a disorder that is becoming more prevalent in our society, it is important to research each of the factors influencing the outcome of children with ASD, and pinpoint the ones most beneficial to the developmental progress of children with autism. This research aims to answer a very important question: “What factors contribute to the amount of involvement fathers have with their children who have been diagnosed with Autism Spectrum Disorder?” Through a phenomenological research process, fathers will be interviewed to share their experiences as fathers to a child with autism. The

interview questions will explore each father's coping skills, parenting styles, cultural backgrounds, and the amount of time they spend being involved with their child.

## **Chapter II: Literature Review**

Little is known about the factors that contribute to the amount of time that a father spends with his child with autism. A diagnosis that is becoming more prevalent in our society, autism is a disorder that brings many ramifications for both the child and the parents. However, not all families manage the disorder well. There are families with a father highly involved in the life of his child with autism, and there are families with an absent father, leaving the mother as the primary caregiver for the child. In order to reduce the stress levels of both the mother and the father, as well as to improve the developmental progress of the child, it is important to identify the factors that may contribute to a father's increased involvement, such as coping skills, parenting style, and cultural background.

### **Coping Skills**

Parents must deal with their child's diagnosis of a developmental disorder experience a great deal of stress, sense of uncertainty, and practical, day-to-day challenges, all of which they need to learn to cope with effectively. The stress from raising a child with Autism Spectrum Disorder stems from its variety of symptoms, some of which can be severe and debilitating for the child (Phetrasuwan & Miles, 2009). Children who have been diagnosed with a developmental disability tend to have more problematic behaviors and need greater resources for social and academic development (Rubin et al., 1995), which contribute to higher stress levels amongst parents. The stress can be compounded by parents' worries and anxieties about a child's development and wellbeing. Bebko et al. (1987) found that parents and clinicians agree that the most stressful autism-related factors for mothers and fathers of school-aged children are the

children's communication impairment, uneven cognitive abilities, and problems in social relationships. Parents self-report that their children's behavior problems are the major cause of their stress (Bebko et al., 1987).

Problems associated with raising a child with autism are typically more stressful for mothers because they are often the child's primary caregivers (Eisenhower et al., 2005). This is an important point to consider when exploring the role of father involvement in improving the family dynamics of a child with ASD. If a father were to contribute more by way of spending more time interacting with their child with autism, then a mother's stress level may decrease. Interventions to help mothers reduce their stress levels are very important (Phetrasuwan & Miles, 2009). A study done by Phetrasuwan and Miles (2009) found that the main sources of stress for mothers were managing the child's behaviors in public, dealing with the child's mood changes, feelings of being upset, knowing how to appropriately discipline the child, and giving themselves permission to take time out for their own activities and needs (Phetrasuwan & Miles, 2009). Although this was a very thorough study, it lacked any information regarding the fathers of these children and how they could contribute to lessening the mothers' stress. This gap in literature supports the need for further research into the interactions that fathers have with their children with autism and the advantages these interactions can have on all individuals involved. If fathers were more involved, then mothers could feel less pressured to make major parenting decisions on their own and may feel more free to take time out for their own self-care, which could help lower mothers' stress level.

Certainly, mothers are not the only parents who experience stress while raising a child with a developmental disability. Fathers of children with disabilities also experience

a higher level of stress in comparison to fathers with normally developing children (Darling et al., 2012). This is a possible reason that fathers may decide to not be involved in the lives of their children who have been diagnosed with ASD. Literature review reveals that little research has been published regarding fathers' experiences, as the bulk of the research has focused on mothers (Butcher et al., 2008). The studies that did include fathers mostly looked at aspects other than factors that predict the amount of their involvement with their child with autism or their coping skills. A study conducted by Darling, Senatore, and Strachan (2012) examined fathers of children who have been diagnosed with a developmental disability and their levels of life satisfaction. The results revealed that the reason fathers express lower levels of life satisfaction is greatly contributed to the lack of involvement with their child with autism. Other contributing factors to lower life satisfaction among fathers of disabled children include coping skills, problems with parenting, and health reactions (Darling et al., 2012). These are all variables that can be changed or taught to help fathers increase their level of involvement, which will improve both their personal life satisfaction and their children's development.

Konstantareas (1991) discussed a specific model used to examine the ways in which parents are affected by having a child who is developmentally or cognitively delayed. This important study allowed for the understanding of a topic that is clinically significant relating to predictors of stress in mothers and fathers who have different parenting experiences and obstacles. Konstantareas (1991) confirmed that "Understanding the effect of a handicapped child on parents has been influential in our own clinical work and research primarily with severely disturbed, minimally verbal, or even mute autistic children" (p. 359). He also discussed the effect of different parenting

strategies on the progress of a child with autism. One of the determining factors for concept maintenance and generalization of the delayed child is “parent involvement” (Konstantareas, 1991). It is important to consider “parent involvement” with a focus on the father because of the scarcity of studies in existing literature that target fathers as the central sample population.

Since it has been shown that parents of children with Autism Spectrum Disorder typically report higher levels of parenting stress (Dumas, et al., 1991), understanding and managing parents’ stress has been one of the most frequently researched topics regarding families of children with autism (Davis & Carter, 2008). Davis and Carter (2008) provided a large amount of evidence supporting their claim that elevated stress levels are found among mothers of older children on the Autism Spectrum. Different from most studies in this body of research, which mainly focused on the mothers as the primary caregiver and rarely recognized the fathers as being of enough importance to include in the research, Davis and Carter (2008) included both mothers and fathers, and examined the relationship between various child characteristics and parents’ stress levels. In addition, the study compared mothers’ stress with the fathers’ experience of stress, and found that mothers and fathers experienced different types of stress (Davis & Carter, 2008). Fathers were mostly stressed by their child’s externalized behaviors, whereas mothers’ sources of stress were due to regulatory problems (Davis & Carter, 2008). Fathers did not report their stress as being related to the child’s problem behaviors, their own mental health, or the mother’s mental health (Davis & Carter, 2008). This is the opposite of mothers’ experience with stress. Davis and Carter (2008) pointed out, importantly, that while both fathers and mothers of children with autism have higher

levels of stress than parents of typically developing children, they do not report the same level of stress. A possible reason for this difference could be that fathers have a minimal amount of involvement with their children in comparison to the mothers. Also, Davis and Carter (2008) reported that fathers of children with ASD reported lower levels of depression than mothers, which is a further reason for examining emotions and coping skills as possible predictors of father involvement.

Another reason of the importance of this study is that parents of developmentally delayed children are less likely to focus on their own emotions, which could be detrimental to their own physical health and the physical health of their children (Baker & Crnic, 2009). Baker and Crnic (2009) sought to determine the degree to which parents, specifically those who have early developmental delays, tend to prioritize emotions in relations to the child's development. The results of the study revealed "parents of children with developmental delays reported lower prioritization of emotions during discourse than did parents of typically developing children" (Baker & Crnic, 2009, p. 450).

A critical component to focus on regarding parents' emotion involves recognizing feelings of stress and learning to appropriately manage them. The positive result of Baker and Crnic's (2009) study is the finding that, although parents of developmentally delayed children may not pay attention to their own emotion, they do have a reported awareness of their child's deficits in adaptive functioning and emotions (Baker & Crnic, 2009). The implication is that parents are aware of what is most beneficial to the development of their delayed child, and, as such, they will be compelled to appropriately cope with their own emotions to prevent them from impeding their

child's development. As reported in recent research, stress is an emotion or feeling that parents will likely start to feel at one time or another and how they cope with these feelings is going to greatly affect how they parent their child with autism.

As mentioned above, coping skills is a factor that potentially affects parental involvement. *Coping* is best described as “the ways in which an individual responds to a stressful situation” (Taylor, 1983). Stress and coping theory predicts that people individually appraise their own stress and then begin to cope (Johnson & Simpson, 2013). An active coping style, where the individual takes a proactive role in handling the stress they are experiencing, is considered the most effective intervention for families of children with autism (Taylor, 1983). However, denial and avoidant coping skills are other styles of coping that people tend to adopt (Lee, 2009). These styles often find the individual allowing others to help them to alleviate their stress or denying that they are experiencing any stress. The strength of an individual's coping skills significantly influences how they perceive and manage stress. Pottie and Ingram (2008) discussed the daily stress, coping, and well-being of parents who have children that have been diagnosed with Autism Spectrum Disorder, with an objective to investigate how parents adapt to the daily stress of raising a child with ASD. The study also discussed the use of the transactional model of stress (Lazarus & Folkman, 1984) and its incorporation into this area of study. This model requires that a parent assesses an event and utilizes certain cognitive and behavioral responses to process appropriately (coping) (Lazarus & Folkman, 1984). Using this model, coping is determined by the existence of a match between a stressor and the coping responses (Lazarus & Folkman, 1989).

Parents of children with ASD are automatically presented with additional and different stressors from parents of typically developing children. This amount of added stress requires an appropriate level of coping skills in order to manage day-to-day life. The relationship between parents' coping skills and their psychological well-being is complex and extensive (Pottie & Ingram, 2008). When parents made conscious efforts to express and control their emotions in the face of a stressor while parenting their child with autism, they expressed less daily negative moods (Pottie & Ingram, 2008). As such, identifying ways of coping with stress will improve parents' well-being and reduce the psychological distress for both parents and their families (Friedman, Holmbeck, Jandasek, Zukerman, & Adad, 2004).

