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# PERCEPTIONS OF KOREAN AND KOREAN-AMERICAN MOTHERS OF CHILDREN WITH AUTISM: THE IMPACT OF DISABILITY ON THE FAMILY AND SIBLING RELATIONSHIPS

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**by**

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# PERCEPTIONS OF KOREAN AND KOREAN-AMERICAN MOTHERS OF CHLIDREN WITH AUTISM: THE IMPACT OF DISABILITY ON THE FAMILY AND SIBLING RELATIONSHIPS

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The purpose of this study was to understand Korean and Korean-American mothers’ perspectives under cultural contexts in regard to the disability itself, family/sibling adjustment to the child with Autism Spectrum Disorder, and the support for those families. From in-depth interview, main themes are discovered that (a) resources & support, (b) sibling relationship, (c) family dynamics, and (d) cultural comparison. Practical implications for serving culturally and linguistically diverse families are discussed, and more future research on culturally and linguistically diverse family dynamics should be conducted.

# Table of Contents

# List of Tables

# List of Figures

# Chapter 1: Introduction

The family is a significant feature of all cultures, and offers a foundation of nurturing, guidance, and support for the child. Thus, children with disabilities cannot be discussed without considering the family. The importance of a supportive family has been emphasized for decades, recognizing the family as a whole system providing educational, social, and emotional supports (O'Shea, 2001). The trend toward family quality of life is now reported everywhere in the world, marking an increased recognition of the importance of family support as opposed to a sole focus on individual support (Poston et al., 2003). For instance, in 2004, the United States placed a high value on family support in the reauthorization of the *Individuals with Disabilities Education Act* (IDEA) in 2004. The IDEA includes an Individualized Family Service Plan (IFSP) which is tailored to the family's unique concerns, priorities, and resources (Ferguson & Ferguson, 2006).

## STATEMENT OF PROBLEM

Research findings suggest that that students with disabilities and their families are at high risk for a variety of negative outcomes: job opportunities, financial constraints, anxiety, physical illness, sibling relationship, and social isolation (Burton & Phipps, 2009; Harris, 2008; Hastings, 2003a; 2003b; Murphy et al., 2006; Parish & Cloud, 2006; Tétreault et al., 2014). It has been suggested that families of children with autism spectrum disorders (ASD) face unique difficulties (Meadan, Hall, & Ebata, 2010).

Across the country, ASD is one of the fastest growing disabilities in the United States (Centers for Disease Control and Prevention, 2014). This developmental disorder is characterized by deficits in social interaction and communication, as well as restricted, repetitive, and stereotyped patterns of behavior. Symptoms of ASD are often recognized during early childhood years and they can tend to present on a continuum, ranging from mild to severe symptoms (American Psychiatric Association, 2013).

According to the data from the CDC (2014), the overall prevalence of ASD was 14.7 per 1,000 (one in 68) children around the age of 8 years who lived in 11 sites of the United States during 2010 (Baio, 2014). The incidence rate of children with ASD has increased sharply over the past 20 years (Baio, 2014; Centers for Disease Control and Prevention, 2014). Beyond the United States, many countries show high incidence rate of children with ASD. South Korea has the highest rate of children with ASD in any country, with 26.4 in every 1,000 children being diagnosed with ASD (Kim et al., 2011). The research estimated the prevalence of ASD among children aged 7-12 year to be 2.64%. This figure is considerably much higher than 1.47% prevalence of ASD rate in the United States in 2010. As families of children with ASD are more prevalent than before, the needs of family support services are also emerging (Turnbull et al., 2004).

However, the cultural context must be considered when determining appropriate family support services (Antony & Banks-Joseph, 2010; Christina, Roy, & David, 2012; Park & Turnbull, 2001; Shin, 2002). For instance, the experiences of raising children with ASD can be very disparate between the United States and South Korea. Even though both countries have a noted increase in the number of children being diagnosed with ASD, they have different cultures, traditions, values, and social services. Researchers often distinguish between South Korean and American cultures based on the model of collectivist versus individualist orientation (Cha, 1994; Han & Ahn, 1994; Shin, 2002). Korean culture is regarded as a collectivist culture which emphasizes family values, role-based family system, strict hierarchal relationships, and conformity to the rules. On the other hand, American culture can be explained by individuality, privacy, and equality, as they are encouraged at an early age to be independent and to develop their own goals in life (Cha, 1994; Han & Ahn, 1994; Shin, 2002).

In this context, raising a child with ASD could be different in South Korea and the United States (Belsky et al., 2000; Farver & Lee-Shin., 2000; Farver et al., 2000; Park & Turnbull, 2001). Researchers agree on the importance of understanding ASD within the context of culture (Antony & Banks-Joseph, 2010; Christina, Roy, & David, 2012; Park & Turnbull, 2001; Shin, 2002). They support the idea that we must engage in cross-cultural practices (Kalyanpur & Harry, 1999), as families tend to require different types of support as a reflection of their attitudes and the availability of the support system (Shin, 2002). Despite the need to better understand cultural differences in the support of families with children with ASD, there have been few studies that have engaged in serious discussion of cultural factors (Daley, 2002). Several studies have focused on the immigrant experience and the ways that conditions in the new country affect families (Cho, Singer, & Brenner, 2000). However, most cross-cultural studies have focused on immigrants to the United States. Conducting a comparison between Korean families and Korean-American families could support our understanding of cultural differences related to disability. To address this gap in the literature, I sought to conduct a qualitative investigation of the lived experiences of two mothers: one Korean and one Korean-American, both with children who have been diagnosed with ASD.

## PURPOSE OF STUDY

The purpose of this exploratory study was to better understand and compare the experiences of Korean and Korean-American mothers of children with ASD. I was specifically interested in examining each mother’s perceptions of the disability, the relationship between her child with ASD and typically developing siblings, as well as the support for the family of a child with ASD. We already know that raising a child with ASD places some extraordinary demands on parents as individuals and on the family as a whole. It may put stress on the parent's marriage, other children, work, finances, and personal relationships and responsibilities. There are special demands on these siblings of children with ASD. For example, siblings in adulthood are assumed to go through caregiver burden. As most ASD research focuses on childhood, additional research is required for a better understanding of various family factors with regard to sibling relationships as well as family life events. Discovering those factors will make their childhood easier and will teach skills that will make them more effective and resilient adults. Thus, I would like to understand the perspectives between Korean and Korean-American mothers on family/sibling relationship issues. The research questions that guide this study are:

1. How do Korean and Korean-American mothers perceive family support services for families of children with Autism?
2. How do Korean and Korean-American mothers perceive the relationship between their child with Autism and their siblings?
3. How do Korean and Korean-American mothers view their child's disability and its implications for their families?

# Chapter 2: Literature Review

In this chapter, the literature review focused on the following research: understanding of Autism Spectrum Disorder, prevalence of ASD, family system and family quality of life, family dynamics of children with ASD, multicultural issues, Korean culture, and reporting Korean-American parents' perceptions in the United States. The purpose of this study sought to explore and understand the experiences of Korean and Korean-American mothers of children with ASD in regard to response to disability, family dynamics, and social support.

## UNDERSTANDING OF AUTISM SPECTRUM DISORDER

With the publication of the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-V; APA, 2013), the term Autism Spectrum Disorders (ASD) has broadened to encompass disorders such as Autism, Asperger's Syndrome, and Pervasive Developmental Disorder (PDD-NOS). Children with ASD display persistent deficits in social communication and social interaction across multiple contexts and restricted, repetitive patterns of behavior, interest, or activities. For instance, Berkell (2005) stated that children with ASD manifest impaired social communication by significant limitations in reciprocal eye contact, responsive smiling, joint attention, and social imitative play. In addition, one of the defining features of ASD is that children are inflexible in regard to minor change or transition in the environment as well as their interests and preferred acitivities are generally narrow and restricted (Berkell, 2005). As the term "spectrum" refers to the wide range of symptoms, skills, and levels of severity that children with ASD can have, the support for children with ASD will be required for different levels.

Scientists do not know the exact causes of ASD, but research suggests that both genes and environment play important roles. Most people who develop ASD have no reported family history of ASD, suggesting that random, rare, and possibly many gene mutations are likely to affect a person’s risk. However, they are studying that how certain environmental factors may interact with certain genes (Landrigan, 2010).

Recent efforts have focused on early identification and intervention of ASD. The effects of autism can have a significant impact long after childhood, which is why diagnosis and intervention at an early age remain so important (Harris & Delmolino, 2002). Therefore, under the DSM-V criteria, earlier diagnosis of ASD is encouraged but also allows for individuals whose symptoms may not be fully recognized until social demands exceed their capacity to receive the diagnosis. Even though ASD can be diagnosed by 2 years of age based on DSM-V, the median age of first diagnosis is 4 years old in the community settings (Baio, 2014).

**Spectrum of Symptoms.** There are a number of different levels of symptoms falling under the same umbrella of *Autism Spectrum Disorder*. However, people are diagnosed within ASD based on support level under DSM-V rather than categorizing the diagnosis. Among them, people with autism who are regarded to be cognitively higher functioning with an IQ of greater than 70 are identified with high-functioning autism (HFA) (Sansosti, Powell-Smith, & Cowan, 2010). While many people consider children with HFA do not need a help with basic skill, they do need a support at home, school, and work (Rao & Beidel, 2009; Sansosti et al., 2010). For example, they present symptoms such as extreme sensory issues, social cluelessness, anxiety and depression, lack of executive planning skills, emotional dysregulation, difficulty with transitions and change, and difficulty with following verbal communication (Sansosti et al., 2010).

## THE PREVALENCE OF AUTISM SPECTRUM DISORDER

Despite of strict criterion, the CDC (2014) announced that ASD affects 1 in 68 individuals under 21 living in the U.S. From the report, prevalence of ASD in U.S. children increased by 119.4% from 2000 to 2010 (Baio, 2014; CDC, 2014). For example, almost 30 percent higher identification than the report in 2012 of 1 in 88 children with ASD (CDC, 2014). In other words, more than 3.5 million Americans live with an ASD and it is the fastest-growing developmental disability (Buescher et al., 2014; CDC, 2014). The researchers identify that ASD is almost five times more common among boys than girls, and white children are more likely to be identified as having ASD than are black or Hispanic children. They also noted that almost half of children with ASD have average or above average intellectual ability (an IQ above 85) and, thus, are considered "high functioning".

In regard to prevalence of ASD, it is not surprising that the global prevalence rate of ASD has increased over time since the earliest epidemiologic studies were conducted in the late 1960s and early 1970s. However, it is unclear how much variability there is across countries as most studies have been conducted in Westernized countries (Elsabbagh et al., 2012). There is some limited evidence that we find differing incidence rates across countries; for example, a recent study by Kim et al. (2011) concluded that South Korea has a higher prevalence of ASD compared to prevalence of the United States during 2010. The researchers found that almost 2.64% of South Korean children aged 7 to 12 have ASD which is strikingly different from previously reported data in Korea ranging from 0.6% to 1.8% (Kim et al., 2011).

