

PARENTAL EXPERIENCES OF KOREAN-AMERICAN IMMIGRANT PARENTS OF
CHILDREN WITH DEVELOPMENTAL DISABILITIES: STRESS AND HOPE

by

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(Under the Direction of M. Elizabeth Vonk)

ABSTRACT

Caring for children with developmental disabilities (DDs) poses unique stress and demands on parents. The parents of children with DDs reported higher physical and mental problems compared to other parents of children without DDs. Over the past decades, the number of immigrant families from diverse cultures has shown rapid growth. Korean-Americans (KA) are one of the fastest growing populations in the United States. Immigrant parents of children with DDs may have unique experiences in caring for their child with DDs, but no study to date has examined KA immigrant parents' experiences in terms of dealing with parental challenges. The purpose of this study is to understand the process of how KA immigrant parents manage parental challenges in raising their children with DDs. In this study, a grounded theory approach was employed. Snowball and theoretical sampling were utilized to select participants; 20 KA parents participated in the study. In-depth interviews (either face-to-face or on the phone) were conducted in the parents' native language, Korean. This study utilized qualitative software, Nvivo 10, for analyzing data, and it applied grounded theory data analysis methods (i.e. open and axial coding).

From rich and illustrative descriptions provided by KA immigrant parents who raise children with DDs, the hope for development theory was developed in relation to experiences in caring for children with DDs. In everyday life, parents encountered challenges due to a wide variety of reasons, making them feel overwhelmed. Nevertheless, they have continued caring for their children. Parents' hope for their child's development in terms of any aspect can be their fuel in their long journey. Once parents had hope for their child's development, parents invested their time and finances and tried whatever they could do to fulfill their hope. Depending on the degree to which they obtained their desired outcomes, parents experienced different emotions ranging from positive to negative. Social support can affect investments, outcomes, and emotional reactions, and as such parents adjusted their hope for their child based on achieved outcomes. This caring management process seems to be repeated across their life course. Findings, implications for social work practice, limitations, and recommendations for future study are also discussed.

INDEX WORDS: Developmental Disabilities, Korean-American immigrants, Parenting stress, Parenting experiences, Hope

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DEDICATION

First and foremost, I dedicate this to God who prepares a way for me and gives me strength and hope. “I can do everything through Him who gives me strength” (Philippians 4:13).

I also dedicate this to my father, mother, and older brother who have supported me throughout this entire process. Thanks dad, Hyung dong Kim. You always say, “I am so proud of you and I know how hard it is to survive in a foreign county and get a doctoral degree.” Your encouraging words and understanding gave me power to overcome every difficulty. I love you.

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CHAPTER 1

INTRODUCTION

The Center for Disease Control and Prevention (CDC) recently reported that nearly 10 million people in the United States are diagnosed with developmental disabilities (DDs) (Boyle et al., 2011). This means that about 1 in 6 children in the United States, ages 3 through 17 years, have one or more developmental disabilities including attention deficit/hyperactivity disorder (ADHD), autism spectrum disorder (ASD), cerebral palsy, intellectual disability (ID), learning disability, Down syndrome (DS), and other developmental delays. The growing prevalence of DDs highlights the need for promoting the well-being of individuals with DDs as well as that of their families.

Caring for a child with DDs poses unique stresses and demands. When these children's parents are the primary care providers who spend more than 40 hours each week caring for their children, they report feeling weary, lacking energy, or feeling depressed, angry, or frustrated (Wong & Poon, 2010). Research indicates that caring for a child with DDs has a significant impact on parents including adverse psychological functioning such as high levels of stress, depression, anxiety, and pessimism (Falk, 2014), lower family cohesion, lower marital satisfaction, and lower physical health as compared to parents with typically developing children (Gau et al., 2012). For example, mothers of adults with DDs are more likely to have arthritis, high blood pressure, obesity, and limitations in activity (Williamson & Perkins, 2014). In addition, poor psychological well-being is associated with parent and child relationships; studies

found that parental stress predicts coercive parent-child behaviors and less responsive parenting (Wong & Poon, 2010; Andra & Thomas, 1998).