Kyunghye Lee (2003) examined the ways in which maternal coping skills help moderate stressful life events and in turn affect a child's behavioral intervention program. Early intervention programs are crucial for the development of children with autism (Paynter & Keen, 2015). A large amount of research supports early intervention programs, which include family-focused components as the most crucial component for increased developmental functioning for children with autism (Lee, 2003). Since many early intervention programs have highlighted the importance of coping skills, programs and workshops have been developed to enhance active, adaptive coping skills (Lee, 2003). Mothers who used more adaptive coping skills reported significantly less depression, which led to lower levels of stress and improved their child's behavioral outcomes (Lee, 2003).

Also attempting to understand the benefits of maternal coping skills, Erguner-Tekinalp and Akkok (2004) examined a coping skills training program and how it affects

the stress levels of mothers of children with autism. The results they found indicated that the training did not have any effect on reducing the stress levels of the mothers in the training group (Erguner-Tekinalp & Akkok, 2004). The poor results of this training program has a culturally-based component as it was administered in Turkey, where the government pays for the costs of special education for children with disabilities (Erguner-Tekinalp & Akkok, 2004). This difference in cultural setting is significant because maternal stress often comes from financial burdens, which is commonly seen in western cultures (Erguner-Tekinalp & Akkok, 2004). Besides the factor of governmental financial assistance, the authors believed the training was ineffective but did not investigate the reasons for the apparent lack of effectiveness, which is a limitation to this study. Another limitation is that fathers were not included in this training program. This training program may have affected fathers differently because fathers may not find financial burdens as a stressor, which affects many mothers, and may benefit from coping skills training.

Further on the issue of coping, Gloria K. Lee (2009) investigated coping differences between mothers and fathers. It is known that mothers and fathers use different coping styles when handling parental stress (Hastings, et al., 2005). Mothers adopted more adaptive coping mechanisms than fathers (Lee, 2009), and preferred to use problem-focused coping skills and tended to lean on professional and personal support systems more than fathers (Lee, 2009). The results of this study are consistent with other findings. Lee (2009) also found that mothers reported higher levels of stress because they were the primary caregiver to the child with autism. This begs the question, “Could a father’s increased level of involvement contribute to lessening a mother’s stress level?”

When a research study includes both mothers and fathers, it provides much more informative results because mothers and fathers respond to their children in different ways and handle stress using different methods. Fathers of children diagnosed on the autism spectrum are a key demographic that should be accorded a great deal of importance for research in the treatment of autism. Fathers' stress and life satisfaction levels are now a key area of research because of the continuing evolution of families (Darling et al., 2012).

### **Parenting Styles**

Parenting a child with autism is a difficult task because of the host of symptoms the child may have. In addition to typical diagnostic criteria for autism, children with autism may also have emotional symptoms, social problems, and disruptive and maladaptive behaviors (Gau et al., 2010). With greater needs, however, children with autism sometimes receive less parental involvement than typically developing children (Konstantareas & Homatidis, 1992). The lack of interaction between the parents and the child may be due to the child's symptoms or the parents' parenting styles. For instance, a child with autism may have deficits in verbal and rely on gestural communication, which leads to a parent feeling not as connected to their child (Konstantareas & Homatidis, 1992). Likewise, a parent may not understand that the symptoms are common in children with autism and may interpret them as the child choosing not to connect to them, which results in the parent feeling less connected and becoming less involved in the child's life.

Studies have revealed fathers to be less involved in the care of their child than mothers (Gau, 2010). Although there are many possible reasons for this discrepancy, there are no definite predictors. Among these reasons is that fathers may adopt a different

parenting style, such as one that appears to be less involved. Diana Baumrind (1966, 1971, 1973) contributed to the majority of work on measuring different types of parenting styles (Dominguez & Carton, 1997). Baumrind conducted extensive research with parents and children and created a model for parenting that is widely used and empirically validated (Baumrind, 1973). Baumrind (1966) identified three different parenting styles: authoritarian, permissive, and authoritative. Parents who adopt an authoritarian parenting style are very directive and value obedience (Baumrind, 1966). On the other hand, authoritative parents view parenting as a collaborative process—while they listen to their child's input, they enforce rules and boundaries that help to guide the child (Baumrind, 1966). Parents who adopt more of a permissive parenting style make few demands on a child and use very little punishment (Baumrind, 1966). Various parenting styles result in different ways that a child will be spoken to, interacted with, and disciplined. Research has shown that the authoritative parenting style is correlated with successful outcomes within various areas of a child's development (Dominguez & Carton, 1997). However, since these styles have only been researched in the context of children with typical development, little information is available about the most effective parenting style for children with autism (Gau, 2010).

In the first study to investigate behavior problems and parenting styles among children with autism, Gau and his colleagues (2010) found that less affectionate interactions with children with autism were more prominent among fathers. Although this study was conducted using a sample of individuals living in Taiwan, the findings of the study were shown to be consistent with Western studies in that mothers of children with autism are found to be more affectionate and to spend more time with their child than

their parenting counterpart (Warfield, 2001). This study provides evidence that fathers are less involved with their child with autism but does not offer clear predictors for why this is the case.

Given the importance of parenting style in child development, it is appropriate to examine how and why a parent decides to choose a specific parenting style. Also important is to explore how parent react and adapt when their chosen parenting style is unsuccessful. Abraham Maslow (1970) proposed that people are motivated by a variety of needs in order to satisfy an ultimate need for self-actualization. Self-actualization is the highest point on a hierarchy of needs and results in individuals feeling that they have reached their full potential (Maslow, 1970). Since parenting is a major component of a parent's life, determining whether the success of a parenting style affects one's self-actualization may help to understand whether the success of a parenting style—or the lack thereof—will increase a father's motivation to spend time with his child with autism.

It is well established that parenting a child with a developmental disability is associated with increased levels of stress (Woolfson & Grant, 2006). However, the relationship between parenting behavior or style and parenting stress has been under-researched (Hastings & Beck, 2004). Is there one parenting style that a child with autism responds to more favorably, thereby decreasing parental stress? Much of the stress that a parent of a child with autism experiences is due in large part to the fact the child is likely to be dependent for longer, which places a demand on the parent across a lifespan and leaves them with the need to provide more support than they would to a child with typical development (O'Connor, 2002). Woolfson and Grant (2006) examined the role of authoritative parenting in parents of children with developmental disabilities and found

that parents of children with developmental disabilities used more authoritative parenting styles than those of typically developing children (Woolfson & Grant, 2006). However, some parents find it stressful to implement a constant form of authoritative parenting, which requires high level of repetition for children with ASD. The limited successes achieved through their parenting attempts, or other demands on time and parenting that the parent may be experiencing at the time, could be discouraging and cause parents to be inconsistent in their parenting style (Woolfson & Grant, 2006). It is worth noting that coping skills are important with relation to parenting styles. For instance, a parent may adopt a less demanding parenting style, such as the permissive style, as an immature adaptive coping response (Woolfson & Grant, 2006). Additionally, when a father adopts a more authoritarian style of parenting with his child with autism, he may become frustrated because the child does not have the ability to adhere to the rules without extensive behavioral training. As such, knowing which parenting style is more effective with a child with autism may reduce the father's frustration and lead to his greater involvement in the child's life.

Since a significant difference exists between the amount of time that mothers and fathers spend with their child with autism, it is important to look at the factors that contribute to this difference. The reason mothers report higher levels of distress during parenting is that they often spend the largest amount of time taking care of the child with autism (Jones et al., 2013). Although family research in the field of autism spectrum disorders has traditionally focused on maternal outcomes alone (Jones, et al., 2013), there is a need to research paternal outcomes to better promote the progress and development of the child. In one of the few studies that compared mothers and fathers, mothers

reported more positivity toward their children (Hastings, et al., 2005), which could be attributed to coping skills and lack of knowledge of behavioral differences linked to autism. Although little is known about what contributes to differences in mothers' and fathers' involvement, Pottie and Ingram (2008) did rule out the severity of autism symptoms as a predictor of daily positive or negative mood in mothers or fathers.

In a study by Jones and her colleagues (2013), it was found that, in accordance with previous research, mothers of children diagnosed with Autism Spectrum Disorder reported more psychological distress from depression, stress, and anxiety. Mothers also reported levels of positive gain in their daily functioning compared to fathers (Jones et al., 2013), which may be a result of more intensive involvement in the daily lives of their children and more influence from by the child's behavior (Jones et al., 2013). (This specific sample reported that 97% of the members identified the mother as the primary caregiver.) Future research is needed to explore the effect of the distribution of responsibilities between mothers and fathers on their respective level of happiness, which could improve the time involved with the child (Jones et al., 2013).

## **Culture**

Culture is often defined as a "group of people's way of life, consisting of predictable patterns of values, beliefs, attitudes, and behaviors" (Mandell & Novak, 2005, pp. 110). When examining factors that make people different from one another, culture cannot be ignored. Each person has a cultural background that can be significantly different from the next person. Among other things, a cultural background can influence the way a person conceptualizes a medical diagnosis. This is also true for the way that parents understand the diagnosis of a developmental disorder given to their child.