Almost two-thirds of ASD cases in the overall sample were undiagnosed and untreated in the mainstream school, which led to the need for using strict screening and comprehensive population coverage to produce more accurate ASD prevalence (Kim et al., 2011). Overall, global prevalence estimates on ASD highlight the potential impact of geographical, socioeconomic, and cultural factor could be significant factors to evaluate prevalence, assessment, as well as services for other countries (Elsabbagh et al., 2012). In general, the prevalence rate of ASD increases rapidly across countries which led to promising opportunities for furthering research in the area (Elsabbagh et al., 2012).

As children with ASD are more prevalent than before, researchers address growing needs of developing system or services for those families of children with ASD (Turnbull et al., 2004). Raising a child with ASD can influence on the lives of every family members so that it is significant to examine not only the needs of individual with ASD but also the needs of families.

## FAMILY SYSTEMS AND FAMILY QUALITY OF LIFE

A number of studies reported that the impact of a child's disability on family dynamics, relationship, and overall functioning of the family. In the 1950s, Dr. Murry Bowen (1978) introduced *Family Systems Theory* wherein it was posited that families are systems of interconnected and interdependent individuals. The family is a structure of subsystems so that each action or change affects every other person in the family. As such, the family system is a complex whole that cannot be understood by examining members separately (Bowen, 1978).

Thus far, a number of studies have explored the family system of children with disabilities. Turnbull, Turnbull, Erwin, and Soodak (2006) pointed that there are four major subsystems within a traditional nuclear family: (a) the marital subsystem that includes interactions between spouses or significant others who function as marital partners; (b) the parental subsystem that includes interactions between parents and their children; (c) the sibling subsystem that includes interactions among brothers and sisters; and (d) the extended family subsystem that includes interactions among members of the nuclear family and other relatives. This conceptual framework creates potential bidirectional and transactional interaction within the family (see Figure 1).

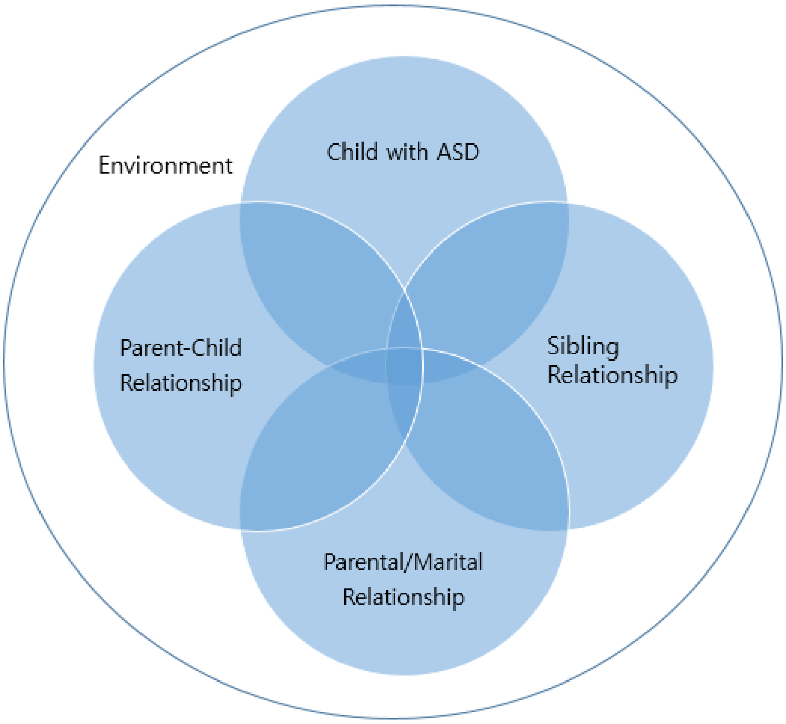

Figure 1: Family System Theory Conceptual Model

When we focus support only on an individual with a disability, this is representative of an old paradigm of disability wherein we perceive disability as a deficit within the individual (Turnbull et al., 2004). However, a broader perspective on the new paradigm of disability has been introduced. Instead of “fixing” only an individual with a disability or their parent, integrating the influence of others and the environment could be linked to adequate supports, services, accommodations, and relationships that are available to accomplish outcomes (Turnbull et al., 2004).

This new paradigm carried out significant changes on support delivery system, from parent involvement to family-centered services (Turnbull et al., 2004). Allen and Petr (1996) analyzed different definitions into the following definition regarding family-centered model: “Family-centered service delivery, across disciplines and settings, views the family as the unit of attention. This model organizes assistance in a collaborative fashion and in accordance with each individual family’s wishes, strengths, and needs” (p. 64). One of the key elements of the family-centered model that every reviewed article included was a family as the unit of attention (Allen & Petr, 1996). Family as the unit of attention is described as focus on the needs of not just the child with disability and the child’s mother but also other family members to serve the family adequately (Allen & Petr, 1996; Turnbull et al., 2004). This model was the first to really provide a strong rationale for considering systems of family support for students with disabilities; that is to say, extending beyond the child and their parent, and including siblings and other integral family members.

The evidence presented in this section suggests that the need of a family should be referred for family quality of life (Turnbull et al., 2004). The needs of a family could be associated with ten domains of family quality of life that are family interaction, daily life, parenting, financial well-being, emotional well-being, health, physical environment, productivity, social well-being, and advocacy (Park et al., 2003) (see Figure 2). Interestingly, family members have different perceptions regarding service outcomes and life satisfaction (Crowley & Taylor, 1994). For instance, Crowley and Taylor (1994) compared mothers and fathers on their perceptions of family functioning, life stressors, and sources of support.

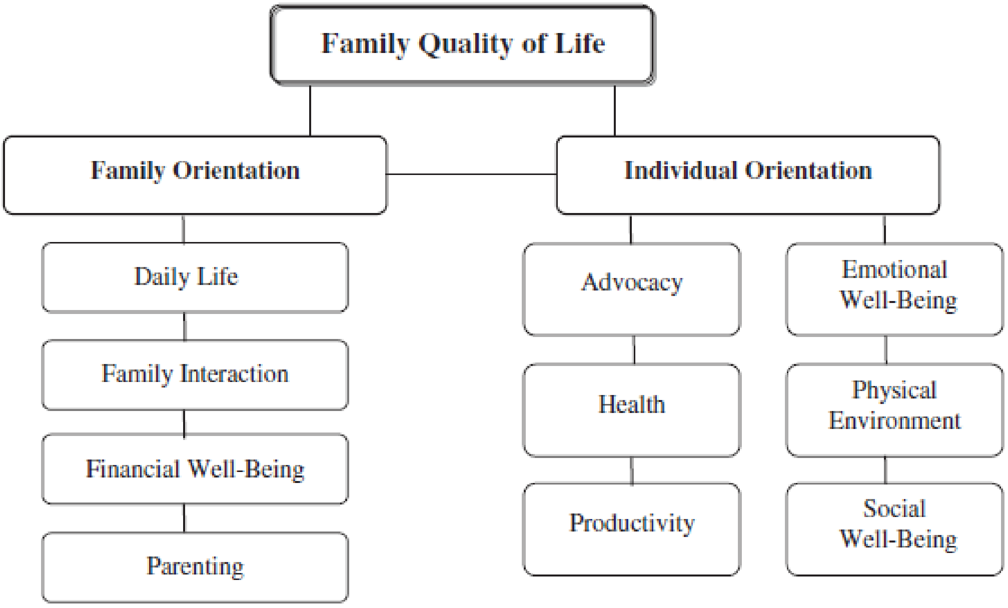

Figure 2: Ten domains of Family Quality of Life

*Note.* Reproduced from Park et al. (2003)

Different perceptions among family members could be associated with the experiences of family members (e.g., mother and father) of children with disabilities is not invariant and can be influenced by age, gender, disability condition, life cycle, and the role in the family (Park et al., 2003). Numerous researchers have demonstrated that each family members addresses different needs and supports (Harris, 2008; Kang-Yi, Grinker, & Mandell, 2013; Meadan et al., 2010; Turnbull et al., 2004; Rao & Beidel, 2009; Rivers & Stoneman, 2008). Therefore, each family members' experience and concerns should be considered when determining how to provide the best support to children with ASD and their families.

## PARENTS OF CHILDREN WITH ASD

Compared to parents of children without disabilities, parents of children with disabilities generally experience higher levels of stress (Hayes & Watson, 2013; Meadan et al., 2010). Interestingly, when examining families of children with various types of disabilities, empirical evidence suggests that parents of children with ASD experience more stress than parents of children with other types of disabilities or typically-developing children (Baker-Ericzen, Brookman-Frazee, & Stahmer, 2005; Estes et al., 2009; Hutton & Carson, 2005; Tomanik, Harris, & Hawkins, 2004; Pisula, 2007; Weiss, 2002). For example, mothers of children with ASD reported more distant relationships with children with ASD and higher level of depression than mothers of children with Down syndrome and Fragile X (Abbeduto et al., 2004).

The cause of this stress has been discussed by Bromley et al. (2004) and it is believed that these outcomes are associated with lower levels of family support and with higher levels of challenging behavior among children with ASD. Whether the child is low-functioning or high-functioning, the challenging behavior of the children with ASD can influence parents' level of stress and impede family functioning (Rao & Beidel, 2009). However, other research demonstrated that the cause of stress might also be associated with factors such as children with ASD demonstrating poor affect and lack of interests in others (so it is more difficult for parents to bond with the child), as well as having a younger child in the family and mother's age (Duarte et al., 2005).

Some studies concluded that mothers reported more anxiety and stress than fathers (Hastings, 2003c; Herring et al., 2006). This difference between parents has been explained as mothers potentially having disproportionate responsibility for caregiving (Gray, 2003) and, thus, experiencing the major stressors for the family. Gray (2003) stated that mothers reported emotional distress and lifestyle changes in regard to the responsibility of taking care of the child with disabilities while fathers reported an indirect effect of the child's disability on their lives.

Findings from other studies also indicate that parents of children with ASD tend to report lower marital happiness, and family adaptability and family cohesion than parents who do not have children with disabilities (Higgins, Bailey, & Pearce, 2005). Although raising a child with ASD can be a unique stressor, some studies have reported that a number of families show evidence of resilience (Bayat, 2007; Twoy, Connolly, & Novak, 2007). A recent study by Twoy et al. (2007) found that parents of children with ASD were using a social support system to deal with challenges of raising a child with ASD. The support system could include close friends, extended families, other families with the same situation, and agencies and programs. Similarly, Mackintosh, Myers, and Goin-Kochel (2006) asserted that other families of children with ASD were the most frequent source of support and information system.

## SIBLING RELATIONSHIPS OF CHILDREN WITH ASD

As we try to deliver support not just mothers but for all family members, it is not surprising that there is a growing need to address to siblings' needs and issues (Arnold, Heller, & Kramer, 2012). Nevertheless, the research on the needs of siblings is sparse (Hodapp, Glidden, & Kaiser, 2005). Most of the previous research on siblings have focused on the siblings of children with Down syndrome, Intellectual disabilities, or developmental disabilities, and have not specifically considered children with ASD. Because of what we know about the differences in parental stress between children with ASD and other disabilities, it would seem important to consider these same pattern among siblings.

In the literature, the siblings of children with disabilities have been described as the "forgotten child" (Madan-Swain et al., 1993). Of the few studies that have been conducted on siblings of children with ASD, we know that siblings go through good and bad times to adjust to their siblings, and quality of sibling relationship can be varied among siblings.