Although caring for a child with DDs presents tremendous challenges, parents also reported benefits and rewards. Their ambivalent feelings encompass joy and happiness as well as sorrow, physical exhaustion, and burdens (Nurullah, 2013). Moreover, a study found that the parents of a child with DDs have more positive aspects impacting their families than negative aspects (Heiman, 2002). The positive aspects could be achieved by their successful adaptation to stressful situations. For example, using effective coping strategies can prevent the parents of children with DDs from having psychological distress (Lyons et al., 2010).

During the past decade, the number of families from diverse cultures caring for children with disabilities has grown in the United States. In particular, Asian Pacific Islanders (API) are currently among the fastest growing racial and ethnic groups in the United States (CPACS, 2009). From 1996 to 2005 alone, U.S. immigration rates from Asian countries increased by 30%. Consistent with the increased rate of immigration to the United States, the number of Asian American families having children with DDs has increased as well. Yet, the existence of Asian Americans with DDs is not adequately documented in the United States. The CDC divides racial and ethnic groupings only into white, black, and Hispanic, excluding Asians (Boyle et al., 2011). It is estimated that 500,000 out of 10 million people in the United States with DDs would be Asian-Americans, because Asian Americans account for 5% of the United States population.

Immigrant parents may have unique experiences in caring for their child with DDs in the United States. It is assumed that immigrant parents may experience much greater challenges than their nonimmigrant counterparts. Research found that immigrant families of a child with DDs face a lack of access to services, such as health care and social services, a lack of understanding

about the health care and special education systems, a lack of information, language and communication barriers, different cultural views and beliefs, and financial hardships (Welterlin & LaRue, 2007; Al-Hassan & Gardner, 2002). In addition, Asian Americans do not usually use mainstream services because of language barriers and their different views on the etiology of disabilities. Their traditional perceptions lead them to engage in culturally specific help-seeking behaviors (e.g. acupuncture, traditional healers, and clergy) instead (Keum-Hyeong & Wynne, 2000).

The Georgia Council of Developmental Disabilities conducted the state's first community assessment of Asian American mothers of a child with DDs. The findings demonstrated that the mothers generally reported emotional, physical, and financial issues as well as language and cultural barriers (CPACS, 2009). The parents reported they need culturally competent services and support (CPACS, 2009). Another barrier is difficulty in navigating Medicaid, Medicaid waivers, and health insurance systems (CPACS, 2009)—the complexity of bureaucratic issues and the language barrier make it difficult to access the necessary information. Caregivers want a place that provides comprehensive and culturally sensitive assistance (CPACS, 2009).

Statement of the Problem

Over the past two decades, pathological perspectives have had a profound effect on disability studies, and research has examined the negative aspects of raising children with DDs. As a result, a proliferation of research has examined parental stress among parents of children with DDs. Research studies have found that parents had higher levels of stress as a result of caring for their child with DDs (Harley et al., 2010; Norlin & Broberg, 2013), but other research found that not all parents experience high levels of stress and showed good psychological

adjustment to their challenging circumstances (Faso et al., 2013; Bitsilka & Sharpley, 2004). Consequently, researchers have become interested in investigating protective factors that mitigate deleterious effects. Some research has investigated aspects of resiliency and found that psychological resilience factors such as optimism and hopefulness predicted life satisfaction, stress, and depressive symptoms (Faso et al., 2013; Bitsilka & Sharpley, 2004).

However, the research has primarily used white and middle-class samples. Researchers and service providers have paid limited attention to diverse ethnic groups and different socioeconomic groups caring for children with DDs, which indicates that the research has ignored cultural and environmental contexts (Parish, Pomeranz, Hemp, Rizzola, & Braddock, 2001).

Hasting (2002) stated that cultural and socioeconomic factors affect parental beliefs, methods of coping, and approaches to parenting. For example, the parents' perceptions of their children with disabilities—when parents are from collectivist cultures—could be highly influenced by societal attitudes toward people with disabilities and public response. Also, individuals from collectivistic cultures were found to be more likely to use emotional-focused coping strategies while those from individualistic cultures were more likely to use problem-focused coping strategies (Chun, Moos, & Cronkite, 2006).