There has been a growing consensus to require a more global method to identify Autism Spectrum Disorder (Norbury & Sparks, 2013). An ASD diagnosis is largely based on whether a behavior exhibited by a child deviates from what is considered to be “typical” (Freeth et al., 2013). However, the problem for clinicians is that the definition of “typical” differs across cultures. Cross-cultural comparative studies on ASD are sparse (Zaroff & Uhm, 2012) but are necessary in order to understand how a disorder such as autism is defined and perceived in various cultures. Because the goal of this research is to identify factors that contribute to the amount of time a father spends with his child with autism, it is important to examine the father’s cultural background. The way a father perceives a diagnosis of autism can affect his amount of interest in being involved in the child’s treatment.

Chamak and Bonniau (2013) examined French parents’ experiences with the diagnosis of autism and attempted to compare the situation in France to other countries around the world. The result of the study indicated that French parents preferred biological explanations for their child’s diagnosis because it made them feel decreased levels of guilt (Chamak & Bonniau, 2013). If the cause were to be biological as opposed to social or behavioral, then the parents would think they were the cause of the child’s problems. If a father was from a culture that did not emphasize a biological cause for autism, then he may be more likely to feel guilty and not want to be involved in the treatment of his child.

Further, if a father does not understand the symptoms of autism, he may misperceive his child’s behavior. The common symptoms of autism may lead him to feel that he is not able to connect to his child or control the child’s behavior. For example,

lack of eye contact and the inability to use universal gestures such as pointing are distinctive features of ASD in western countries (Freeth et al., 2013). However, this is not the case in other cultures. In Chinese and other European cultures, using direct eye contact and pointing is considered impolite (Freeth et al., 2013). Therefore, these symptoms of autism would not be significant diagnostic indicators of ASD in these specific cultures. Culture and parental belief systems in general can predict how parents identify, understand, and manage differences in development (Kang-Yi et al., 2013).

Burkett and colleagues (2015) researched the influence that culture has on African-American families' perceptions of diagnoses of autism and the treatment that follows. They found that there is a significant delay in the diagnosis and treatment of Autism Spectrum Disorder within African American families (Burkett et al., 2015). This is a significant health care disparity that is likely due to cultural differences in African-Americans' perception of health care (Clark, 2014). It is not uncommon for African-American individuals to refrain from seeking medical treatment and to go to the doctor sparingly. This is a potential issue for the treatment of children diagnosed with autism, as early intervention can result in drastically better outcomes. The cultural factors affecting African-Americans with respect to early diagnoses of autism and timely interventions include biases toward health care professionals, health care accessibility, symptom presentation, and family interpretations of the child's symptoms (Kalb et al., 2012). As with other cultures previously mentioned, the African-American culture can influence how autism is perceived and managed.

There are other contextual factors of culture, such as economic status, that may affect family perceptions of what is a problem and the stigma that is attached to a

possible problem (Norbury & Sparks, 2013). Families who live in poverty have the priorities of maintaining a residence and providing supplies to the family, and may be reluctant to seek professional services for a child who is diagnosed with autism (Norbury & Sparks, 2013). A father in a family such as this may spend less time with their child than a father who does not have the pressure of worrying about securing the welfare of his family. Understanding a father's cultural background is crucial in understanding the amount of time he chooses to be involved with his child with autism.

### **Father Involvement**

Flippin and Crais (2011) highlighted the need for more father involvement in early autism intervention. It has been well researched that communication development in children is a process guided by adults who assume a very active role in this development (Konstantareas et al., 1988). Given the increasing body of evidence of the benefit of co-parenting, and growing direct father involvement in general, one would assume that fathers would be more involved in the lives of their children who have been diagnosed with autism (Flippin & Crais, 2011). Unfortunately, this is not the case, and mothers continue to be the primary participant in both autism research and the implementation of early intervention techniques with their children (Crais et al., 2006). More literature has become available that indicates that mothers and fathers each play an important role in specific areas of their child's development, particularly in the area of communication (Flippin & Crais, 2011).

Flippin and Crais (2011) focused their research efforts on language development and how fathers contribute to a different type of language development from mothers. Language development research is important for children with autism, who may have

significant delays in their speech (American Psychiatric Association, 2013). As a spectrum disorder, autism can manifest in children in the form of varying degrees of speech delays, no acquisition of any language skills to very minimal speech delays. One of the first studies conducted to research speech found that fathers were able to adjust the child's speech development as well as mothers were, although fathers were not in contact with their child as much as the mothers (Golinkoff & Ames, 1979). The quantity of the interactions may not directly affect the quality of the speech that the fathers use with their children (Golinkoff & Amers, 1979). Fathers have interaction and communication styles that are unique from those of mothers (Flippin & Crais, 2011). Compared to mothers, fathers use vocabulary that is more varied, more rare, and more abstract (Flippin & Crais, 2011). Early research by Gleason (1975) hypothesized that fathers' language styles provided the child with a bridge to transition from the supportive language that is used in the home to the more complex language demands of the outside world. This hypothesis, known as the "bridge hypothesis," was later supported by Tomasello and his colleagues' (1990) work. Since children who have been diagnosed with autism may already have communication and language deficits, being exposed to fathers' language could be highly beneficial. This proves a need for the increased involvement of fathers with their child who has been given an autism diagnosis.

Another area of development that researchers are interested in is play skills. One of the initial features of autism identified by Leo Kanner (1943) is a deficit in reciprocal social interaction, with additional behavioral deficits including lack of imitation skills, lack of imaginative skills, and lack of peer play (El-Ghoroury & Romanczyk, 1999). In a study performed by El-Ghoroury and Romanczyk (1999), the sample population

consisted of fathers, a group that has been largely neglected in previous research of families of children with autism (Rodrique et al., 1992). The results indicated that mothers and fathers both provide directive statements during child play, but children with autism made more vocal-verbal imitations toward fathers than they did toward mothers (El-Ghoroury & Romanczyk, 1999). Vocal-verbal imitations are important signs of developmental progress for children with autism because this is a diagnostic criterion concerning functional adaptation for these children (El-Ghoroury & Romanczyk, 1999). El-Ghoroury and Romanczyk's (1999) study provided a critical piece of information in support of the need for increased father involvement. "Fathers may make important contributions to children's early language skills and should be included in all efforts to improve language development" (Panscofar & Vernon-Feagans, 2006, p. 585). Indeed, although literature is scarce with respect to father involvement in the lives of children with ASD, there is some consensus that father involvement positively affects the communicative progress among children with autism who have significant linguistic delays.

With respect to another area of play skills, children with autism do not follow the same pattern of play stages as children who develop at typical rates. They tend to spend a significantly longer amount of time in the exploratory stage of play (Flippin & Crais, 2011). Father-child play is more active and generative; therefore, a father plays a critical role in the development of a child's play skills (Flippin & Crais, 2011). It is interesting to note that some fathers report feeling frustrated about not knowing the correct way to play with their child (Flippin & Crais, 2011). This could be a reason that some fathers are less involved with their children. However, as the play skills of a child with autism increase,

their language development tends to increase as well (Flippin & Crais, 2011). Therefore, the need is great for a father to be involved in their child's early autism intervention plan, which can stimulate the child's progress and cognitive development in future years.

A study by Flippin and Watson (2011) focused on the object play skills of children with autism. Children diagnosed with ASD experience impairments with development of object play skills (Flippin & Watson, 2011). In typically developing children, object play skills emerge from four phases of consecutive play levels: exploratory play, relational play, functional play, and symbolic play (Flippin & Watson, 2011). Each of these four phases of play includes the incorporation of objects at increasingly more sophisticated levels, starting with a child beginning to investigate a toy using gestures and movements and culminating with a child being able to substitute one object for another and using their imagination to create fantasy/pretend play (Flippin & Watson, 2011). The play of children on the autism spectrum tends to be less elaborate and more repetitive (Williams et al., 1996). For example, a child who is developing at a typical rate may use a toy car to drive around the floor and pretend to arrive at an imaginary place, whereas a child with autism may use that toy car to fixate on the ways in which the wheels continuously spin without stopping. It is important to note that these deficits in object play skills may lead to deficits in other developmental areas, including language and social skill development (Flippin & Watson, 2011).

Flippin and Watson (2011) found a strong positive correlation between a father's verbal responsiveness during playtime and a higher level of object play in a child with ASD. More importantly, this study provided evidence for the fact that both parents, mothers and fathers, play important roles in influencing play development for children

with ASD (Flipping & Watson, 2011). The increase in play skills may lead to additional improvements in the areas of language and social skills. Furthermore, research shows that fathers' responsive behaviors may elicit more symbolic child play (Flippin & Watson, 2011). This further supports the need for an increased level of father involvement during times of play.

Early intervention is critical for providing the best chance for the highest level of developmental improvement for children with autism and paves the way to achieve positive outcomes (Paynter & Keen, 2015). In 2005, early head start programs began to emerge that provided intensive family services for children and families (Raikes et al., 2005). Considering the positive results for language development and social skills of children with autism when their fathers participate in their lives, father involvement in early head start programs is an area that should be examined for predictability of future developmental progress. A study conducted by Raikes, Summers, and Roggman (2005) was the first study to look at predictors of father participation in these types of early start programs. Fathers have been shown to make significant contributions to infants and toddlers' development of emotional regulation (Cassidy et al, 1992; Park et al., 1988; Roggman et al., 2004), social competence (Pettit et al., 1998; Roberts 1998), and cognitive development (Black et al., 1999; Nugent 1991). Nevertheless, the question remains as to why father involvement in early start programs is so variable.