Some siblings have reported negative experiences with their brother or sister who has ASD. Anxiety, anger, jealousy, embarrassment, frustration, loss, and loneliness are the feelings that children will likely experience (Benderix & Sivberg, 2007; Kaminsky & Dewey, 2002; Sage & Jegatheesan, 2010; Verte, Roeyers, & Buysse, 2003). Similar to relationships with mothers, because of the characteristics of ASD, there are barriers to the sibling bond that can cause additional stress (Wheeler, 2006). For example, Orsmond and Seltzer (2007) found that siblings of individuals with ASD felt less emotionally close with and more overburdened by responsibility than siblings of individuals with Down syndrome. Similarly, Verte et al. (2003) reported that siblings of children with ASD had an increased risk of internalizing behavior problems, were more depressed, and experienced more stress. Other studies have found that siblings of children with ASD had underdeveloped social skills, feelings of loneliness, or difficulties with social adjustment, as well as more serious problems of attention, behavior, and social adjustment (Hastings, 2003b; Kaminsky & Dewey, 2002; Verte et al., 2003).

It is interesting to note that several studies have reported contradictory results; findings that indicate that siblings of children with ASD did not differ from siblings of typically-developing children. For example, social competency of siblings of children with ASD was not dissimilar to that of siblings of typically developing children rather they were relatively well adjusted to the siblings of children with ASD (Kaminsky & Dewey, 2002; Pilowsky et al., 2004; Verte et al., 2003). On the contrary to the findings of negative influences of having a sibling with ASD, researchers found that siblings of children with ASD were not much different with typically developing children.

Instead of talking negative impacts, there were studies that reported the positive impacts of having a sibling of children with ASD (Petalas et al., 2012; Wheeler, 2006). In general, positive outcomes that siblings frequently mention are learning patience, tolerance and compassion, understanding of disability, and having opportunities to handle difficult situations. Furthermore, siblings of children with ASD had higher social competence and a more positive self-concept, especially sisters of children with ASD (Macks & Reeve, 2007; Verte et al., 2003).

It is clear that siblings of children with ASD have positive and negative experiences to adjust to their siblings. And those experiences contribute to the quality of the sibling relationship. As well as their own experiences, the quality of the sibling relationship appears to be influenced by factors such as birth order, gender, age, sibling temperaments, family socio-economic status, family size and composition, and family roles (Meadan et al., 2010; Rivers & Stoneman, 2008; Sanders, 2004). Characteristics and severity of the disability and siblings' understanding of ASD have also been noted as factors that can influence the sibling relationship (Sanders, 2004). For example, when looking at temperament, siblings of children with ASD who are more persistent are more satisfied with their relationship with the children with ASD (Rivers & Stoneman, 2008). This individual characteristic may serve as a factor that protects the sibling from potentially negative emotional response when interacting with their sibling with ASD. In regard to the siblings' age, studies revealed that some of siblings felt like a burden to take care of their siblings of ASD, especially for the youngest one (Benderix & Sivberg, 2007).

Some research have demonstrated that parenting stress is related to sibling adjustment (Giallo & Gavidia-Payne, 2006). When using the term adjustment, we refer to internalizing and externalizing behavior problems of the sibling of the child with ASD. In other words, if parents stress out from raising a child with ASD, it could affect sibling adjustment as well (Hesse, Danko, & Budd, 2013). Others have demonstrated that parent stress did not significantly related to sibling relationship, but have highlighted parental satisfaction (Hesse et al., 2013). The quality of a parent’s relationship with a child affects perceptions of a sibling’s adjustment (Hesse et al., 2013).

At the same time, it is important to recognize the relationship between parent functioning such as parent stress and sibling adjustment is likely to be bidirectional, whereby sibling characteristics such as stress may contribute to parent stress (Giallo & Gavidia-Payne, 2006). It indiciates that sibling adjustment should be considered within the context of the family, and need to provide direct support to all members of family, not just siblings (Giallo & Gavidia-Payne, 2006).

A number of previous studies are reviewed from the assumption that siblings of children with disabilities are regarded as a homogeneous group. But they are a heterogeneous group that everyone has very different experiences and opinions according to a variety of characteristics. It indicates a need for further research of siblings and their relationships under families of children with disabilities. Moreover, most research on the siblings of children with ASD has been conducted within western culture frameworks which might be different from eastern culture frameworks. Along with it, it is not consistent with the result of research that has positive and negative effects on living with sibling of children with ASD (Kaminsky & Dewey, 2002).

### MULTICULTURAL ISSUES

Over the last two decades, it has become important to address the families of children with disabilities from diverse cultural background. Professionals will likely encounter families who have different values and beliefs from those of the majority of American families and, as such, it is critical that they have the knowledge necessary to provide appropriate supports and services (Harry, 1992b; Lynch & Stein, 1987).

A number of studies have been reported regarding family adjustment to the disabilities. However, there has been a paucity of research focusing on family adaption specific to ASD, and most of them emerge from Western cultural perspectives (National Research Council, 2001; Sage & Jegatheesan, 2010). Welterlin and LaRue (2007) pointed that research on immigrant families who have children with ASD are lacking though the number of immigrants is increasing in the United States. It is crucial to understand family with diverse cultural background because the most basic unit of cultural identity is the family (Dyches et al., 2004). Different cultures, languages, and religion are the factors made various experience of families of children with disabilities (Chan & Lee, 2004).

Similarly, Jegatheesan, Miller, and Fowler (2010) asserted that disability could be interpreted and understood by family members within cultural and religious beliefs. They reported that perceived causes of disability emerged from individual rationale (e.g., mother's dietary practices) to cultural rationale (e.g., blessing, punishment). For instance, specific judgments may be made on children with disabilities based on etiology of disability and the cultural background of the family. Some Latino mothers have reported accepting their child as a blessing or gift from God (Skinner et al., 1999), similar to African American families whose religion strongly influences their family (Dyches et al., 2004). On the other hand, disability is perceived as a stigma among Asian families, and they often regard their child's disability as a burden and an indicator of inferiority (Park & Turnbull, 2001; Sage & Jegatheesan, 2010).

When negative perception of disability impacts parents of children with disabilities, the sibling relationship can also be affected in a negative way because the role of parents is significant in nurturing their relationship (Sage & Jegatheesan, 2010). Though there is few research specific to sibling relationships within cultural context, one recent study by Sage and Jegatheesan (2010) reported different perceptions of sibling relationships of children with autism between European American and Asian American family. The results indicated that the perceptions and experiences of two typically developing siblings of children with ASD are different due to cultural and socioeconomic backgrounds (Sage & Jegatheesan, 2010). For example, European-Americans tend to view the etiology of autism are directly tied to genetics; they tend to respect differences between individuals so were not ashamed of their child and did not expect their typically-developing sibling to take on a caregiver role with their sibling with ASD (Sage & Jegatheesan, 2010). In contrast to European-American families, Asian-American families in the Sage and Jegatheesan (2010) study reported that the etiology of ASD is based on Karma; they often tried to hide the disability and there was an expectation that the typically-developing sibling would take on a caregiving role with their sibling with ASD (Sage & Jegatheesan, 2010). Likewise, Choi and Lam (2001), who surveyed Asian parents, reported that parents perceived disability as a manifestation of misfortune caused by others, oneself or God, as fate, or the unhappy consequence of misdeeds in a previous existence. Taken together, these findings demonstrate that understanding the perceptions and experiences based on cultural background is essential to address their needs.

Although multiculturalism has always been extensively discussed in American society (Dyches et al., 2004), Asian-American children in special education have received relatively scant attention. Certainly, research on specific national group represented in the Asian immigrant population are more missing though there are immense cultural differences between groups (Cho et al., 2000).

### AUTISM IN KOREAN CULTURE

Among Asian Americans, Koreans are the fifth largest Asian-American community after Chinese, Indians, Filipinos, and Vietnamese (Barnes & Bennett, 2002). As of 2013, approximately 1.1 million Korean immigrants (overwhelmingly from South Korea) reside in the United States, representing close to 3% of the 41.3 million foreign-born population (Department of Homeland Security, 2014). Although there is a growing number of incoming Korean immigrants, there remains a paucity of literature addressing the experience of Korean-American families with children with ASD.

In South Korea, the prevalence of ASD is estimated to be 2.64% which is the highest rate ever reported for ASD in any country (Kim et al., 2011). Researchers found that two-thirds of the school children identified as having autism in that study had gone previously undiagnosed and without services (Kim et al., 2011). Collectively this research suggests that there is a greater need to raise awareness about autism in the Korean community, whether in South Korea or in the United States, with the ultimate goal of enhancing access to services (Kim et al., 2011).

When we look into Korean culture and community, Korean attitudes towards children development vary according to a range of socio-demographic characteristics, country of residence, language skills, geographic origin within Korea, and religion (Kang-Yi et al., 2013). However, Korean attitudes towards children with disabilities are mostly negative in general. Therefore, under-referral of autism in the Korean community may be driven by lack of awareness, stigma, and lack of access to culturally appropriate services. Because of negative attitudes toward the term ASD, many families avoid registering their children as individual with ASD to access school and social services (Kim & Kang, 2003). Kim et al. (2011) also addressed that under-referral of ASD in Korea is because children with high functioning autism are in general education class without any referral.

Korean parents’ attitudes toward raising children differ from those of most American families. Despite rapid cultural changes in Korea in response to western culture, Koreans’ parenting style, parent-child relationships, and children’s development and behavior continue to be strongly influenced by Confucianism ideals, which highly value parental control over children’s lives and decision-making (Hong, 2006).

This view is supported by Park and Turnbull (2001), who write that parent-professional partnerships in Korea are based on the principles of Confucianism. As described in the study, Korea is known as the country which adapt Confucianism ideals which include “five virtues”: benevolence and humanism, righteousness, proper conduct, wisdom, and trustworthiness (Chan, 1998). Among these virtues, *proper conduct* is the concept that Koreans understand that professionals, such as teachers and doctors, must be treated with respect and deference (Park & Turnbull, 2001). Furthermore, Confucianism reflects the importance of gender and birth order on sibling relationship (Hwang & Charnley, 2010). As older children should take care of younger children, and boys have more responsibility than girls in Confucianism, siblings of children with ASD have reported responsibility differently (Hwang & Charnley, 2010). For example, sisters and younger brothers of older autistic siblings experience challenges more. However, they understood their responsibility over their siblings instead of regarding it as a burden (Hwang & Charnley, 2010).

Understanding Confucianism context is relevant to not only patterns of Korean living in South Korea, but also patterns of Korean living in the many different societies, including the United States (Kang-Yi et al., 2013). It is a similar result from the study by Bornstein and Cote (2009) that it is common for immigrants in the United States to maintain their traditional cultural practices. However, acculturation, the process of cultural adaptation by individuals, might have an impact on thinking and expression of Korean-American (Bornstein, & Cote, 2009). As such unique Korean culture, it has influenced on the lives of Korean family of children with disabilities. Under Confucianism and collectivistic perspectives, Korean has a different perspective on a caregiving role, a different parenting style, and a different commmunication style.