Society perceives Asian Americans with disabilities as a “silent minority,” which leads to the invisibility of this population in the public's mind and encourages their special needs to be neglected (Keum-Hyeong & Wynne, 2000). In view of the increasing number of Asian American immigrant families of children with DDs, it is crucial to explore the process of stress and coping and how cultural and environmental contexts have influenced their adaptation process. Because each subgroup of Asians has their unique culture, investigating a single homogeneous ethnic

group would provide deeper understanding. Korean-Americans (KA) are one of the fastest growing populations in the United States (Chen & Lee, 2004), and Georgia has the second fastest-growing Korean population in the nation (CPACS, 2009). However, no studies to date have examined the process of dealing with caregiving difficulties among KA immigrant parents of children with DDs who live in southeast regions of the United States.

Purpose of the Study

The current qualitative study seeks to understand the process of how the KA immigrant parents manage parental challenges that they experience in raising their children with DDs. The three primary research questions of this study are as follows:

1. How does caring for children with DDs affect KA parents or family members?
2. What resources and strategies do the KA parents use in managing their challenging experiences?
3. How do cultural and environmental contexts affect their caring experiences and coping strategies?

Significance of the Study

Individuals with DDs and their families are involved with human service systems across their lifetime. At times of diagnoses, infants with DDs and their families often receive services from hospital-based programs, and social workers provide support for the families who are in desperate need (Laws, Larish, Scheyett, & Egan, 2010). During preschool, children with DDs receive early intervention services, and some families receive formal support services. School-aged children with DDs generally receive special education services through their education systems. As they transition into adulthood, the services they receive are very diverse including

vocational education, community services, higher education, settlement employment, or out-of-home residential services (Laws et al., 2010).

In line with the increasing cultural diversity in the United States population and the prevalence of DDs, social workers are likely to encounter individuals with DDs and their families from culturally and linguistically diverse backgrounds in numerous service areas including schools, mental health centers, child welfare organizations, governmental benefit offices, and so on. The code of ethics offered by The National Association of Social Work (NASW) stipulates social workers' responsibilities in regard to ethnicity in assisting their clients. The code explains these responsibilities as follows:

- (a) Social workers should understand culture and its function in human behavior and society, recognizing the strengths that exist in all cultures;
- (b) Social workers should have a knowledge base of their clients' cultures and be able to demonstrate competence in the provision of service that is sensitive to clients' cultures and to differences among people and cultural groups.

As a result of the number of service demands on KA immigrant parents, it is imperative that social workers facilitate, organize, and provide necessary support and services for them. Discoveries from this study could be used as a knowledge base for understanding Korean culture and how the culture influences the raising of children with DDs in the United States. This knowledge will allow service providers in social work fields to increase their cultural sensitivity and competence. Cultural sensitivity is the awareness of differences in the values, beliefs, and behaviors of other cultures. Cultural competence is defined as "a set of behaviors, attitudes, and policies that enable a system, agency, and individuals to function effectively with culturally diverse consumers and community" (Stone, 2005, p. 34). Also, the results will be utilized to advocate for KA immigrant families of children with DDs and to increase the availability of services to this population. Finally, the results gained as part of this study will assist service

providers in developing culturally competent interventions, which may benefit KA families of children with DDs.

Definition of Key Terminology

Adaptation. *Adaptation* refers to changes that occur in individuals and families with regard to environmental demands (Berry, 1997).

Coping. *Coping* is defined as “constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person” (Lazarus & Folkman, 1984, p. 141).

Culture. *Culture* is defined as “a system of learned and shared standards for perceiving, interpreting, and behaving in interactions with others and with the environment” (Stone, 2005, p. 20).

Cultural competence. *Cultural competence* is defined as “a set of behaviors, attitudes, and policies that enable a system, an agency, or individuals to function effectively with culturally diverse consumers and communities” (Stone, 2005, p. 34).

Developmental disability. *Developmental disabilities* are “a group of conditions due to an impairment in physical, learning, language, or behavior areas” (CDC).