Raikes, Summers, and Roggman (2005) examined prior studies to explore the possible characteristics of the father that could predict the likelihood of his participation in an early start program. There was no relation found between father involvement and level of education, unemployment, or residency (Fagan, 1999). The ultimate finding was

that fathers who are more skilled in gaining education, being employed, and finding residency are more likely to participate in early start programs (Fagan, 1999). This finding may parallel the factors that could predict father involvement with children who have autism. Therefore, factors such as coping skills, parenting styles, and knowledge of developmental disorders across different cultures are important characteristics to examine with fathers who have children with Autism Spectrum Disorder.

### **Chapter III: Method**

This qualitative study explored the factors that contribute to the amount of time a father spends being involved in the daily life of his child with autism. The purpose of this study was to examine the extent to which paternal coping skills, parenting styles, and cultural backgrounds affect the amount of involvement a father has in the life of his child who has been diagnosed with autism. The results of this study contribute to the growing body of research regarding Autism Spectrum Disorder (ASD).

#### **Qualitative Research**

As mentioned before, the study was completed using a qualitative methods approach. “Methodology of choice” is a viewpoint that is emerging in the postmodern, multicultural society within which we are living (Jovanović, 2011). No longer is quantifiable data the only type of data that yields valid results (Cho & Trent, 2006). As opposed to quantitative research, where the purpose is to find effectiveness or causality, qualitative research aims to “explicate the unique, idiosyncratic meanings and perspectives constructed by individuals, groups, or both, who live in a particular context” (Cho & Trent, 2006, p. 328). A highly unique situation that a person may find himself in is being a father of a child who has autism and being forced to live within a very specific context, all the while experiencing very specific situations, which could quite possibly contribute to the lives of others living in similar situations.

Qualitative research utilizes approaches that are both interpretive and naturalistic (Creswell, 2013). After the interviews, the researcher then evaluated the interviews in a neutral way that allows for a non-biased interpretation process to occur. This specific

study included interviews that are semi-structured and naturalistic. Within the qualitative research approach, this study utilized the phenomenological tradition.

### **Phenomenology**

Phenomenology is a qualitative research approach as well as a way of viewing how things appear through specific experiences (Finlay, 2012). This research method was originally developed by Edmund Husserl as a philosophical way of conducting research (Wertz, 2005). The difference between scientifically based research processes and Husserl's phenomenological method is that the latter begins with a description of the subject matter that is unbiased in nature (Wertz, 2005). Through the works of researchers such as Karl Jaspers and Maurice Merleau-Ponty, the phenomenological movement evolved throughout the 20<sup>th</sup> century (Spiegelberg, 1972). Amedeo Giorgi, who was greatly influenced by Husserl and Merleau-Ponty, is credited with leading the phenomenological movement within the field of American psychology (Cloonan, 1995). In 1970, he offered the first phenomenological research course at Duquesne University and later founded the Journal of Phenomenological Psychology, which was the first journal to publish research in qualitative psychology (Wertz, 2005).

The modern use of the method of phenomenology offers researchers a systematic way of studying and learning about specific phenomena that are difficult to understand, observe, and measure (Wilding & Whiteford, 2005). Being able to hear about the effects of a specific phenomenon directly from the individual who is experiencing that situation first hand allows for unique research findings that lead to valuable contribution to a larger community. Phenomenology is especially useful for counseling psychologists who are

exposed to the struggles and successes that their clients experience throughout their naturalistic, daily routines (Wertz, 2005).

Phenomenology is a specific tradition of qualitative research that is best suited for this study because it provides a way of understanding a father's subjective experience of parenting a child with autism that allows us to honor their personal narratives. With the use of an interviewing process, fathers are able to tell their stories, which provides rich narratives to the researcher trying to understand which factors contribute to father involvement for children with autism. Phenomenology focuses on the understanding of lived experiences of an individual as opposed to the actual life of that individual (Creswell, 2013). Following that central feature, each father is asked about his own, specific experience of raising a child with autism. In this chapter, a research design for this study is presented and specific procedures that were used to conduct this study are explained. In addition, a detailed explanation of the sampling procedure is provided.

### **Sampling**

This study was inspired by a behavior interventionist's personal experiences throughout the years of her work with children with autism. These experiences found me enmeshed within these children's families. The observation of many professionals that "each individual with autism is unique" (Autism Speaks, n.d.) can also be applied to each of the families of these individuals. Each family dynamic is different, with some having both parents involved in the primary care of their child with autism while others have only the mother or the father involved.

The families that I, as a behavior interventionist, have come into contact with all have a common denominator—in each case, the mother of the child was fully involved in

the care, intervention, and progress of the child. However, while some fathers are extremely involved in the lives of their child with autism, I have also come across many fathers who are very distant and withdrawn from the entire process associated with raising a child with autism. This study aims to contribute information to the growing population within the autism community.

**Population.** For this study, a group of participants were interviewed to share their experiences of being fathers of children who have been diagnosed with autism. The sample consisted of 10–12 male individuals from Ventura and Los Angeles Counties who took part in a thorough, semi-structured interview process. Each father was between the ages of 21 and 60 years old. If an individual met the prerequisites for participation, he was involved in an in-depth interview process in order that sought to discover his level of coping skills, parenting style of choice, and cultural background, and how each of these factors may influence his views on developmental disabilities, specifically Autism Spectrum Disorder.

**Sampling Method.** The purposive sampling method of criterion-based sampling is best suited for this study. Purposive sampling is used with qualitative research and allows the researcher to select participants and research sites that are best suited to “purposefully inform an understanding of the research problem and central phenomenon in the study” (Creswell, 2013, p. 156). Participants were chosen on the basis that he has something important to add to the existing research regarding father involvement for children with autism. It is imperative that each person who is chosen to participate has a story to share about the experiences that he has lived (Creswell, 2013).

More specific to purposive sampling, this study was criterion-based in the nature of its sampling procedure. Criterion sampling is the most efficient procedure when all of the participants have experienced the same phenomenon (Bloomberg & Volpe, 2012). In order to participate in this study, a participant must be a father of a child who has been formally diagnosed with Autism Spectrum Disorder. With criterion sampling, it is important to remember that the information that is shared is not meant to be generalized, but is meant to be extremely specific and particular in nature (Pinnegar & Daynes, 2007). For this reason, once the participants have been selected, extensive details were collected from each. Every father of a child diagnosed with autism has a story to tell, no matter how elaborate or vague it may be. For this study, their stories will make significant contribution to the growing research field for Autism Spectrum Disorder.

## **Materials**

This study sought to answer the research question surrounding the factors that play a role in the amount of time that a father is involved in the life of his child who has been diagnosed with autism. More specifically, what roles do coping skills, parenting style, and cultural background of a father play in how much they are involved with the daily lives of their children who have been diagnosed with autism? Information to answer this question was gathered through demographic questionnaires, the defining of key terms that are crucial to the understanding of the phenomenon, and additional scales and questionnaires that would contribute to the information connected to the experience of each father.

**Demographic information.** Each participant was given a demographic questionnaire to complete. The questionnaire included information about each

participant's age, educational background, occupation, relationship status, ethnicity, the age of his child who has been diagnosed with autism, and how many years it has been since his child formally received the diagnosis of autism.

**Perceptual information.** During the interview process, each father was asked to share his unique experience about being a father of a child diagnosed with autism. They were asked to explain whether they went through a process of changing their perceptions about the idea of having a child who has been diagnosed with Autism Spectrum Disorder (ASD). They were asked to further explain ways in which they have been affected by having a child with autism, as well as how they chose to parent the child and handle stressful situations, which occurs almost inevitably.

**Additional information.** In order to further validate this study and these experiences, each father also answered The Brief COPE (Carver, 1997) and the Parental Authority Questionnaire-Revised (PAQ-R) (Buri, 1988), which measure coping skills and parenting styles, respectively.

### **Data Collection**

The primary data collection method for this research project was conducted through the use of an experiential interview. Each participant took part in a semi-structured interview process that included both open and closed ended questions. This was a sufficient data collection method because it elicited an in-depth, interactive process between the interviewer and the participant, which promoted personal accounts and perspectives that are rich in context (Bloomberg & Volpe, 2012). Using an interview also allowed for data to be collected in a natural environment and facilitated a discovery of differences between cultures (Bloomberg & Volpe, 2012).

**Use of Instruments.** The interview was used to understand the personal experience of each of the fathers. This was the piece of data most crucial to answering the research question. The demographics survey was used to obtain ethnicity, age, and occupational factors that may influence the amount of time that the father spends with his child with autism. The results of the final two scales, The Brief COPE (Carver, 1997) and The PAQ-R (Buri, 1988), were analyzed in order to see if having a specific level of coping skills or a particular parenting style are important in being able to spend a sufficient amount of time with the child.

**Development of instruments.** The interview instrument will be developed by the researcher and will contain questions that will elicit information-rich answers that can be compiled to create a full, complete experience of the participant. The Brief COPE and The PAQ-R are scales that have already been developed and have proven reliability and validity statistics. The final survey, the demographics questionnaire, will also be created by the researcher and will include information that will contribute specifically to this study.