As culture is embedded in one's identity, Korean-American has lived under Korean culture. However, they also have embraced American culture since they have been under American culture and system. Looking into Korean-American life can be beneficial to understand Korean culture as well as American culture. Public attitudes and social services in society could be perceived through the study of recent immigrants' experiences, which includes between-group and intra-individual comparison study (Cho et al., 2000). Immigrants can also compare with the group in the country of origin (Cho et al., 2000). For example, Park & Turnbull (2001) examined how first-generation Korean-American parents perceive special education services in the United States. The result was shown that first-generation Korean-American parents regarded their children with disabilities more positively as they got some benefits in the United States (Park & Turnbull, 2001). By looking into parent experience, service delivery system in the United States can be interpreted that it is working well.

Overall, both within- and between-group comparisons help understanding how national contexts affect parental experiences in raising children with disabilities (Cho et al., 2000). In addition, comparison between family groups of the same culture in different national contexts could circumvent a barrier that overlook many aspect of the context because researchers who have been accustomed to the culture in the United States (Kalyanpur & Harry, 1999). Nevertheless, to date, research have not been conducted on comparing immigrant families of children with disabilities to their counterparts in their countries of origin (Cho et al., 2000). Given the importance of the embedded cultural context in family life, it is important to make clear not only sources of support or stress that reside in the environment but also the beliefs of family members (Antony & Banks-Joseph, 2010; Dyches et al., 2004; Park & Turnbull, 2001; Shin, 2002).

One of good examples is a study conducted by Cho et al. (2000) about comparing Korean mother experience and Korean-American mother experience to examine similarity and difference between them. As their nationality is rooted from South Korea, there are some similarities between them regarding raising the children with disabilities such as negative emotions for reaction to diagnosis (Cho et al., 2000). However, Korean and Korean-American reported different experiences and thoughts when raising the children with disabilities. For example, Korean-American mothers reported more sources of practical support than Korean mother, which made Korean parents frustrated and caused more stress on parenting (Cho et al., 2000). And Korean mother felt like they are not equal partners professionals as they need to treat with respect and deference, in the meanwhile Korean-American satisfied with the partnership with professionals in the United States educational system (Park & Turnbull, 2001).

Interestingly, Korean parents addressed that the only therapies for children with ASD were music therapy, massage therapy, play therapy, psychotherapy, and attachment promotion, while parents in other countries prefer behavioral and developmental interventions which is proved to be effective (Kang-Yi et al., 2013).

## THE CURRENT STUDY

To understand the perception on the diagnosis of ASD, sibling relationship and support needs, a vast body of research was reviewed in this chapter. Since the research has reported the needs of supporting a family as a whole, it requires in-depth research on the family perspective. A family has their own unique culture which forms itself in terms of rules, roles, and beliefs. Moreover, the ethnic culture may strongly influence family lives. Therefore, a family reports their own unique needs and supports. They involves maternal, parental, and sibling supports. Especially the research on the sibling supports is limited that requires more research.

Taken together, it is significant to consider the cultural context to perceive one’s family. The current study is specifically focused on Korean family of children with ASD. It has been noted that there is a high prevalence rate of ASD in Korea, but there is also a significant number of Korean who have immigrated to the United States. However, there is scant attention on the nature of Korean family functioning with children with ASD in terms of parental attitudes and sibling relationships. In general, the research is conducted on Korean-American immigrants’ experiences in the United States. The current study highlights a comparison between a Korean and Korean-American family. It could be expected to understand how cultural contexts affect parental experiences in raising children with disabilities from conducting between-group comparison study. This will further our understanding of how to serve the needs of culturally and linguistically diverse families of children with ASD.

# Chapter 3: Method

A cast study approach was used to help understand the lived experiences of two mothers of children with ASD, one Korean and one Korean-American. Multiple case studies were selected because it enables the researcher to qualitatively explore differences within and between cases (Yin, 2003). The cases were chosen carefully so that I could explore similar results across cases, or contrasting results based on a theory (Yin, 2003). Case study methodology uses a variety of data collection techniques to produce evidence that contributes to a better understanding of the case, but the most commonly used technique is participant interview (Gill et al., 2008). This method is appropriate when exploring an area that has not been previously researched and about which little is known. My purpose in this study was not to present generalizable findings, but to gain an in-depth understanding of two mother's perceptions of relationships with their child with ASD and their siblings, and generate hypotheses regarding differences that may be related to culture.

## RESEARCH SITES

The interviews for these two case studies were conducted in Seoul, South Korea and Houston, Texas. Seoul is the capital and largest metropolitan area in Korea, with a population of over 10 million. There are approximately twenty-nine segregated schools serving children with disabilities in the elementary and secondary grades in Seoul (Korea Ministry of Education and Human Resources Development, 2002). In addition to segregated schools, many general education schools served children with disabilities in self-contained classrooms (Park, 2002). Compared to the elementary program, early childhood programs are very limited and almost 85% of children with disabilities who would qualify the early childhood special education, do not attend any programs (Park, 2002). The Korean parent lived in apartment complexes populated by middle-class Koreans in a highly concentrated urban setting.

The Korean-American parent resided in the Houston area, which is one of ten places with the largest number of Asians in 2010 (United States Census Bureau, 2012). The participant was middle-class and had lived in Michigan before. Public school special education, and support services were available to these families. About 95% of ages 6-21 who were served under IDEA in 2012-13 were enrolled in general education class (United States Department of Education, 2014). In specific, Texas has the system called 'The Department of Assistive and Rehabilitative Services (DARS)' that administers programs to ensure providing same opportunities to live independent lives of people with disabilities. DARS provides services from early chlidhood intervention services to vocational rehabilitation services (Department of Assistive and Rehabilitative Services, 2015).

### RECRUITMENT

The two mothers of children with ASD were recruited in various ways. The Korean participant was recruited by sending flyers to one private segregated school and one community welfare center that served individuals with disabilities. The Korean-American participant was recruited through dissemination of flyers to a parental support group in Texas, Korean-American church, and the author's personal connection. The Korean-American mother was recruited first, and then I ensured that I was able to find a Korean participant with similar demographic background (i.e., age of her child and type of disability, number of siblings, SES, marital status). Criteria for selecting the participants were as follows: (a) mother, (b) child diagnosed with HFA (c) a family has at least one typically-developing sibling, and specific to the Korean-American family, (d) have lived in the United States more than 10 years. The two recruited mothers were the principal informants for their families.

## PARTICIPANTS

Two case studies were developed through interviews conducted with two upper-middle-class families, one from a Korean community in Seoul and another from a Korean-American church community in Houston, Texas, United States. Both mothers were contacted via email by the researcher to explain the study, respond to questions, and obtain written informed consent.

Two (one Korean and one Korean-American) mothers participated in this study. Each family had a son with ASD and siblings who were typically-developing. Table 1 provides a summary of the parents' background and Table 2 provides a summary of the children. All names are pseudonyms.

| | Park family | Lee family |
|---|---|---|
| Native Language | Korean | Korean |
| Number of years in the U. S. | - | 28 |
| Religion | Protestant | Protestant |
| Education (Mother & Father) | M: Bachelor's<br>F: Bachelor's | M: Bachelor's<br>F: Doctoral |
| Occupation (Mother & Father) | M: Part-time job<br>F: Businessman | M: Housewife<br>F: Engineer |
| Age (Mother & Father) | M: 60<br>F: 62 | M: 55<br>F: 59 |
| Primary caregiver | Mother | Mother |
| Number of children | 2 | 3 |
| Language spoken at home | Korean | Korean and English |
| SES | Middle | Middle |

Table 1: Family Information.

| | Park Family | Lee Family |
|---|---|---|
| Name, age, & gender of a child with ASD | Joon, 30, & Male | Dan, 23, & Male |
| Name, age, & gender of typically developing child | Jihye, 26, Female | Becky, 25, & Female<br>Priya, 21, & Female |
| Language spoken with children | Korean | Mostly English |
| Related Services for a child with ASD | Music Therapy<br>Physical Therapy | Vocational Job Coaching<br>Physical Therapy |

Table 2: Child Information.

### PROCEDURE

The researcher conducted a semi-structured interview with each mother. The researchers sometimes modified the wording and the order of questions to ensure a better understanding from the participating mothers, or to allow mothers to express their emotions on more sensitive themes. A naturalistic analysis approach was used wherein the participants were asked to respond to open-ended interview questions and added questions were added as prompts to guide the conversation. Participants were provided with sample questions in advance, so that they had a frame for the conversation and were more likely to be comfortable.

The interview settings were determined by mothers to support their comfort and convenience. Both mothers chose to do the interviews in Korean at their homes with the researcher, who is a native Korean speaker. Each interview lasted approximately 60-90 minutes and was audio-recorded for transcription purposes. In addition, the researcher kept field notes of other information from personal observations and impressions about the interview and home visits, such as descriptions of the homes and family routines. The recording was transcribed directly for analysis and partially translated into English in order to provide direct quotes.

The interview protocol was developed by the researcher, and was comprised of approximately 40 questions on four topics: (a) General background of the child and family (e.g., Tell me a little about your child with ASD, other typically developing siblings, and the family as a whole); (b) Disability and the family (e.g., What are some challenges/positives of having a child with ASD?); (c) Sibling relationship (e.g., How would you describe your children’s relationships with one another?); and (d) Support needs (e.g., Are there any suggestions you might offer to professionals who work with children with ASD and their siblings/parents?). Probing questions such as, “Tell me more” and/or “Give me an example,” were used to elicit answers to the specific questions or to obtain additional details (See Appendix A for a complete list of interview questions).

### DATA ANALYSIS

The researcher examined transcripts of the two interviews to identify themes and patterns. The identified themes and patterns were generated through multiple readings of the interview data. Transcribed interview data were color-coded and margin notes were made. Related ideas and concepts were grouped and categories and sub-categories were developed; there were then analyzed using in depth, cross-case analysis (Yin, 2003). The five analytic techniques summarized by Yin include pattern matching, explanation building, time-series analysis, logic models, and cross-case synthesis. Using those techniques, a data is analyzed based on four features: (a) attending to all the evidence, (b) addressing all major rival interpretations, (c) addressing most significant part of case study, and (d) using prior expert knowledge (Yin, 2003). The interview transcriptions and findings were shared with the participants to establish credibility and validity. Participants were given the opportunity to add or edit the information, but did not make any changes. Multiple strategies were implemented to ensure reliability and validity. They included (a) some interview questions were asked repeatedly in different forms to check the accuracy and consistency of information, (b) both mothers and siblings were invited to be interviewed for various information, (c) bilingual peers debriefed and checked the accuracy of translation, and (d) an expert performed a content check and feedback.

# Chapter 4: Discussion of Findings

Several themes emerged from the interviews conducted with mothers of children with ASD; these themes were related to the impact of disability and cultural differences between Korean and Korean-American culture. During the interviews, both mothers shared that they were influenced by Korean cultural tradition in spite of living in different contexts. Through my analyses, the following themes emerged: Resources and Support, Sibling Relationships, Family Dynamics, and Cross-Cultural Differences. Each theme is discussed below.