Immigrant. An *immigrant* is an individual who leaves one country to reside permanently in another (Hoefer, Rytina, & Campbell, 2007). *First-generation immigrants* refer to the first people who immigrate to a new country.

Parental stress. *Parental stress* is related to the parenting environment and to processes that lead to aversive psychological and physiological reactions arising from attempts to adapt to the demands of parenthood (Psychological Assessment Resources).

Resilience. *Resilience* is the process of adapting well in the face of adversity, trauma, tragedy, threats or significant sources of stress (American Psychological Association).

Stressors. *Stressors* are events or situations that trigger a change, including goals, roles, values, or structures, and that cause anxiety in the family system (Boss, 2002).

Stress. *Stress* is a condition in which environmental demands exceed a person's ability to deal with stressors. *Feeling stress* is "the struggle with...demands that cannot easily be met...if the ratio of demands to resources becomes too great...the person feels helpless to deal with the demands to which he or she is exposed, and this can result in feelings of panic, hopelessness, and depression" (Lazarus, 1999, p. 58).

Chapter Summary

This dissertation consists of five chapters and an appendix. Chapter 1 introduced parental stress and unique experiences of immigrant parents who care for children with DDs, most importantly the rationale for the study focusing on KA parents of children with DDs. Chapter 2 will provide a comprehensive literature review on the experience of parents who raise children with DDs including family life span, contributing factors to parental stress, growth, immigrant families of children with DDs, and KA immigrant families. Chapter 3 will present the research methodology including the grounded theory design, the data collection, data analysis, validity and reliability, and researcher subjectivity. Chapter 4 will describe the hope for development theory and each category within the theory. Finally, Chapter 5 will discuss findings, limitations, implications for social work, and recommendations for future study.

CHAPTER 2

LITERATURE REVIEW

This chapter begins by defining developmental disabilities (DDs) and introducing family life span experiences and the complex relationships between DDs and parental stress and growth. Although DDs encompass various types of disorders, articles focusing on specific disorders, such as Intellectual Disability (ID), Down syndrome (DS), and Autism Spectrum Disorder (ASD), are reviewed. The following section reviews studies focusing on immigrant families of individuals with DDs and, specifically, KA families of children with DDs. The last section introduces the Double ABCX model as a theoretical framework to guide the research questions.

Developmental Disabilities

I first examine the definition of developmental disabilities and characteristics of some types of DDs. Carroll (2013) demonstrated that “the concept of DDs is at once a scientific, cultural, legal, and personal construct. It is defined in different ways for different purposes in each of these domains” (p. 5). The Developmental Disabilities Services and Facilities Construction Act of 1970 first introduced the concept of DDs. Subsequently, the Developmental Disabilities Assistance and Bill of Rights Act of 2000 defines developmental disabilities as follows:

- A. In general-the term “*developmental disability*” means a severe, chronic disability of an individual that-
 - i. Is attributable to a mental or physical impairment or combination of mental and physical impairments;
 - ii. Is manifested before the individual attains age 22;
 - iii. Is likely to continue indefinitely;
 - iv. Results in substantial functional limitations in 3 or more of the following areas of major life activity

- a. Self-care
 - b. Receptive and expressive language
 - c. Learning
 - d. Mobility
 - e. Self-direction
 - f. Capacity for independent living
 - g. Economic self-sufficiency; and
 - v. Reflects the individual's need for a combination and sequence of special, interdisciplinary, or generic services, individualized supports, or other forms of assistance that are of lifelong or extended duration and are individually planned and coordinated;
- B. Infants and young children - An individual from birth to age 9, inclusive, who has a substantial developmental delay or specific congenital or acquired conditions, may be considered to have a developmental disability without meeting 3 or more of the criteria described in clauses (i) through (v) of subparagraph (A) if the individuals, without services and supports, have a high probability of meeting those criteria later in life.