**Recording and safeguarding of information.** Whereas most interviews were recorded using a note taking process performed by the researcher, some interviews were also recorded using a personal recording device. At the start of the interview process, each participant was given a code, and the identity of each participant remained confidential. The code for each participant was applied to the interview, the demographics questionnaire, The Brief COPE, and The PAR-Q. Once the interview was completed, it was transcribed. If it was recorded, the information was transcribed from the recording device to a document in order to provide an easier way for the researcher to

visually analyze patterns and trends. In addition, any handwritten notes that were taken during the interviews were also compiled into a document and a personal narrative was created from each participant's interview materials. The completed surveys (The Brief COPE, The PAQ-R, and the demographics questionnaire) have been kept in a locked filing cabinet with the researcher being the only person who has access. Identifiers have been stored in a physically separate and secure location from the data files, and were only associated with data files through the use of a code that has also been stored in a separate and secure location. All information obtained for the purpose of this research will be stored for seven years after the completion of this study.

### **Data Analysis**

Each interview conducted for this interview was transcribed or transferred to a separate document and put into a summary format. This allowed the researcher to have a visual analysis of each interview and to take notes on the side of the summaries regarding any additional qualitative commentary that they might add (Hycner, 1985). Following the transfer of each interview into summary format, the researcher analyzed each interview using an open interpretation method and bracketed any significant meaning or interpretation that the researcher found crucial to the individual experience of each participant (Hycner, 1985). This helped the researcher to better understand what the participant meant exactly by each of the components they included in their experience. Next, the researcher reviewed the summaries of each interview as a whole multiple times in order to identify the emergence of any themes (Giorgi, 1975).

Once the interviews have been analyzed multiple times, the researcher turned to the general themes that have emerged from each experience and try to relate them to the

research question (Hycner, 1985). The researcher's next task was to code themes found in the text. A code is a qualitative assignment, usually consisting of a word or a short phrase, which provides a summative or salient attribute to part of the interview (Saldaña, 2009). A software program, HyperRESEARCH, was used to electronically analyze, sort, and retrieve codes and patterns. HyperRESEARCH was first developed in 1990 in order to assist qualitative researchers in analyzing data that they have collected for their research projects (Lewins & Silver, 2014). This software program was useful to the researcher to help to build theories upon the information that was gathered (Creswell, 2013). The information output by this software program, in addition to the themes that emerged from the interview summaries, was used by the researcher to determine if the information given by each participant was useful in answering the research question. Once this was complete, the researcher began to cluster the general themes they have gathered from all of the interviews to determine if there were any emerging themes (Hycner, 1985). The themes that were identified were then included in a summary for each interview. These summaries, and their respective themes, were examined in greater detail to determine if specific themes transcended throughout all of the interviews. These became the themes that the researcher conceptualized and used to answer the research question.

### **Ethical Considerations**

The utmost importance in regards to research is that it is conducted in a way that minimizes potential harm to the individuals who have volunteered to participate in the study (Bloomberg & Volpe, 2012). For this study, the protection of the identity and confidentiality of each participant is of the utmost importance. Each individual was referred to using a code and the participants' names and corresponding code listings have

been stored in a location separate from the data that is collected, both of which have been stored in a locked box. Each participant signed an informed consent sheet upon beginning the interview process. Data will be stored for seven years following the completion of the research study. Only the researcher will have access to the data and the master list.

It is important to recognize that participants were asked to share their experiences of being a father to a child who has been diagnosed with autism, which may be a sensitive topic for some participants. There was a possibility of some emotional discomfort that might result from the interview. In order to help with any emotional feelings that the interview might elicit, each participant was provided with a list of three referrals of psychological professionals whom they may contact at their own discretion.

## **Chapter IV: Results**

The purpose of this phenomenological research study was to obtain an understanding of the lived experiences of 10 individuals, all fathers of children who have been diagnosed with Autism Spectrum Disorder (ASD), and to explore factors that may influence the amount of time they choose to participate in the lives of their child. This study explored lived experiences, personal coping skills, adopted parenting styles, and cultural backgrounds. The research question focused on what the major factors are that influence or determine the level of father involvement within the lives of children who have been diagnosed with Autism Spectrum Disorder.

The qualitative data for this research study was obtained through the presentation of 10 main interview questions. In addition to these open-ended interview questions, the participants were also given two inventories in order to support further understanding of this research phenomenon. The Brief COPE was used to identify some of the coping strategies and styles that each of the participants may have utilized while handling the often stressful situation of being a father to a child who has been diagnosed with a neurodevelopment disorder. The Parental Authority Questionnaire-Revised (The PAQ-R) assessed which parenting style the participants identified with as they were growing up. Research has found similarities between the parenting behavior of an individual's parents and the individuals' own adopted parenting style later in life (Buri, 1989). These resources were used collectively to answer the research question and to better understand the phenomenon of being a father to a child with autism.

### **Demographics of the Participants**

Ten male participants volunteered to participate in this research study. By the end of the study, three participants decided to withdraw their participation. Their dropping out could be an indicator of a number of different things: it might have been because they could not find time to participate, they were less involved in the lives of their children, or that they found it was emotionally taxing to discuss their reality of having a child on the autism spectrum. Whatever the reason, it is important to mention these three individuals even though they were not able to complete the interview process.

As for the seven individuals who did complete the study, their ages ranged from 26 to 55 years. All participants lived in Ventura County or Los Angeles County, in the State of California. They varied in their occupations and education levels. All were currently married when they were participating in this research study, except one who was currently separated and in the process of getting a divorce. They also all differed in the current ages of their children with autism and how long they have been living with that diagnosis. Five of the participants were from a Caucasian background, one was from a Hispanic background, and one was from an African-American background. Table 1 summarizes the participants' demographic information.

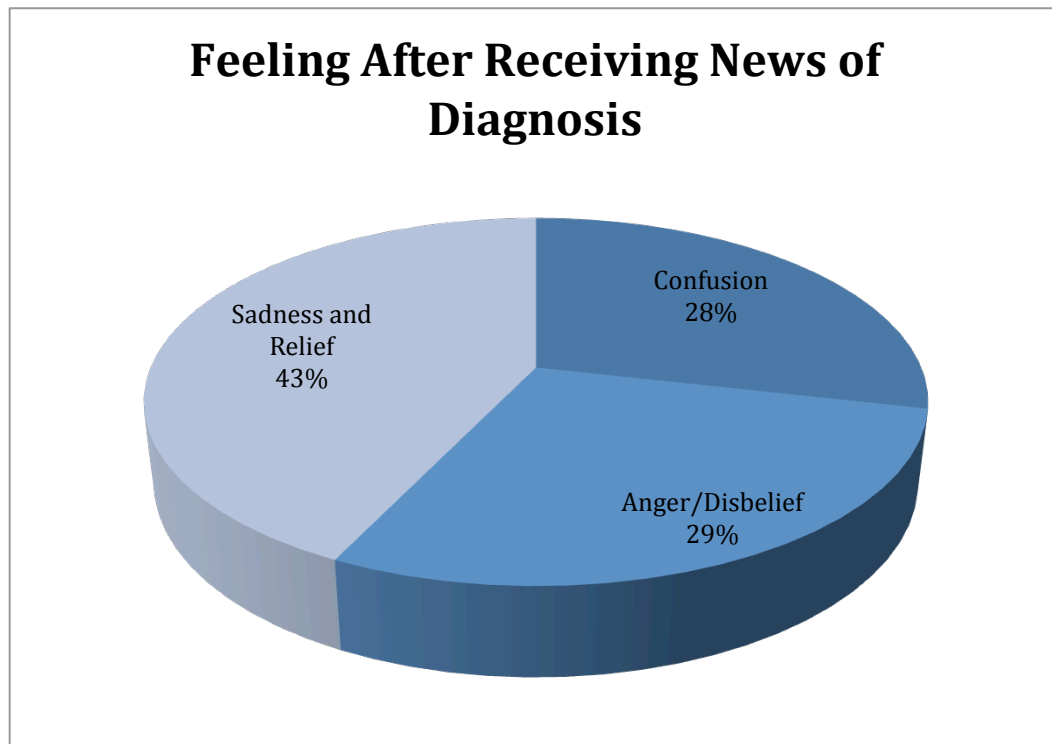
Table 1

<b>Participant</b>	<b>Age Range</b>	<b>Relationship Status</b>	<b>Educ. Level</b>	<b>Occupation (Current)</b>	<b>Ethnicity</b>	<b>Age of Child</b>	<b>Year of Diagnosis</b>
Richard	36-45	Married	College Degree	Comp. Tech. Currently Unemployed	Caucasian	13	2003
James	46-55	Married	Graduate Degree	Engineer	Caucasian	20	2002
Jorge	36-45	Married	High School- No Diploma	Clerk at a Grocery Store	Hispanic	3	2015
Jackson	36-45	Married	College Degree	Marketing/ Consulting	Caucasian	12	2013
Randy	36-45	Married	College Degree	Car Sales	Caucasian	9	2011
Matthew	26-35	Separated	Some College	Firefighter	African American	4	2015
Mitchell	36-45	Married	College Degree	Supervisor- Park and Rec.	Caucasian	13	2009

### **Participants' Experiences of Being a Father to a Child with Autism**

Just as the presentations of the symptoms of Autism Spectrum Disorder (ASD) in children vary greatly, so do the experiences that the fathers shared with the interviewer. No single experience was the same as the other. The diverse ways in which this disorder affected these fathers' lives differently speak to the appropriateness of autism being labeled as a *spectrum* disorder. Upon receiving the diagnosis for their child, some fathers experienced anger, others sadness, some relief, and for a few, nothing reportedly really changed at all. Figure 1 displays the distribution of the fathers' reactions to the diagnosis.