## RESOURCES & SUPPORT

Both participants shared their dissatisfaction with certain aspects of support system and resources. Both mothers felt confused before diagnosis since their children did not show a big difference with other children when they are young. As a result, they did not receive access to services and resources as soon as possible. Moreover, the Korean mother discussed that her child with HFA was not provided many options for services and program since he was not as severe as other children with disabilities. Both mentioned about lack of resources and supports for children with HFA but also their families. The participants' commentary related to resources and support can be categorized into three subthemes: (a) Diagnosis of HFA, (b) Informal Social Support, and (c) Formal Social Support.

**Diagnosis of High Functioning Autism.** Most of all, parents' dissatisfaction seemed to center around the confusion and frustrating experienced when trying to obtain a diagnosis of NFA for their children. Both mothers went through many trials and errors because of uncertainty on the diagnosis of HFA. For example, Mrs. Park (Korean mother) said "Doctor says the child's prognosis is good, however he compares it with the broken pottery. He diagnosed with 'Hyperactivity' while the others assumed 'Attention Deficit Disorder', 'Asperger's Syndrome'. That is what I heard." Similarly, Mrs. Lee (Korean-American mother) went through a difficult time to figure out the diagnosis of disability. She said, "It was not severe enough to enter a segregated special school, but not a normal, neither one nor the other. It was difficult all the time as it was a borderline case. It took a long time to figure out his symptoms… finally he was evaluated in high school. We have been struggling for a while."

In addition, both parents seemed to have received little information early on to help them understand their child's difficulties. Doctors diagnosed the children with all different types of disabilities, which made parents unsure how to deal with the symptoms. For instance, Mrs. Lee said "I did not know at all when he was a baby. When he entered elementary school, I was trying to teach some stuff and he could not even know how to grab a pen. However, when I went to see a doctor, he said that it is just because of lack of skills."

**Informal Social Support.** Previous research has found that most families of a child with ASD are supported by other families of children with ASD (Mackintosh, Myers, & Goin-Kochel, 2006; Twoy et al., 2007). Both mothers in this study reported receiving support from other mothers of children with ASD whom they met at their child's school. Mrs. Park said "There was a girl like my son. Her mother talked to me and thought it would be good to find a school that has a resource classroom for middle school." Similarly, Mrs. Lee said "I spontaneously met some mothers who have a son like me in American church. We talked and shared our children symptoms while camping and got to be friends." However, Mrs. Park mentioned the difficulty she had keeping up with other parents as their children got older. As she did not have much connection with other parents of children with ASD outside of school, she could not find resources or services available for adults with HFA.

"I no longer meet other mothers of children with ASD much. When they were young, we met at school or at field day. However, as they get older, we didn't have many chances to be in touch unless we were in the same program. Most of them move out and lose our contact information… and the program has age-limit as they get older. For example, up to 30 years old, up to 35 years old. As a result, people go their separate ways after 35 years old and it is difficult to keep in touch."

Along with the informal support from other families of children with disabilities, parents of children with ASD also reported supports from close friends and extended family (Twoy et al., 2007). However, it seems that these types of informal supports were less reported by these two Korean mothers. Wang and Casillas (2012) explained this trend lay in the decline of the extended family system for Asian-American families, which could also apply to Korean families. Moreover, the reason could be described by Asian culture that regards disability as a stigma (Park & Turnbull, 2001; Sage & Jegatheesan, 2010). As having a child with ASD could be a disgrace to the family, they might not want to share their difficulties with extended family members or other people outside of their core family unit. I noted this as a theme in the interview with Mrs. Lee. She explained: “I have some relatives in America and we occasionally meet up. One of the problems is that I felt disconnected from them. I do not want to meet up with other families.” It seemed easier for Mrs. Lee to find a support from people like other parents with similar experiences, instead of her extended families.

Mrs. Lee shared her experiences at school and the support she received from school professionals. There were some incidences where her son with ASD caused problems. Every time something of concern took place, a teacher or a principal would help manage the situation before it worsened. She could receive supports from school since school professionals have been well aware of his family. As her typically developing child is also in the same school, she could get more connection with other teachers and staffs which help not only her but also her children dealing with school issues. Mrs. Lee stated: “My son was suspended when he was a middle school student. One day I got a call from school. He explained that something had happened so that I went to the school. And I figured out that one of my son’s classmates had teased him. My son was a tease, as always I guess. I asked him what happened but he did not answer much, I guessed that something had happened. What I heard was that one classmate took my son’s pen and ran away at that time. My son got mad that he poked the classmate’s hand with his pen. It is a very serious matter in the United States. The teacher explained about the situation, and then a principal came to ask me how it happened. By the way, the principal’s daughter is a close friend of my daughter so that she knows me well…She said that do not call the other parent yet because they are so mad that they are not going to be nice. She could not help with suspending him because of a school policy and observers at that time. So he got suspended for a day."

Interestingly, both cases addressed religion and their church communities as one of the strongest types of informal supports received. This view is supported by Cho et al. (2000) who describes religion as a significant tool that guides Korean and Korean American parents toward acceptance of children with disabilities. Religion is described as a mechanism for helping both siblings and parents in becoming more tolerant of and loving toward their child with ASD, as well as to build resiliency and overcome the hardships they may face.

Throughout the interview, Mrs. Park talked about the word of Lord as a source of strength for every member of her family. "I talked to my daughter and said, 'Let's go to see a psychiatrist.' But she said that it is not medicine that could heal, and she will ask for healing herself through the gospel and bible as she is going church." Her family went to bible study for a few years with other families. The bible study teacher always talked to my daughter about overcoming her negative attitude by accepting the word of the Lord that makes her better able to handle hardships.

Similarly, Mrs. Lee believed that it is their daily night prayer routine that helps them get through each day. Mrs. Lee stated that living by faith is extremely helpful for her children in teaching them to be positive and loving. She said, "I think it has a big influence. They have been reading the Bible, praying, and growing under the Lord since childhood."

**Formal Social Support.** In regard to formal social support, I noted some differences between the responses from Mrs. Park and Mrs. Lee. Formal social support was operationalized as medical services, vocational services, transportation, and the public education system. Mrs. Lee stated that her child with ASD received diverse public services and highly valued them, as compared to Mrs. Park who did not have the same experiences. This would aligns with the suggestion by Cho et al. (2000) that Korean-American mothers receive more available practical support than Korean mothers. Mrs. Lee stated,

> "I highly appreciate the current Texas Department of Assistive and Rehabilitative Services (DARS) program. In DARS program, they help the child to get a job and train somehow. If the child gets a job, the DARS program provides them with the opportunity to practice [at workplace]. They follow the child at their workplace, and directly teach and explain what to do."

In contrast to Mrs. Lee's experience, Mrs. Park seemed to report fewer formal social support services or resources available for her child. For her son diagnosed with HFA, she found it challenging to find resources that might help them to deal with situations and were developmentally appropriate. In Korea, most sources for children with HFA rely on the book or journal article from the United States. The prevalence of HFA is not estimated precisely in South Korea as it has been usually confounded by diagnosis with another disability or no diagnosis at all. Specifically, Korea has less accessible resources because they are developed outside the country and need to be translated in order to be utilized in the Korean context. As a result, parents are at a loss when trying to figure out which resources to use._Moreover, Mrs. Park complained that her son was not eligible for various benefits for family of children ASD because of his HFA diagnosis. She felt quite dissatisfied with access to services, stating: “There is no benefit. Only transportation fee, free subway tickets. That is the only benefit we get.” A possible explanation for this might be due to the Korean welfare service system that is directly tied to the degree of disability. Korean Welfare of Disabled Persons Act classifies the degree of disability into six grades. As children with HFA have IQs that fall in the normal or even superior range, they are usually classified as a third grade disability—which means there are limited services available to them. Although her son received vocational training from Seoul Rehabilitation Center for the Handicapped Person, he has had major hurdles in trying to find a full-time job position and accommodations in the workplace.

Although there were some fairly substantial differences in receiving formal social supports, both mothers reported that they appreciated these services and noted the need for more formalized support services for individuals with ASD, particularly as they transition out of the public education system. There is a paucity of services and resources geared toward adults with ASD, especially HFA who may need supports that are less intense than adults with LFA. Mrs. Lee stated, “Recently there is nothing much for Dan to do. Usually staying at home, there is nowhere to go. I have arguments with him for that reason.” Formal social supports for adults with disabilities is an important topic that has been addressed by other researchers (Eaves & Ho, 2008; Gray et al., 2014; Levin, 2013). Gray and other researchers (2014) reported that a significant number of adults with ASD stay at home with families and unemployed. As a result, it is not surprising that there is a need for developing support interventions to improve their living and social skills.

Overall, both families of children with HFA seemed to access their informal social supports more easily than formal services and social supports. While their children with ASD received some formal social supports, siblings and other family formal seemed to be more difficult to find. Both mothers agreed that there was a need for increased formal supports to address the needs of siblings and family members of children with ASD. Mrs. Lee stated, “I wish there are support services for siblings of children with disabilities. I have never seen those services in Michigan or Texas. I do not know whether they have those kind of services. It would be really helpful to have those services. Because siblings think like ‘Why am I like this? Why do I go through these situations?’ Then other siblings of children with disabilities share like, ‘Yes, I have a similar experience.’ In this way it would be beneficial to understand their siblings with disabilities.”

As mentioned in the literature review, the research on the needs of siblings of children with disabilities is significantly lacking. It is not surprising that there is an absence of the sibling support services or resources considering the fact that very little attention has been paid to the experiences of typically-developing children being influenced by their siblings with disabilities (Hodapp et al., 2005). Future research is necessary to better understand how sibling support could best function, either through formal or informal support systems.

### SIBLING RELATIONSHIP

While there were no formal social supports reported for siblings of children with ASD, siblings went through ups and downs living with children with ASD. Both mothers shared their experiences with typically developing children. Sibling relationship is discussed by participants under three subthemes: (a) Stress and Demands, (b) Positive Sibling Relationship, and (c) Coping Strategy.

**Stress and Demands.** Several studies have focused on the potential negative impact of a siblings’ disability on children’s psychosocial and emotional adjustment (Kaminsky & Dewey, 2002; Roeyers & Buysse, 2003; Hastings, 2003b; Verte et al., 2003). In the interviews conducted for the present study, both mothers discussed the typically-developing siblings' psychological difficulties. As parents' attention is concentrated on the child with ASD, the other siblings often felt left out or disappointed with the lack of attention focused on them. Furthermore, they felt an unfair burden compared to their sibling with ASD, specifically related to their parents' high expectations of academic achievement and good behaviors. The mothers interviewed assumed that their children felt stress because of responsibility often placed on them to take care of or look out for their siblings with disabilities.

Mrs. Park stated, "They went to the same school and Jihye [sibling] got hurt a lot. So even now, she is sort of obsessed with it and afraid of getting attention from others' eyes." Although this improved overtime, Mrs. Park reported that her daughter continues to feel depressed, subdued, burdened, and pessimistic to this day. As her children got older, Mrs. Park found out that Jihye often felt left alone because of the time and energy her mother focused on the child with ASD.

"Jihye is very reticent and quiet student, and she experienced bullying. Her classmates always talked behind my daughter's back. She was mature for her age because I always talked about and was concerned about her brother. She thought that I was always tired because of my son. And she was worried that I would be stressed out if she tells this story. Therefore, she did not talk about bullying issue to me at all. She told me when she was in high school…She put up with it for years."