DDs is an umbrella term and includes severe chronic disabilities in physical and/or cognitive aspects of an individual. For example, cerebral palsy and epilepsy are largely related to physical issues, while Down syndrome and fetal alcohol syndrome involve both physical and intellectual disabilities. The Center for Disease Control and Prevention (CDC) reported that 1 in 6, or 15.04 % of children ages 3 to 17 years in the United States have one or more *DDs* such as ADHD, ASD, cerebral palsy, hearing loss, intellectual disability (ID), learning disability, vision impairment, blindness, DS, and other developmental delays. The prevalence of *DDs* among this population increased by 12.84% between 1997 and 1999 (Boyle et al., 2011). The most prevalent disorders in family studies of *DDs* are ADHD, ASD, Down syndrome, and ID. In this study, I focused on children with ASD, DS, and ID, and excluded children with only ADHD. While ASD, DS, and ID are lifelong conditions, ADHD is not considered as lifelong condition even though the research found over half a percent of children with ADHD have persistent symptoms of ADHD up through young adulthood (Sibley et al., 2016).

Intellectual Disabilities

The American Association on Intellectual and Developmental Disabilities defines intellectual disabilities, formerly known as mental retardation, as “a disability characterized by significant limitations both in intellectual functioning (reasoning, learning, problem-solving) and in adaptive behavior, which covers a range of everyday social and practical skills. This disability originates before the age of 18.” Individuals with Intellectual disabilities are characterized as having problems with regard to their thought processes. The CDC reported that the cause of intellectual disabilities is unknown, but the most commonly known cause includes Down syndrome, a fragile X, birth defects, and fetal alcohol syndrome.

Down Syndrome

The National Association for Down syndrome (NADS) reported that Down syndrome is the most common genetic-chromosomal disorder, occurring in 1 of 690 births (2012). Individuals with DS have extra chromosomes which change body and brain development. Individuals with DS present mild to moderate mental and physical challenges (NADS, 2012) and have some common physical features such as small ears, a flattened face, and a small neck. Also, they have multiple physical problems including congenital heart defects, low muscle tone, vision and hearing problems, and thyroid conditions (NADS, 2012).

Autism Spectrum Disorder

Autism spectrum disorders (ASD) are complex developmental disorders that can cause significant social interaction difficulties, including communicative difficulties as well as restricted, repetitive, and stereotyped behavioral challenges (APA, 2013). During recent years, the estimated prevalence of ASD has increased. The Center for Disease Control and Prevention (CDC) asserts that the average number of reported ASD cases increased by 57% from 2002 to

2006, estimating that 1 in every 110 children has ASD (CDC, 2009). Recently, the CDC updated the prevalence of children having ASD to be about 1 in 68 children in the United States (CDC, 2014).

According to Wing (as cited in Sicile-Kira, 2004), there are three observable symptoms that characterize ASD:

1. *Impairment of social relationships*: An individual may not use or understand nonverbal behavior, may not develop peer relationships that are appropriate to his or her development level or may appear aloof and indifferent to other people.
2. *Impairment of social communication*: There may be a total delay in the development of speech. The individual may not sustain or initiate conversation or use language in a stereotypical and repetitive manner.
3. *Impairment of imaginative thought*: An individual may have an all encompassing, intense preoccupation with one interest or topic or have inflexible nonfunctional rituals or routines. Repetitive motor mannerisms, such as hand flapping or spinning of objects, may be observed. Often there is a lack of make-believe or social imitative play (Sicile-Kira, 2004, p. 20).

The manifestation of the core deficits of autism is maintained in adolescence and adulthood even though there might be a little improvement in a few behavior symptoms (Seltzer et al., 2004; Kanner, 1943). Boys are five times more likely to have ASD than girls (Baio, 2014). Among the types of DDs, ASD showed the largest increase in prevalence from 0.19% between 1997 and 1999 to 0.74% between 2006 and 2008. The DSM-5 made substantial revisions to the DSM-IV criteria for ASD. A multi-categorical system of diagnosing “Pervasive Developmental Disorders” was deleted. Instead, the DSM-5 replaced the multi-categorical system with a single diagnostic dimension: autism spectrum disorder that encompasses all previous pervasive developmental disorder such as autism, Asperger disorder, and PDD-NOS (APA, 2013).

Family Life Span

The experience of having children with DDs is not a one-time incident, but rather an on-going process through parents’ life spans, because DDs are life-long chronic disabilities.