Figure 1



For the fathers who experienced relief, it was clear that they had been struggling for years with feelings of helplessness. Having a child diagnosed with ASD can leave a parent at a loss. Nothing seems to work and the child seems to always feel upset or in a great amount of discomfort. Not being able to help your child for so many years and then finally being told why the child may be acting a certain way is like being given a map with a destination listed on it. It's a starting point to helping the child.

*"We knew that he was upset a lot but didn't know why. When the doctor told us [about the diagnosis], my wife was so upset. I was too, but I was also happy because now we knew how to help him." –Randy*

Randy's words are a perfect depiction of the sense of relief that parents may feel, even though receiving a diagnosis of a lifelong disorder for your child is, at the same time, a devastating moment. The fact that relief can be felt alongside devastation shows the complexity of the frustration with having a child with challenges and not being able to help him or her.

Not all fathers felt a sense of relief. Feelings of confusion were not uncommon among the fathers who participated in this study. These feelings of confusion came in a couple of different forms. Some of the confusion came in the form of anger, while for others it came in the form of indifference as some fathers stated "nothing really changed" for them. Autism was something new and unknown to most of these fathers. When asked what the word "autism" meant to them, three of the seven fathers gave incorrect definitions or descriptions, even after years of their child living with this disorder.

*"It just means that a person has trouble socially and might not be as smart. I don't really know a lot about it." –James*

*"I just know that it means that the child is unhappy a lot and can't talk." –Jorge*

These vague and inaccurate descriptions are from fathers who are parents of children with autism and are exposed to the disorder on a daily basis. This is an illustration of how this disorder may be misunderstood by people, despite the fact that it is one of the most prevalent childhood disorders of our time.

Once the fathers received the news that their child had autism, their lives were changed in an instant. Stress levels of these fathers are typically higher than those of fathers with typically developing children. Although the fathers in this study revealed that their stress levels were generally low now, they conveyed that the levels were higher when they first received the news about their child. Many of the fathers expressed the importance of behavioral interventions in the progress of their child and how it helped decrease their levels of stress.

*“Once we could get him the help that he needed, progress happened. So much. He doesn’t get as upset as he used to. It is my favorite when the four of us can do things together now, peacefully.” –Mitchell*

Generally speaking, stress among these fathers resulted from somewhat similar reasons. Children with autism exhibit extremely intense behaviors that may include aggressive acts towards self and others, lengthy tantrums, as well as property destruction (Clipperton-Allen & Page, 2015). This was listed as a source for stress by many of the fathers that were interviewed. In addition to the problem behaviors that the children exhibited, some of the fathers also revealed that it was a challenge for them to have a child who did not express emotions in a way that a typically developing child would. Some of them missed hearing their child say, “I love you,” or express desire to give them hugs and kisses. These behaviors are not innately learned by a child with autism. There were a couple of fathers who mentioned that most of their stress was affected by work

and things unrelated to raising a child with autism. These experiences gave strong insight into how a father was involved in the life of their child with autism.

### **Levels of Father Involvement**

For the sake of this research study, father involvement was categorized into two different groups; *active* father involvement and *passive* father involvement. The definitions for these two levels of father involvement were taken from a past meta-analysis study (Harris, 2010) that analyzed father involvement levels and early childhood socio-emotional development. The interviews of this study found that three of the seven fathers participated actively within the lives of their child with autism. This means that these fathers were engaged in performing activities with the child, created communication patterns and attachment styles with the child, and participated in a number of care giving roles.

*“[My wife and I] do the same things with him, just switching off. We find that it works the best instead of having set roles. We both do dinner, homework, baths, bedtime... all of it. We also both like to play with him. He likes to play different things with us, but lately he is interested in playing the same thing, Monster Trucks. He loves it. There really isn't one thing that one of us does that the other one doesn't do.” –Randy*

The remaining four fathers participated in the lives of their children at passive levels.

There was a general presence of the father in the life of their child and the fathers also made financial contributions to the child. Beyond that, they did not express that they spend much time doing other things with the child during their daily routine.

*“Sometimes I like to play games with him. He likes to play with me. My wife brings him here to class every day. My wife does food and bathing too. I am at work a lot. When I get home, I am tired. She likes doing all that stuff anyways.” –Jorge*

*“Well, I know that I get to do all the fun parts. Trust me, I am told that all the time. I work a lot. So I am sometimes there for bedtime and bath time.*

*But [my wife] always tells me that I just do all the fun stuff and she does all of the hard work. We always fought, and still fight, about how I cannot make it to a lot of the appointments...” –Matthew*

It is important to note that these labels of *active* and *passive* are not intended for judgment purposes of these fathers. They are simply to be used as a tool to measure how much time a father spends with their child with autism. Any level of involvement by a father in the life of their child is significantly more valuable than no involvement at all.

### **Theme 1: The Importance of Coping Skills**

All three of the actively participating fathers have high levels of healthy coping skills that they utilized to manage their stress levels. Through their interviews and results of The Brief COPE, these fathers revealed that they use strategies that focus on active coping (putting forth an effort to cope with situations), self-distraction, and seeking emotional support from others. It is important to note that the self-distraction techniques employed by these fathers are healthy in nature and mostly focus on extra time spent doing things such as recreational activities.

*“I love to exercise [to deal with stress]. I find such peace in it. In the beginning, I would go out on long runs and bike rides...” –Randy*

In contrast, the fathers who are more passive when being involved in the lives of their children used only low or moderate levels of coping skills. Their repertoires of skills necessary to cope with extremely stressful and anxiety-provoking situations were smaller. Three of the passively involved fathers use low levels of self-distraction techniques, such as reading on occasion and substance use. This is not a healthy form of coping.

*“I don’t get stressed very often but when I do, I like going out with my friends on a regular basis. I have known them since elementary school. We like to drink and hang out.” –Matthew*

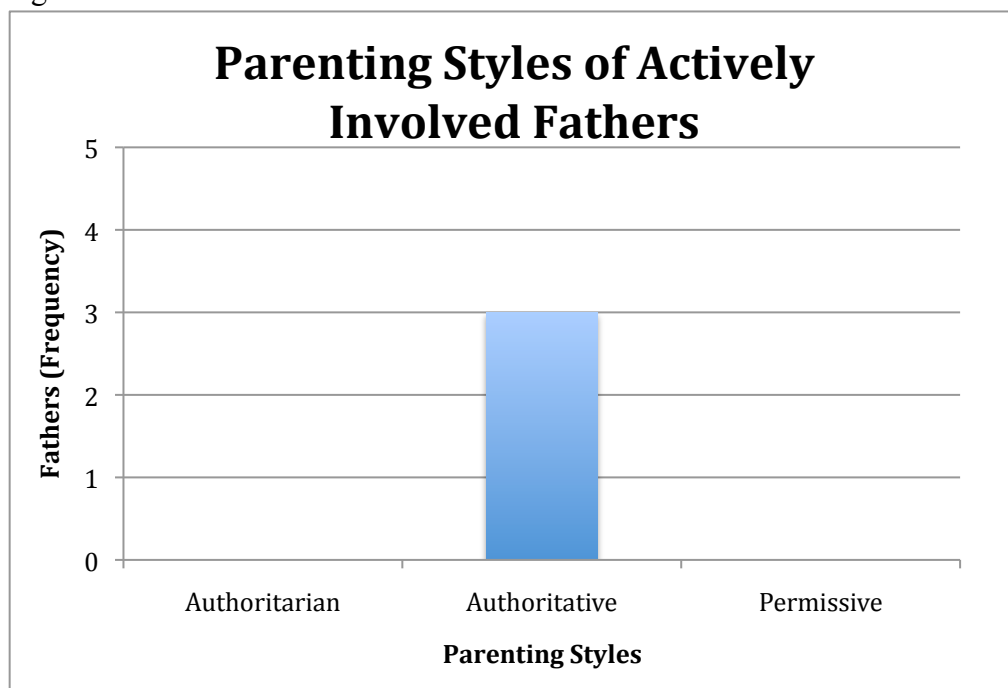
There was one father who was not actively involved in participating in his child's life, yet The Brief COPE results showed that he did have a high level of coping. He only used one thing to cope with stress, which was his religion. He indicated that he prayed a lot about his situation and attended church more often than he did in the past.

## **Theme 2: Parenting Styles Matter**

There was one parenting style common in all fathers who had active participation in their child's life. The authoritative parenting style was adopted by all of these three fathers. This is the parenting style that works on a more flexible, collaborative basis. Rules are set but are also based on a foundation with a loving parent who is open to discussing the reason for a rule. Another crucial element to this parenting style is that when a rule is proves unrealistic in the context of their child's life, the parent is open to modifying that rule without being quick to punish.