Mrs. Park felt sorry for her daughter and guilty that she could not take care of her as much. Madan-Swain et al. (1993) described the typically-developing sibling of a child with ASD as the "forgotten child." In this case, it seemed true that the Park family totally revolved around one child with ASD. Although Jihye fully appreciated the burdens her mother shouldered, she still felt left alone and stressed out from having a sibling with ASD who demanded a disproportionate amount of attention.

Likewise, Mrs. Lee shared similar impressions of her typically-developing children. Her oldest daughter, Becky, who does not express herself much, did not talk much about negative feelings or experiences with her sibling with ASD. On the other hand, her youngest daughter, Priya, experienced social stigma at school. She stated, “Until now, my youngest daughter is the one who had a negative impact from my son. She told me later. At that time she did not talk to us about it. When she is doing something with her friend and someone asks, ‘You are Dan’s sister?’ Whenever it happens, she felt a sense of embarrassment. Even though she was very outgoing in her way, maybe she got hurt.”

Mrs. Lee’s daughter and also Mrs. Park’s daughter reported difficulty building friendships and relationships. Attending the same school as their sibling seemed to have had an influence on the siblings’ social life. They had some difficulties dealing with the bias from others. Moreover, both mothers addressed their youngest sibling had more negative impacts from a child with ASD. These findings are in accord with a recent study by Hwang and Charnley (2010) indicating that younger sisters or brothers of older autistic siblings challenge more compared to older typically developing siblings. On the other hand, older siblings might not address their difficulties because of responsibility as the oldest child. Mrs. Lee talked that her oldest daughter might feel burdensome to meet high expectations from the parents. She stated, “I wish my oldest daughter become a doctor because she is smart and interested in biology. She planned to go to pre-medical school. After she got in university majored in biology, for pre-medical school, she found out something else than that. At that time, she just did whatever we ask, and she was trying her best to follow our words. One of the reasons for that is because of my son. Because of him, as the oldest daughter, she could support him in many ways as a doctor. Someday we are going to be old and die that we always keep in mind with it. Looking back on it, maybe I gave her too much burden.”

The findings of present study supported a study by Benderix and Sivberg (2007). They reported that older siblings seemed to have more responsibility for their siblings with disabilities. Overall, birth order has been associated with sibling relationship from literature review. Similarly, Mrs. Lee discussed some different experiences between her oldest daughter and youngest daughter.

**Positive Sibling Relationships.** Despite the stress and demands from living with a child with ASD, both mothers reported a positive sibling relationship. As reviewed in the literature, positive experiences reported by typically-developing siblings included acceptance, understanding diversity, being mature, and having a family time (Petalas et al., 2012; Wheeler, 2006).

Mrs. Lee stated that three of siblings hang out together all the time from daily routines to church retreat. Although there were some embarrassing moments for typically developing siblings, they always supported each other and had a sibling bonding. She stated,

"When our Priya had a difficult and tough time, she always called her brother not mother. She talked everything to him and wanted him to keep it between them. Likewise, my son had a problem, then either older sister or younger sister. Though there is no one to talk, there is something among them without me knowing."

Having a positive sibling relationship helped to build up their own support network in the family. Mrs. Lee reported that positive sibling relationship had a good influence on a child with ASD. One of the ASD symptoms is a lack of skill in interacting with others. However, siblings can help a child with ASD to develop social skills or communication skills. Mrs. Lee stated, "Our son could speak well like communicating with others for nowadays. The reason that he could speak like that is due to oldest daughter and youngest daughter."

Similarly, Mrs. Park's daughter admired her brother's linguistic talents. She stated, "As a brother knows so many things… Current company woman supervisor is chatting with a foreigner, actually she cannot speak English. So he did a work for her. She said that brother knows a lot more than me." As a child with HFA has a cognitively higher IQ, a sibling highly appreciated their talent and is proud of them as a brother. Overall, Mrs. Park reported less positive experience regarding sibling relationship compared to Mrs. Lee's experience.

There might be many factors related to the varying quality of sibling relationship. The factor related to the quality of sibling relationship is not clearly discovered. However, one of the factors may be the family size. Some studies reported that siblings tend to do better in bigger families than smaller. Specifically, Mrs. Park has only two children while Mrs. Lee has three children in the family. This difference may explain why Lee family reports more positive siblings relationship. Three siblings are like a team that they share anything whenever they are happy or sad. However, Mrs. Park's daughter might feel lonely in the context because there is no one talk about what she felt and experienced other than parents.

**Coping Strategies.** Both mothers reported a religion as a siblings' coping strategy. Religion played the key role to adapt and accommodate children with ASD. Mrs. Lee stated, "It is so relieved to have older and younger sisters; with faith in Lord, they love more their siblings, accept better on the sacrifice for siblings, and understand more the difficulties of having a sibling with ASD."

She explained that her typically-developing children are involved in the church and their first priority is always serving the Lord. Similarly, Mrs. Park also reported that how her daughter went through difficult times. She always had a negative self-concept or attitude in the past. At that time, Mrs. Park suggested her to take a medication for a short term. However, she decided to handle it with the word of Lord instead of medication. To overcome emotional disturbance, she went to the bible study and studied from the teacher. Both mothers' interview is consistent with findings obtained from Cho et al. (2000). Researchers already talked about the significant role of religion for Korean and Korean American mother to adapt to children with disabilities.

In summary, these findings revealed that siblings seemed to be well-adjusted to children with ASD. However, they always had a few challenges in daily life which means their needs must not be overlooked.

## FAMILY DYNAMICS

When it comes to sibling relationships, family dynamics should be discussed. Bowen (1978) explained that family members are linked to each other that it cannot be understood without concerning about a whole family. Therefore, siblings' needs should be investigated within the context of the family (Giallo & Gavidia-Payne, 2006). It is no doubt that having a child with ASD affects all family members. Both mothers' interview could be analyzed into three themes that are impact on the mother, impact on parent relationship, and impact on the family.

**Impact on the Mother.** Both mothers shared their stress and demands on raising a child with ASD. Interview findings are consistent with Hastings's (2003) and Herring et al.'s (2006) findings, which reported high level of maternal stress related to a child with ASD. For instance, Mrs. Park stated, "In my case, my husband business was bad, my older child have been diagnosed with ASD, my younger child was always negative on everything, and I need to work to help pay for living costs. So I talked to her. My younger child is always saying 'I cannot do this, I cannot do that!' and keep being negative; And I try to ask her to do something, it does not work; I bought her clothes to please her…but after all she still says 'No, I cannot!', a negative attitude coming out again. I was so exhausted. How would it be one plus five not one plus one. I'm going crazy. How could they make me this much tired as a family?"

Mrs. Park felt like she was always the one who was trying to fix the situation. She reported depression, frustration, anxiety, and exhaustion from taking care of a whole family. Nevertheless, she also felt responsibility to take care of all family issues as a primary caregiver of a child with ASD. As previously discussed, mothers typically felt more responsibilities to take care of a child with ASD than fathers (Baker-Ericzen et al., 2005; Gray, 2003). Likewise, Mrs. Lee reported that the responsibilities of raising a child with ASD weighed her down in and out of family. She stated, "I went to school for volunteer everyday like a sinner. If a teacher needs help, I was willing to help anything…" Whenever a teacher needs help, she was willing to be there to show respect to the teacher as a caregiver. Due to taking care of her son, she gave up on pursuing her graduate study either. She said, "At that time I came here and went to school studying accounting. But I felt that it was extravagant for me to study in this situation. So I dropped out of school, and my health was getting worse at that time. It was too much for me to study for myself while raising three children. So I gave up…"

As she mentioned, she devoted her whole life for raising the child with ASD as well as taking care of family. In addition, she felt always worried on everything about her son. For example, when her husband wanted to travel with her, she always could not let go of her son. She was anxious about the future of him as well as his siblings. She said, “I want my daughters not married at some point. I just feel like that. I do not know. I know it is a wrong thought as we live together…but if they have a child like my son, they will be [effected] in many ways forever…”

She worried about not only the child with ASD but also his siblings because she took care of every family members as a primary caregiver. However, maternal stress could be relieved when siblings help her out. Mrs. Lee stated, “In summer, we sent them together to game camp. It is the time that we can take a rest. Throughout a year, I and my husband travel together while all children go for camping. And I feel relaxed wherever I go because there is older sister and younger sister.”

It is no doubt that mothers experience stress, anxiety, and frustration regarding raising a child with ASD. However, as Mrs. Lee said, it could reduce by receiving a support from family members. This is aligned with the previous finding that caregiver’s stress can be reduced on account of the shared caregiving experiences with family, friends, community, and support group (Murphy et al., 2006; Twoy et al., 2007). Therefore, parent empowerment has been received a lot of attention to reduce the stress of parents and increase family adjustment (Baker-Ericzen et al., 2005).

**Impact on Parent Relationship.** One of mothers' demands came from lack of support from husbands. Both mothers reported that they took care of everything about a child with ASD while their husband could not help. Mrs. Park stated, "Regarding the relationship between husband and wife, we cannot really say since it is our responsibility. We should have had just one child. Why did we have one more child that makes her life difficult? Moreover, my husband did not play a head of household role well. Whew! I thought that it is my destiny to take care all of them. We just live together legally."

She expressed burden and frustration as taking care of all family issue by herself. Mrs. Lee also shared that she was the one who always bring a child with ASD to the hospital and take care of him all the time. Although she understood that how busy her husband was at work, she felt frustrated with her husband's lack of awareness of their child with ASD. Her husband always treated her and typically developing children nicely, while very strict to a child with ASD. To specific, she and her husband often had a different discipline on a challenging behavior that brought marital conflict. She stated,

"It was difficult at the first time, I and my husband have a different opinion now. My husband thinks that he can do anything if we train and discipline him in a Korean traditional way. On the other hand, I think we should accept him as the way he is. He scolded him a lot to discipline his behaviors. I understand that there is something we can fix, but in my opinion, let's accept him as the way he is and try to see strengths in him. In fact, we are still struggling about that a lot."

Marital conflicts are occurred due to the different perspectives on raising a child with ASD. As they immigrated to America in their 30s, Korean culture influenced on their perceptions. In the same vein, Bornstein & Cote (2009) reported that diverse cultural values are existed in the United States as immigrants bring them into the country. Similarly, Mr. Lee still stick to Korean style of raising a child that is strict education style. This finding indicated that cultural difference should be considered in regard to the support for family of children with ASD.

Obviously, discord with marital relationship could be very stressful for a child with ASD, as well as for his/her siblings. Previous research has reported that parenting stress influenced on sibling adjustment to a child with ASD (Giallo & Gavidia-Payne, 2006; Hesse et al., 2013). Mrs. Lee stated, “We went for summer vacation to Bahama. I do not remember exactly about what happened, but my husband was disciplining him in the middle of vacation which made me and my two daughters feel terrible.” Her two daughters also stressed out when their parents had a argument on a child with ASD. It can be related to the family system theory by Bowen (1978) that family is interconnected.

**Impact on The Family.** Overall, as a primary caregiver of a child with ASD, both mothers expressed stress and concerns for a child with ASD. In addition, marital conflict is also one of the stressors that mothers mentioned. However, as mothers discussed earlier, they appreciated the support from other family members. Above all, a child with ASD influences all family members in both positive and negative ways (Allen & Petr, 1996; Turnbull et al., 2004). Among them, one of the positive impacts is the increased level of family cohesion.