Introduction of children with DDs requires parents to adjust to a new environment and to modify

their resources as their children grow. Having a child with DDs affects overall family life span in regard to parents' psychological well-being, family members' relationships, financial well-being, community involvement, and so on. The family takes on financial burdens caused by lack of employment and extra costs for services and treatments that are not covered by insurance. A longitudinal study found that mothers of children with DDs are less likely to work full time as their children with DDs get older compared to mothers of typically developing children (Parish, Seltzer, Greenberg, & Floyd, 2004). Not only does the disability itself affect their family life, but these families live in a world where normalcy is presumed among the general public (Lawrence, 2008). Stigma from society appears in interactions with community members and professionals. As such, the experiences of the parents of a child with DDs vary at different times in the life course. The following section provides an overview of family experiences of having a child with DDs from the point of first diagnosis to adulthood.

Initial Diagnosis and Reaction

Parents learn about a child's diagnosis of DDs in different ways. In the case of DS, parents can identify a child's diagnosis at birth. On the other hand, ASD and ID are barely recognized by parents or professionals at first, because the diagnosis of ASD and ID relies on behavioral symptoms or cognitive development. Thus, the parents gradually have a sense that something is wrong with their child, and the time of identification is often prolonged. Although awareness of ASD's symptoms and the ability to provide early diagnoses has increased, many children still do not receive diagnoses until they are school age (Wolkmar, 2005). Disparities in the identification of an ASD are evident based on race/ethnicity and socioeconomic background (Mandell et al., 2009; Sullivan, 2013; Thomas, Zahorodny, Peng, Kim, Jani, Halperin, & Brimacombe, 2012). The National Early Intervention Longitudinal Study (NEILS) found that it

took up to 1 year between sensing that something was wrong and receiving diagnostic services among families of infants and toddlers with disabilities (Bailey, Scarborough, & Hebbeler, 2003). Ethnic minorities reported negative experiences when entering early intervention, stating that it required great effort to find early intervention services compared with their white counterparts (Bailey et al., 2004).

The emotional reaction that parents experience when learning about their child's diagnosis is similar across DDs. Parents reported that when they first learned that their child had a DD, they felt a wide range of common human emotions such as fear, mourning, denial, guilt, grief, anger, and so on (Goff et al., 2013; Bingham, Correa, & Huber, 2012; Heiman, 2002). The emotional reaction can be interpreted as a palliative coping strategy, which is defined as “modulating tensions following a problem by trying to alter the perception without taking concrete action to change the stressor” (Bingham, Correa, & Huber, 2012, p. 378). Those feelings came from their expectations for their family and children as well as from a lack of knowledge about their children's diagnosis (Goff et al., 2013). Clarification of the diagnosis helps parents prepare for the future rather than remain uncertain about the diagnosis (Heiman, 2002). In helping families accept a child's diagnosis, a medical professional plays an important role. For parents, the time at which a disability diagnosis is made is traumatic, but they feel less traumatized when the medical professional offers sufficient information, shows sympathy, and communicates well (Bingham, 2012).

School Years

School is an external resource that significantly affects families of school-aged children with DDs. Because children spend most of their day in school during the early development period, school can play a role of respite care for caregivers and can provide a venue for formal

education. The common issues the parents encounter during a child's school years include relationships with school personnel, the child's full inclusion in a regular classroom, and individualized education program (IEP) meetings. The collaborative relationships between educators and parents are critical for school-aged children with DDs in terms of providing effective education services as well as fostering parents' psychological well-being (Ruble, Dalrymple, & McGrew, 2010). The IEP is mandated by the Individuals with Disabilities Education Act (IDEA). The studies that investigated the experiences of parents' IEP meetings found that parents felt alienated and neglected because the educators dominated the decision-making process (Fish, 2008; Kalyanpur et al., 2000). Also, collaborative relationships with educators were negatively correlated with the socioeconomic status and ethnicity of the parents (Salas, 2004).