*"I like [the rule setting] to be a collaborative process. I never had a lot of rules growing up and it was good. But when we had K (child), it was obvious that that was not going to work (laughing). But we like to have a lot of discussions about things." –Mitchell*

Figure 2



Among the more passively involved fathers, there was not a particular parenting style emerged as the dominant one. Two of the four passively involved fathers adopted the authoritarian style, as they preferred enforcing firm rules with very little flexibility. A rule is made and is expected to be followed. If the rule is not followed, a punishment will take place. There is no negotiation of rules within an authoritarian parenting style.

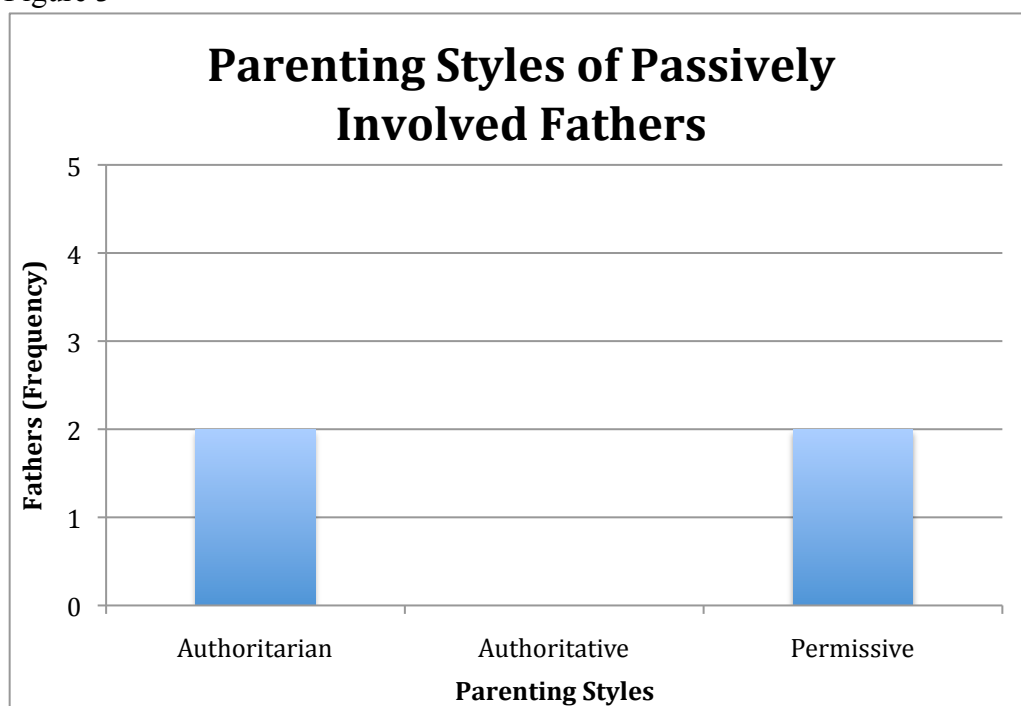
*“I have a lot of rules. My wife and kids know the rules. My older boys know the rules well and know that I make them follow them. They will be punished if they don’t follow rules that I make.” –Jorge*

The other two passively involved fathers adopted a more permissive style of parenting. They are not quick to set rules and are more inclined to allow the child to decide which rules should be made and followed. This is the least structured parenting style. It does not foster healthy boundaries that most children need in order to succeed in life.

*“My wife does a lot of the rule setting. I try and make T (child) follow the rules but sometimes her behaviors are bad. I have some rules but the girls don’t really follow them (laughing).” –Richard*

When parenting a child who has autism, there is no strict guideline on how to make rules. Each child is unique and often evolving in the skills that they are learning. As such, flexibility is crucial in parenting because boundaries are important but should not be flexible according to the child’s development and changing needs.

Figure 3



### Theme 3: Culture May Be an Indicator of Father Involvement

Some cultural trends were exposed within the results of this study. Of the seven fathers who participated in this study, five were Caucasian, one was Hispanic, and one was African-American. The Caucasian fathers, although not all actively involved in their child's life, all reported that their cultural backgrounds did not play a role in how they viewed "autism." Expressing the same sentiment though not with the same words, they reported having known about autism and that the older generations of their families were accepting of their children and their autism diagnosis.

*"No [impacts because of cultural background] that I can think of. My parent's and my wife's parents are all very involved with both of the kids."*  
 –Mitchell

The two individuals in the study who identified with non-Caucasian backgrounds were both involved in the lives of their children with autism at passive levels. They both stated that they did not remember being exposed to the word "autism" while they were growing up in their respective cultures. Neither of them knew other people with autism or with a child or relative was diagnosed with autism.

*"I did not know about autism until I came here [America]. It was a new word to me. My parents do not like when he cries and do not understand why we cannot get him to stop crying."* –Jorge

*"I don't know anyone in my family who had autism or who knows someone who had autism. Never thought about it really. My parents don't seem to see my kids very much... any of them..."* –Matthew

There was not a clear relationship between culture and involvement. Even though all of the fathers who were actively involved within their child's life were Caucasian, there were also two Caucasian fathers who were not actively involved with their children.

However, it may be important to note that no actively involved father in this study is of a non-Caucasian background. This is a topic that would benefit from further research.

#### **Theme 4: Love, Care, and Acceptance**

One thing that was apparent with each of the fathers and their experiences was that they all expressed love, care, and acceptance for their son or daughter. They were asked about things they enjoyed doing with their child, and, despite challenges that they had previously explained, they all described special activities they enjoyed doing with their child. Whether the father was actively or passively involved in their child's life, they revealed acceptance for their child at an incredible level. All of the fathers were asked what the word "autism" meant to them. The answers to this questions portrayed the true level of acceptance that some of the fathers felt toward their child.

*"It's just a word really. My child had autism but he isn't autistic. It doesn't define him. It just guides us all in a direction." –Randy*

In addition to the level of acceptance revealed, the fathers shared a plethora of positive experiences that they have had on their journey. Many fathers enjoyed the emotional connections they have fostered with their children over the years, no matter how great or small or long or short lasting they may be. Children with autism tend to be emotionally static and are not capable of making overt emotional attachments with others. This is difficult for parents. All they want is to feel the love from their child, which they always assumed was automatic, and some parents wait years for this to happen although it is not guaranteed to happen. The fathers in this study, regardless of their involvement levels, spoke of how they have fostered such connections with their child.

*"I never thought I would have a child with autism. I love her with all my heart. It is hard not talking to her... but she signs. She makes up her own signs so I have to learn those. And she uses her [talking device] but it isn't*

*the same. Usually just one or two word answers. I don't always know how she is feeling... She likes to tell jokes on her [talking device]. When she started doing this, I felt that it was a way for her to gain my attention and make me laugh. We would sit and laugh together. She does things that she thinks is funny and I get a real kick out of this. I can't help but laugh. Her personality is my favorite." –Richard*

No matter the struggles that these fathers have endured over the years, or where their child's symptoms fall along the autism spectrum, their love, care, and acceptance for the child shined strongly through the experiences they shared. Even if they did not agree with the diagnosis or the things that doctors told them, and even if the children's behaviors may be challenging to manage, the children were accepted for who they are and loved for the passion they showed for various things and activities.

## **Chapter V: Discussion and Conclusions**

### **Implications**

There are a number of clinical implications that this research provides to the topic of father involvement with a child who has been diagnosed with Autism Spectrum Disorder (ASD) by exploring the personal experiences of fathers who received this diagnosis for their own child. The clinical implications are listed below:

- Receiving the diagnosis of autism for a child is very impactful on the lives of parents, fathers in particular, and how they envision fatherhood.
- Having a child with autism adds a significant amount of stress, which fathers need to find ways to cope with.
- The child's negative behaviors and lack of emotional reciprocity seem to contribute the most to stress levels.
- Father involvement levels appear to be influenced by a number of factors.
- Active coping skills were found to be important when trying to deal with the stress of being a father to a child with autism.
- An authoritative/flexible parenting style may result in higher levels of father involvement compared to authoritarian or permissive parenting styles.
- Cultural backgrounds may or may not affect father involvement, but cultural perspectives most likely do shape the way an individual interprets symptoms of autism.

A father's active involvement in the life of his child with autism is important in the growth and intervention process of the child. The results of this study indicate that coping mechanisms and parenting styles may be important factors in determining how involved a father becomes. Fathers who have authoritative/flexible parenting styles may have an easier time being involved because children with autism are each unique and have individual symptoms and behaviors. The more rigid the father is in how they try to

parent a child with autism, the more likely they are to feel frustrated, upset, and defeated. This may result in them not wanting to be involved in the daily living tasks with their child. Equally important seem to be coping skills. Children diagnosed with ASD contribute stress to a family and a parenting situation. The more healthy and active the father's coping skills are, the easier it will be for him to manage his stress levels and remain involved. Although culture seems to be less of an indicator of involvement levels, it does play a role in how a father perceives his child and his/her symptoms. Culturally sensitive training courses about the history of autism and the importance of early diagnosis and intervention procedures may benefit fathers who find themselves faced with this diagnosis for their children.