Both mothers stated the high level of family cohesion because of a child with ASD. Mrs. Park presented that only family can understand other family members’ stress, demands, and support: “Me and my children hang out together a lot. Sometimes my daughter asks her brother to go somewhere together because she has a timid personality…Even now she texted me ‘Mom, I finished the work’ ‘What time do you want to meet up at terminal? Let’s go for shopping.’ This is the way of relieving her stress. Me either. ‘I finished work early today. Do you want to go somewhere? I am on my way from school so let’s meet up.’ There is nothing special. We reduce our stress by having a conversation together or buying a something small and cheap that we like. Others cannot understand because they do not know how it looks like living with a child with ASD. It is not easy to understand. Thus my family is always the best.”

When many difficulties occurred, Park family deal with their stress by taking care of each other. Since a family knows each other the best, they are the biggest informal social support. Likewise, Mrs. Lee stated their family as a team. She stated: “We stick more and more to our family. When we go travel, our family. Our family went travel every summer before our oldest daughter went to college. After that, we did not go travel much. After they grew up, we could not go for a family trip without anyone leave behind. We do not go if one says she could not make it.”

She described the family trip is the happiest memory for her child with ASD as well as her family. She brought up a reason why they stick to their family. She said,

“We have relatives in America but we barely meet up. And one problem is the disconnection with others. I do not want to meet other families. I have two sisters. We had lived together in Michigan before. I talked on the phone sometimes about my son, however they could not understand well. Even though I shared, they just knew a little how much it had been difficult for me. I used to talk about my son in the past but I stopped it later. I did not want to explain them…So I just stick more and more to our family.”

Except for families who have a similar situation with them, Mrs. Lee thought that others, even her relatives, could not understand well how difficult it is to live with a child with ASD. Instead of talking to others, she assumed that it would be helpful to deal with stress and demands within the family. The family shared all ups and downs together as a team that led to higher level of family cohesion.

In summary, these findings show that each family member has unique experiences of living with a child with ASD. However, the mothers' interview clearly noted additional positive influences on the family. Specifically, many families provided evidences of family resilience such as family connection and closeness. (Bayat, 2007; Twoy et al., 2007). Further study should be undertaken to investigate how to enhance family resilience that empowers a family of children with ASD.

## CULTURAL COMPARISON

One of the central goals of the current study was to compare Korean and Korean-American mothers' experiences raising a child with ASD. Some cultural differences were noted as well as a number of similarities. Despite 28 years living in America, Korean-American parents lived under traditional Korean cultural values such as Confucianism (Kang-Yi et al, 2013) that led to differences within their current cultural context.

First of all, one of the major differences is the attitude towards medication. Both mothers expressed negative opinions on medication to reduce challenging behaviors. Mrs. Lee even felt angry when professionals recommended her son to take medication. She reported it was too easy to get a prescription for medication in the United States. She said, "Here in America, if children have some issues, teachers just give them prescription. It is really not good. Medication is very easily recommended here."

Even she felt like a child with Attention deficit hyperactivity disorder/ Attention deficit disorder (ADHD/ADD) was regarded as a normal child in America. Medication is regarded as the easiest and fastest way to alleviate the symptoms of a child with mild disabilities. However, Mrs. Lee disagreed with the use of medication on her son. She stated,

"The doctor told us to take a medicine but I really hated it. Any medicine has a side effect. But he suggested that we should try it. I really do not want to take it at that time. I got a prescription, but I did not give the medicine to my son. I felt like I am giving him a poison in the morning. Moreover, when he takes a medicine, he does not eat meals because of side effects. I was upset when I saw my son getting skinnier and not sleeping much either."

She was aware of many side effects of using medication so that she did not prefer to use medication. This finding is also reported from Mrs. Park's interview. She expressed negative feelings using medication.

Second, Mrs. Lee addressed the independence as a primary American parenting goal. Due to the influence of American parenting, she realized that she should let children live by themselves. It helped reducing burden of typically developing siblings regarding take care of a child with ASD in the future. Mrs. Lee reported, "Currently, they live separately…they live on their own when they go to college in America…I have been thinking lately that I should not expect them. They are living in their own ways, and he is living on his way independently."

She adapted the independence of their children much easily as it is common perception in American parenting. As well, her daughters also reported the independent living in the future while taking care of their sibling with ASD. Unlike Mrs. Lee, Mrs. Park did not address much about the independence of her children. As Korean live separately when they are married, the independence is considered later in the future compared to American. It is much more important for Korean to integrate with others in society.

Third, there are some different perspectives between Korean and Korean-American mother towards practical supports for family of children with ASD. Mrs. Lee is satisfied with the benefits that they can get from the school, society, and the nation. On the contrary, Mrs. Park was frustrated as she could not expect practical supports in Korea. Mrs. Park said that, "I was so frustrated when he was young that one teacher told me to give him up for adoption in America. She said that they will educate and do everything for him to his level.” It is common that Korean expect better support system in America. Along with it, Mrs. Lee stated that, “It is really nice for children and even teachers at school in America compared to Korea.” This finding is in accord with the study by Park & Turnbull (2001) that first-generation Korean-American parents reported positively on some benefits in America.

In addition to better educational system in America, Korean-American mother addressed a better informal social support system from family of children with disabilities advocacy group. Mrs. Lee stated, “In America, there are many groups something like…it does not have any special purposes or not be benefited from it. Instead of it, it has a meaning just share my feelings and experiences with others who have similar experiences like me.”

Compared to Korea, a family support network is well-established in America. A possible explanation for it might be cultural diversity in America. The United States is sometimes described as a "melting pot" in which different cultures have contributed their own distinct "flavors" to American culture. Cultural diversity could contribute many different advocacy group available in America compared to other countries. And a family of children with disabilities can be supported from those support networks.

On the other hand, Korean culture can be seen from Korean-American society because they attempts to preserve an immigrant culture against the back drop of America. For example, there is less understanding of a child with disability under Korean-American society that is similar to Korean society. Lee family used to go to Korean-American church in Michigan. However, they could not well-adjusted themselves to the atmosphere of Korean-American church so that they move to American church. She stated,

“Korean church is very different. There are many things that mothers or close people gather up and do something…It is one of Korean characteristics. Korean church people have less understanding so that we could not stay in the church. We could not take it anymore, and we eventually move to American church."

This finding corroborates the study of Park and Turnbull (2001), who suggested that Asian families often hold a stigma for having a child with ASD. It does not matter how many years they have lived in America, Korean-American persist their own Korean values and beliefs. Even Mrs. Lee's youngest daughter, who is a second-generation Korean-American, wants to learn Korean because she regarded herself in the middle of American identity and Korean identity.

In summary, both mothers considered that the American educational system is better for children with disabilities. Along with it, Korean-American mother discuss a number of Korean culture against the back drop of America. This finding has significant implications for understanding a multi-cultural background of a family to support them.

Table 3 summarizes the themes and presents illustrative quotes for each family.

| Themes | Subthemes | Illustrative Quotes |
|---|---|---|
| Resources & Support | Diagnosis of HFA | - "He says the child's prognosis is good, however he compares it with the broken pottery. He diagnosed with 'Hyperactivity' while the others assumed 'Attention Deficit Disorder', 'Asperger's Syndrome'. That is what I heard." (Mrs. Park)<br>- "It was not severe to enter a segregated special school, but not a normal, neither one nor the other. It was difficult all the time as it was a borderline case. It took for a long time to figure out his symptoms…finally he was evaluated in high school. We have been struggling for a while." (Mrs. Lee) |

Table 3: Summary of Themes and Quotes

*Note.* Mothers' quotes translated by author from Korean to English

| | | |
|---|---|---|
| | Informal Social Support | - “There was a girl like my son. Her mother talked to me that it would be good to find out school that has a resource classroom for middle school.” (Mrs. Park)<br>- “I no longer meet other mothers of children with ASD much. When they are young, we meet at school or at field day. However, after they get older, we do not have much chances to be in touch unless we are in the same program. Most of them move out and lose our contact information…and the program has age-limit if they get older. For example, up to 30 years old, up to 35 years old. As a result, people go separate ways after 35 years old that mostly it is difficult to keep in touch.” (Mrs. Park)<br>- “I have some relatives in America but we occasionally meet up. One of the problem is that I felt disconnected a lot with them. I do not want to meet up with other families.” (Mrs. Lee)<br>- “I think it has a big influence that reading a bible, praying, and growing under the Lord since a childhood.” (Mrs. Lee) |
| | Formal Social Support | - “I highly appreciate current Texas Department of Assistive and Rehabilitative Services (DARS) program. In DARS program, they help the child to get a job and train somehow. If the child get a job, current service in DARS provides the process of practicing [at workplace]. They follow the child’s workplace, and directly teach and explain what to do.” (Mrs. Lee)<br>- “But a teacher said that there is no translated data, no precedent, and no sources after 7 years old while going Ewha Commmunity Welfare Center. There is no translated data that is from abroad. So I was at a loss for words. Then I started worrying about what I should do in the future. From there, it stopped dead.” (Mrs. Park) |

Table 3. (Continued)

| | | |
|---|---|---|
| | Formal Social Support | - “I wish there are support services for siblings of children with disabilities. I have never seen those services here in Michigan or Texas. I do not know well whether they have those kind of services. It would be really helpful to have those services. Because siblings think like ‘Why am I like this? Why do I go through these situations?’ Then other siblings of children with disabilities share like, ‘Yes, I have a similar experience.’ In this way it would be beneficial to understand their siblings with disabilities.” (Mrs. Lee)<br>- “There is no benefit. Only transportation fee, free subway tickets. That is the only benefit we get.” (Mrs. Park) |
| Sibling Relationships | Stress and Demands | - “Jihye is very reticent and quiet student that she experienced bullying. They said something behind her back. She was mature for her age because I always talked about and concerned about a brother. My mother is always tired because of my brother so that if I talk about this story she might feel much stress. She did not talk to me at all. She talked about it when she was in high school…So she put up with that for years.” (Mrs. Park)<br>- “Until now, youngest daughter is the one who had a negative impact from my son. She told me later. At that time she did not talk to us about it. When she is doing something with her friend, ‘You are Dan’s sister?’ Whenever it happens, she felt a sense of awful. Even though she was very outgoing in her way, maybe she got hurt.” (Mrs. Lee)<br>-“I wish my oldest daughter become a doctor because she is smart and interested in biology. She planned to go to pre-medical school. After she got in university majored in biology, she found out something else than that. At that time, she just did whatever we ask, and she was trying her best to follow our words. |

Table 3. (Continued)

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|  |  | One of the reasons for that is because of my son. Because of him, as the oldest daughter, she could support him in many ways as a doctor. Someday we are going to be old and die that we always keep in mind with it. Looking back on it, maybe I gave her too much burden." (Mrs. Lee) |
|  | Positive Sibling Relationship | - "When our Priya had a difficult and tough time, she always called her brother not mother. She asked him that do not talk about what they talked about to mother. Likewise, my son had a problem, then either older sister or younger sister. Though there is no one to talk, there is something among them without me knowing." (Mrs. Lee)<br>- "Our son could speak well like communicating with others for nowadays. The reason that he could speak like that is due to oldest daughter and youngest daughter." (Mrs. Lee)<br>- "As a brother knows so many things… Current company woman supervisor is chatting with a foreigner, actually she cannot speak English. So he did a work for her. She said that brother knows a lot more than me." (Mrs. Park) |
|  | Coping Strategies | - "It is so relieved to have older and younger sisters; With faith in Lord, they love more their siblings, accept better on the sacrifice for siblings, and understand more the difficulties of having a sibling with ASD." (Mrs. Lee) |