Transition to Adulthood

Families of youth with DDs experience substantial changes in the period of transition to adulthood. Parents have to adjust to new routines and cannot be released from the role of caregiving, because young adults with DDs are less likely to move out of their family home (Wehman, 2006). Parents rank the period of transition to adulthood as second in degree of severity in regard to experiences of stress next to the initial diagnosis period (Dyke et al., 2013). The stress can be related to a sudden decrease of federally mandated (IDEA) formal services when young adults with DDs reach the age of 22. After they exit high school, no such formal services are mandated (Tylor, 2015). Parents continue to take care of their adult children with DDs as well as navigate the paths of adults with DDs. In most cases, their adult children with DDs go into a world where there are long waiting lists for those seeking adult services (Howlin, 2005).

Adulthood

Parents of children without a disability expect their children to become independent upon entering adulthood and leaving home. However, achievement of maximum levels of independence is rare for adults with DDs, and parents' involvement in caring for their children with DDs could last the rest of the parents' lives (Taylor & Seltzer, 2010). The literature has described that a crucial dimension of success in adulthood is dependent on the following areas: education, employment, community living, and community integration (Shattuck et al., 2012). However, there are very limited opportunities for postsecondary educational and vocational outcomes among young adults with ASD (Taylor & Seltzer, 2011; Howlin et al., 2004).

Young adults with DDs have high rates of co-residing with their parents compared with adult children without DDs, but there is an increased demand for parents to place their children into a residential home when parents approach midlife or the early years of old age (Seltzer, 2001). The likelihood of moving away from their parents' home differs across types of DDs. For example, adults with DS are more likely to live in the family home than in an institution compared to adults with ASD, adults with cerebral palsy, or other adults with DDs (Stancliffe et al., 2012; Seltzer, 2011). Parents make decisions about residential transition based on various factors. The parents' health condition is one of the factors that influence their decision-making (Essex et al., 1997).

Although raising children with DDs can have negative effects on parents' well-being, the effect weakens with parents' age from midlife to the early years of old age (Ha et al., 2008). A study compared the psychological well-being between parents of adults with DDs and those of adults without DDs from parents' midlife to early years of old age. The authors concluded that the divergence of levels of psychological well-being between the two groups from midlife to

early old age became smaller so that eventually there was no great difference in early old age (Ha et al., 2008). These results were explained by parents' maturity and adaptation to stress over time (Ha et al., 2008).

Stress and Growth

No matter what stage in life one is in, parenting children with DDs can be stressful for many reasons. It is an undeniable fact that having children with DDs can be a life stressor to parents, but it also contributes to parents' growth in some aspects. While family studies in the field of disabilities have focused significantly on stress, few studies have explored the positive psychological changes that come from caring for children with DDs. This section describes how parents experience both parental stress and growth.

Parental Stress

Lazarus and Folkman (1984) defined psychological stress as a relational concept: "Psychological stress is a particular relationship between the person and the environment that is appraised by the person as taxing or exceeding his or her well-being" (p. 19). Many studies reported that parents of children with DDs are at risk of high levels of stress and psychological distress. Compared to parents with typically developing children, parents of children with DDs experienced higher levels of stress and lower well-being (Harley et al., 2010; Norlin & Broberg, 2013). Among mothers of children with various types of DDs, mothers of children with ASD showed more significant parental stress than those of preschool children with developmental delays (Eisenhower et al., 2005; Estes et al., 2009).

Longitudinal data showed that the stress of parents of children with DDs increased as their children advanced from early to middle childhood and then, subsequently, decreased from adolescence for both mothers and fathers (Woodman, 2014). Their levels of stress and

psychological well-being were inconsistent over their lifetimes, but it is worth noting that parenting children with DDs entails lifelong care, which inevitably adds stress. Research showed the different levels of stress and psychological distress between mothers and fathers. In general, existing research reported that levels of stress and depression for mothers are higher than those of fathers of children with ASD (Davis & Carter, 2008; Hasting et al., 2005), and mothers' stress is associated more with child related predictors, while fathers' stress is predicted by the mothers' mental health or stress rather than child-related variables (Hasting, 2003).