The results of this study imply that when a father receives a diagnosis of autism for his child, it would be helpful for him to be offered certain types of parent training courses. These courses can teach skills to develop flexible parenting styles as well as ways to learn appropriate coping skills. The more assistance that is given to these fathers, the more likely they are to become actively involved in their child's life. The ultimate goal is for a child to be able to receive early intervention services so that they can develop and improve their skills and function significantly throughout their lifetime.

### **Limitations**

There are a few limitations in this qualitative research study. Because of the phenomenological nature of this study, the corresponding limitations decrease its validity and generalizability. The results of qualitative studies are not intended for generalization to a larger population. The information that was discovered through the personal experiences shared by the fathers in this study is unique and personal. Also,

generalizability would be difficult to achieve given that the sample size for this study was small. Because of the fact that purposive sampling was used as the sampling method, a very specific group of individuals were chosen because of their experiences of being fathers to children diagnosed with Autism Spectrum Disorder. Therefore, the findings of this study cannot be generalized to all fathers of children with disabilities because the experience of parenting children can be different depending on the stressors that accompany specific disabilities.

Another limitation of this study is that it may be difficult for the researcher to refrain from having personal biases (Creswell, 2003). This may have arisen when the researcher is analyzing the data. Qualitative analysis is subjective in that the researcher is the primary instrument for analysis (Starks & Brown Trinidad, 2007). The researcher guides all of the analysis, which may be a limitation if he/she is not able to eliminate any biases he or she may have.

A third limitation has to do with the demographics of the participants. One of the factors analyzed in this study was cultural background and how it may influence the level of father involvement. There were only two participants that were of a non-Caucasian cultural background. This might affect the results regarding culture that were found in this study. In the future, it would be recommended that this type of study be replicated in a more culturally diverse geographical area.

A final limitation for discussion is the way in which interviews were conducted for this study, which was a one-on-one format between the researcher and the participant. Given that there was no time allotted for rapport building, the participant might have withheld information that they did not feel comfortable disclosing to a stranger. Some

questions were of a personal nature and might not have been easy to discuss on the spot. Also, discussing the experience of fathering a child with autism might have evoked strong emotions for some of the fathers. As a possible defense mechanism, some of the fathers might have avoided certain issues that they knew would cause them to become emotional and feel the pain they experienced in the past.

However, the benefits of the study outweigh its limitations. Phenomenological data does not have a purpose of forming generalizations to larger populations; rather, it seeks to unearth the fundamental qualities and realities of how a phenomenon, such as involvement levels of a father within the life of his child diagnosed with Autism Spectrum Disorder, can be influenced by certain factors. The research accumulates strength and richness by gaining insight into these fathers' personal experiences. This study provides the understanding of actual, lived experiences and the effects that these fathers live with while traversing the often-difficult journey of being a father to a child with autism.

## **Conclusion**

The purpose of this study was to understand how coping skills, parenting styles, and cultural backgrounds can influence the amount of involvement a father has within the life of his child who has been diagnosed with Autism Spectrum Disorder. The diagnosis caused an unexpected shift in the lives of the fathers who participated in this study. Not one of them ever expected that they would have a child with autism. In looking into the lives and lived experiences of each of the participants in this study, the researcher strived to learn more about the possible factors that contribute to the amount of time each of them was involved in the life of their child with autism. More specifically, the researcher

explored how coping skills, parenting styles, and cultural backgrounds each affected father involvement levels.

Through the use of a qualitative, phenomenological interviewing format and supplemental inventories, the researcher attempted to fully understand the unique experience that each participant has lived through while being a parent to a child who has been diagnosed with autism. The researcher met with each participant in person, interviewed them, took note of their answers, and transcribed their answers into experiential summaries. The data collected was analyzed multiple times for the emergence of themes. Along with direct quotes from each of the participants, these themes were used to capture the fundamental quality of this particular phenomenon. One of the most striking themes was how much active coping skills and flexible parenting styles allow for a father to have the capacity to be more involved with their child with autism. Another theme also revealed that cultural backgrounds can shape the way people perceive Autism Spectrum Disorder and whether they will seek treatment for their child.

About one in every 68 fathers in this country will receive a diagnosis of autism for their child. Exploring the lived experiences of these fathers will help to understand to a greater extent the struggles and triumphs that they experience. One thing that was clear from this research study was that it is more than possible for a parent to accept a child with autism and to create enjoyable, lasting memories with the child in the same way that one can with a normally developing child. Every child is a special gift.

*“My child has autism; autism does not have my child.”*  
*-Anonymous*

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## **Appendix A: Key Terms**

- Active Father Involvement: Engagement or performing activities with the child;  
developing communication patterns, attachment styles, and care giving roles  
(Harris, 2010)
- Authoritarian Parenting Style: a parenting style that is controlling, values obedience to set  
standards, favors punishment, and is less warm than an authoritative parenting  
style (Baumrind, 1971)
- Authoritative Parenting Style: a parenting style that emphasizes parental control within  
an ethos of warm, responsive parenting that explains reasons, values the child as  
an individual, and aims to encourage the child towards independence (Baumrind,  
1971)
- Autism Spectrum Disorder (ASD): Persistent deficits in social communication and social  
interaction across multiple contexts and restricted and/or repetitive patterns of  
behaviors, interests, or activities, which are not explained by intellectual disability  
(APA, 2013)
- Coping: the ability to struggle or deal with fairly even terms and with some degree of  
success (dictionary.com, n.d.)
- Culture: the behaviors and beliefs characteristic of a particular social, ethnic, or age  
group (dictionary.com, n.d.)
- Father Involvement: Amount of time that a father spends completing daily activities with  
his child
- Passive Father Involvement: general presence of the father in the child's life, and making  
financial contributions to the child (Harris, 2010)

Permissive Parenting Style: a parenting style where the parent lacks control, makes few demands on the child, but is warm (Baumrind, 1971)

## Appendix B: Informed Consent

### **Informed Consent for father participant.**

**Name of principle investigator:** Kayleigh Hay, M.S. [REDACTED]

**Name of organization:** Antioch University Santa Barbara

**Name of supervising investigator:** Salvador Trevino, Ph.D.

**Name of project:** Factors Influencing Father Involvement with Children Diagnosed with Autism Spectrum Disorder

### **Introduction**

My name is Kayleigh Hay and I am a doctoral student in the clinical psychology program at Antioch University Santa Barbara. I am doing research on the factors that influence the amount of time that a father spends with his child who has been diagnosed with autism. I am going to provide you with information and invite you to be part of this research. You do not have to decide today whether or not you would like to participate in the research. Before you decide, you can talk to anyone you feel comfortable with about the research. The consent form may contain words that you do not understand. Please ask me to explain anything that you may not understand. If you have any questions in the future, you may ask me at any time.

### **Purpose of the Research**

Autism Spectrum Disorder (ASD) cases are increasing in number and is currently affecting one in every 68 children in our country. Much of the research that we have about this disorder and the children that it affects examines mothers and their experiences. I want to understand the experiences of fathers and their involvement with their children who have autism. I want to examine different things that may impact how much time a father chooses to spend with their child. Those different things include ways the father handles stressful issues, styles of how the father parents their child, and the cultural background that the father may come from.

### **Type of Research Involvement**

This research will involve your participation in a structured and semi-structured interview process, which, in addition to the interview, will include the completion of two short surveys and a demographics questionnaire. During the interview, you will be asked a number of questions including how you parent your child and how you were parented as a child. The interview will take about one hour to complete and the surveys and questionnaire will take an additional half hour to forty-five minutes to complete.

If you choose to participate, your experiences will be used towards the research surrounding this common development disorder that is affecting many children. There are no anticipated risks to participating in this study. However, if speaking about your experiences does cause you to feel upset, you will be provided with resources that you may choose to contact in order to help you through the situation. Also, it is important to know that you are free to stop participating in the study at any time.

If you have any concerns before, during, or after the research study is complete, please feel free to contact my supervisor, Dr. Salvador Treviño at Antioch University Santa Barbara at [REDACTED] or me. If you understand and agree to the terms of this research study and would like to participate, please sign below giving your consent for participation.

Your participation is voluntary and all information will be kept secure and confidential and your name will not be associated with any research findings.

\_\_\_\_\_  
Name of Participant (Print)

\_\_\_\_\_  
Signature of Participant

### Appendix C: Demographics Questionnaire

#### Age

\_\_\_\_\_ 18-25

\_\_\_\_\_ 26-35

\_\_\_\_\_ 36-45

\_\_\_\_\_ 46-55

\_\_\_\_\_ 56-60

#### Relationship Status

\_\_\_\_\_ Married

\_\_\_\_\_ Separated

\_\_\_\_\_ Divorced

\_\_\_\_\_ In a relationship

\_\_\_\_\_ Single

#### Educational Background (highest completed)

\_\_\_\_\_ High School \_\_\_\_\_ Received Diploma

\_\_\_\_\_ Some College

\_\_\_\_\_ College Degree

\_\_\_\_\_ Graduate School

#### Occupation (List current occupation)

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#### Ethnicity (Check all that apply)

\_\_\_\_\_ White

\_\_\_\_\_ Hispanic or Latino

\_\_\_\_\_ Black or African American

\_\_\_\_\_ Native American or American Indian

\_\_\_\_\_ Asian/ Pacific Islander

\_\_\_\_\_ Other

#### Age of Child Diagnosed with Autism (current age of child)

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#### Date of Formal Diagnosis (year)

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