Table 3. (Continued)

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|---|---|---|
| Family Dynamics | Impact on the Mother | - "In my case, my husband business was bad, my older child have been diagnosed with ASD, my younger child was always negative on everything, and I need to work to help pay for living costs. So I talked to her. My younger child is always saying 'I cannot do this, I cannot do that!' and keep being negative; And I try to ask her to do something, it does not work; I bought her clothes to please her…but after all she still says 'No, I cannot!', a negative attitude coming out again. I was so exhausted. How would it be one plus five not one plus one. I'm going crazy. How could they make me this much tired as a family?" (Mrs. Park)<br>- "At that time I came here and went to school studying accounting. But I felt that it was extravagant for me to study in this situation. So I dropped out of graduate school, and my health was getting worse at that time. It was too much for me to study for myself while raising three children. So I gave up…" (Mrs. Lee)<br>- "I want my daughters not married at some point. I just feel like that. I do not know. I know it is a wrong thought as we live together…but if they have a child like my son, they will be [effected] in many ways forever…" (Mrs. Lee)<br>- "In summer, we sent them together to game camp. It is the time that we can take a rest. Throughout a year, I and my husband travel together while all children are in camping. And I feel relaxed wherever I go because there is older sister and younger sister." (Mrs. Lee) |
|  | Impact on Parent Relationship | - "Regarding the relationship between husband and wife, we cannot really say since it is our responsibility. We should have had just one child. Why did we have one more child that makes her life difficult? Moreover, my husband did not play a head of household role well. Whew! I thought that it is my destiny to take care all of them. We just live together legally." (Mrs. Park) |

Table 3. (Continued)

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| | Impact on Parent Relationship | - "It was difficult at the first time, me and my husband have a different opinion. My husband thinks that he can do anything if we train and discipline him in a Korean traditional way. On the other hand, I think we should accept him as the way he is. He scolded him a lot to discipline his behaviors. I understand that there is something we can fix, but in my opinion, let's accept him as the way he is and try to see strengths in him. In fact, we are still struggling about that a lot." (Mrs. Lee)<br>- "We went for summer vacation to Bahama. I do not remember exactly about what happened, but my husband was disciplining him in the middle of vacation which made me and my two daughters felt terrible." (Mrs. Lee) |
| | Impact on The Family | - "Me and my children hang out together a lot. Sometimes my daughter asks her brother to go somewhere together because she has a timid personality…Even now she texted me 'Mom, I finished the work' 'What time do you want to meet up at terminal? Let's go for shopping.' This is the way of relieving her stress. Me either. 'I finished work early today. Do you want to go somewhere? I am on my way from school so let's meet up.' There is nothing special. We reduce our stress by having a conversation together or buying something small and cheap that we like. Others cannot understand because they do not know how it looks like living with a child with ASD. It is not easy to understand. Thus my family is always the best." (Mrs. Park)<br>- "We stick more and more to our family. When we go travel, our family. Our family went travel every summer before our oldest daughter went to college. After that, we did not go travel much. After they grew up, we cannot go for a family trip without anyone leave behind. We do not go if one says she could not make it." (Mrs. Lee) |

Table 3. (Continued)

| | | |
|---|---|---|
| | Impact on The Family | - “We have relatives in America but we barely meet up. And one problem is the disconnection with others. I do not want to meet other families. I have two sisters. We had lived together in Michigan before. I talked on the phone sometimes about my son, however they could not understand well. Even though I shared, they just knew a little how much it had been difficult for me. I used to talk about my son in the past but I stopped it later. I did not want to explain them…So I just stick more and more to our family.” (Mrs. Lee) |
| Cultural Comparison | | - “Here in America, if children have some issues, teachers just give them prescription. It is really not good. Medication is very easily recommended here.” (Mrs. Lee)<br>- “The doctor told us to take a medicine but I really hated it. Any medicine has a side effect. But he suggested that we should try it. I really do not want to take it at that time. I got a prescription, but I did not give the medicine to my son. I felt like I am giving him a poison in the morning. Moreover, when he takes a medicine, he does not eat meals because of side effects. I was upset when I saw my son getting skinnier and not sleeping much either.” (Mrs. Lee)<br>- “Currently, they live separately…they live on their own when they go to college in America…I have been thinking lately that I should not expect them. They are living in their own ways, and he is living on his way independently.” (Mrs. Lee)<br>- “I was so frustrated when he was young that one teacher told me to give him up for adoption in America. She said that they will educate and do everything for him to his level.” (Mrs. Park) |

Table 3. (Continued)

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|---|---|
| | - “In America, there are many groups something like…it does not have any special purposes or not be benefited from it. Instead of it, it has a meaning just share my feelings and experiences with others who have experiences like me.” (Mrs. Lee)<br>- “Korean church is very different. There are many things that mothers or close people gather up and do something…It is one of Korean characteristics. Korean church people have less understanding so that we could not stay in the church. We could not take it anymore, and we eventually move to American church.” (Mrs. Lee) |

Table 3. (Continued)

# Chapter 5: Limitations

Though this study contributes to the growing knowledge base on ASD and families under multicultural contexts, this study was subject to limitations. The major limitation of this study is the case study design; although this permitting me to delve into the life experiences of two families, the design is limited in the generalizability of findings to other Korean families. These findings cannot be considered representative of all Korean or Korean-American families. Nevertheless, these findings may open the door to questions that guide future studies on sibling relationships and family needs in different cultural contexts.

Second, the author, who conducted the interviews, also completed the coding and data analysis. Though steps were taken to avoid the researcher bias, there may have been an influence on the findings. Future work should consider gathering data through multiple sources and seeking inter-rater reliability with coding of interview transcripts.

Finally, it is unfortunate that the study did not include family members other than mothers. This study would be able to provide in-depth information through interview with the typically developing siblings or fathers. More research is required to find out different perceptions among family members.

# Chapter 6: Conclusion & Implications

The purpose of this study was to understand perceptions between Korean and Korean-American mothers on the disability itself, family/sibling adjustment to the child with ASD. Despite its limitations, this study had a number of important implications for future research.

First, this study has found that there are cultural contributions to family interaction and family perspectives. Many years of assimilation may have influenced Korean-American parent perceptions. However, the result of this study indicated that Korean-American still embraced some of their traditional Korean values and beliefs. Korean-American society has maintained their own unique cultural values and beliefs while accepting a part of American values and beliefs. For instance, they raised the children with a goal of independence, and were eager to participate in self-advocacy support network. On the other hand, they were pessimistic about the use of medication, and they considered religion as well as family member as their biggest support. Based on the findings, in-depth research is required to understand insights into Korean-American families' perceptions of the different cultural background impacts on the children with ASD as well as their families. Based on the differences reviewed in this study, support for the families of children with ASD can be limited without understanding of Korean culture.

Second, this study has identified that sibling adjustment to the children with ASD could be influenced by many factors. This study confirmed that siblings shared positive and negative impacts from living with a sibling with ASD. Overall, sibling relationship could be varied based on sex, birth order, family size, and family cohesion. Therefore, it would be interesting to assess the factors that impacts on sibling adjustment and sibling bonding. It highlighted the importance of family cohesion to the sibling adjustment process. In other words, sibling relationship should be examined and supported within the family context.

Lastly, one of the challenges that siblings of children with ASD might face is lack of formal or informal support system. It is well-known that siblings of children with ASD might have an issue considering their psychological, behavioral, and relational adaptation. Though typically developing siblings' demands and stress were addressed in the literature, there are available support network systems for those children neither in Korea nor in America. Further research should be carried out to establish the sibling support network system. Sharing the experiences among siblings of children with ASD might be very helpful for reducing the anxiety, stress, and demands. Continued efforts are needed to make siblings of children with ASD more accessible to the sibling support programs.

## CONCLUSION

The results of this study provides descriptive information about the living of Korean and Korean-American families of children with ASD. This pair of case studies of families from two different cultural backgrounds suggests that understanding of cultural background is essential to assess and support the needs of Korean-American families. As the number of immigrants in the United States increases, more research must be applied to support those families.

Additionally, this study adds to a growing body of literature on understanding the needs of siblings of children with ASD. Given the limited research on the siblings of children with ASD, this study have implications for future research. As a family is a unit that interconnected, understanding siblings' needs within the family context is necessary. Moreover, it would be beneficial for typically developing siblings to have an advocacy group. Siblings can share their experiences and feelings with other siblings in the advocacy group.

# Appendix A (List of Interview Question)

## Family Background Information

1. Tell me a little about your child with ASD, other children, and the family as a whole.
    - Birthdate of all children in family
    - When was your child diagnosed?
    - What specific diagnosis was he/she given?
2. Describe a typical day for your family.
3. What are some of the things you like to do together as a family?
4. What kinds of activities are you involved in for leisure? Your children? Your spouse/partner?

## Disability and the Family

1. Tell me what you know about ASD.
2. When you were first introduced to the possibility that your child had ASD, what type of information did you seek out?
3. What does having a child with ASD mean to you? What does it mean to you as a family? Has the diagnosis changed your family life?
4. What helped you and your family most during that time when you first found out about the diagnosis?
    - What was not helpful to you during that time?
    - How are you feeling about things now?
5. How would you describe your relationship with your child with ASD? Your other children?
6. How would you describe your spouse's/partner's relationship with the children?

7. What are some of the challenges of having a child with ASD?
8. What are some of the positives of having a child with ASD?
9. Tell me about your experience as a parent and couple caring for a child with ASD. What are some of the things that you (the parent) like to do with your children/each child?
10. What are your goals for your child with ASD in school?
11. What would be different in your family if you don't have a child with ASD?

## Sibling Relationship

1. How has it been for your other children having a sibling with ASD?
2. What do your children know about ASD in general?
3. Do your children know about your child's diagnosis (including the child with ASD)?
4. How did you tell them about the diagnosis? Do you remember how you explained it to them? What did you say?
5. How would you describe your children's relationships with one another?
    - Do they play together? Are they close? How many times do they argue?
6. What are some of the things your children like to do together?
7. Do you think your child's disability shapes how he/she engages with the family?
8. What do you think would be different in siblings' life if they don't have a brother with ASD?

## Support Needs

1. What types of supports are you currently receiving/received in the past?
2. Are you on the waitlist for any services?

3. Are/were there any specific services that you found particularly helpful to you (as a parent) or your children?
4. Are there any types of support that you wish would have been or could be available to you and your children?
5. What types of support are/were least helpful to you?
6. Are there any suggestions you might offer to professionals who work with children with ASD and their siblings/parents?
7. Are there any sibling support needs (both for the child with and without ASD) that you would like professionals to know about?
8. Are any of your children involved in any support services related to the ASD (i.e., sibling support services, individual counseling, and a group therapy).

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