Parental stress negatively affects both the mental and physical health of parents. Research has identified an increased level of mental health problems, particularly anxiety and depression, as a result of stress (Cramm & Nieboer, 2011; Benson & Karlof, 2009). A study reported that 42% of mothers of children with ASD fell within the clinical range for depression, and 6% of the participants fell within the range for significant anxiety (Davis & Carter, 2008). Parents of children with DDs also experience higher levels of fatigue and greater physical health impairment compared to parents of children without disabilities (Smith et al., 2010b; Mugno, Ruta, D'Arrigo, & Mazzone, 2007).

In addition to mental and physical health concerns, parental stress has an impact on relationships among family members. The quality of parent-child relationships could be potentially affected because parental stress has an impact on parents' ability to provide necessary care for their children. For example, Andra and Thomas (1998) reported that greater parental stress is associated with less attendance at group therapy for their children and less attendance at parental counseling sessions. Those experiencing high levels of parental stress are at greater risk of committing abuse or neglect of their children as well (Svensson, Eriksson, & Janson, 2013).

Low levels of maternal stress are associated with high satisfaction with sibling relationships and positive behaviors such as involvement and empathy among siblings (River & Stoneman, 2003).

Growth

For several decades, researchers have seen caring for children with DDs as stressful and as a burden. In light of this negative view of effects on families, a number of studies have focused on examining the association of having a child with DDs with parenting stress and other forms of psychosocial well-being of parents. Sometimes, in professionals' eyes, parent's high optimism was seen as denying reality (Landsman, 1998). Although parents who raise a child with DDs face tremendous burdens and difficulties, it is acknowledged from research that parents also reported benefits and positive aspects of experiences such as joy and happiness (Nurullah, 2013; Green, 2007; Goddard et al., 2000). A shift of professional interpretation of families with disabilities from pathological to adaptive perspectives has increased research focusing on positive aspects of having a child with DDs (Ferguson, 2002).

Qualitative studies indicated positive appraisals of parents toward their adult children with DDs as well as personal growth. The participants positively perceived their quality of life and even considered having an adult child with an ID as fortunate. Also, they reported they live better lives than the homeless and even than parents of children without an ID (Yoong & Koritsas, 2012). Also, parents asserted that their child with DDs caused them to be much more conscious and thoughtful (Lawrence, 2008), and they appreciated their child for who they are, the family itself, and their learning about differences, diversity, and community (King, 2011).

Moreover, a study found that parents of a child with DDs received more positive aspects of the impact of raising their children than negative ones (Heiman, 2002). Sixty-one percent of research participants reported positive effects of having a child with DDs on their families such

as strength of parental relationship, while 23% percent claimed negative effects on their families such as creating new problems, conflict, and weakening the dyadic relationship. Most of the participants reported that their negative feelings turned to optimistic feelings of joy and love (Heiman, 2002).

It seems that as people experience more personal challenges, their understanding of life events is expanded which results in more opportunities for personal growth (Trute, 2010). Regarding the results of parents' adaptation to children with DDs, a child's age is a factor that influences the rewarding and challenging experiences in that as the child gets older, the experiencing of rewards or positive emotions increases (Green, 2007). The study also found that stigma had a negative indirect effect on perceptions of rewards of caring for children with DDs (Green, 2007).

Immigrant Families of Children with Developmental Disabilities

With increasing numbers of immigrants from Latin America, Asia, and Africa, the numbers of immigrant families having children with DDs in the United States will increase as well. The 2007 National Survey of Children's Health (NCSH) provides demographic information from diverse populations and health care service access. The number of immigrant families having children with DDs is two times greater than non-immigrant families for children aged 3 to 5 years (Lin, Yu, & Harwood, 2012). Although reasons for this increased prevalence among immigrant families are unclear, several factors may be relevant.

The World Health Organization (WHO) reported that in Asian countries, nutritional deficiencies, disease, congenital defects, chemical wars, and lack of access to maternal and child health care can contribute to having children being diagnosed with DDs (Ghosh & Magana, 2009). Compared to children born in the United States to white mothers, foreign-born Black,

Filipino, and Vietnamese children are at higher risk for being diagnosed with DDs (Beccerra et al., 2014). The migration to developed countries to find better services for their children with DDs is also one of the factors that results in a higher prevalence in immigrant families.

Socioeconomic status is another factor. Immigrant families consistently have experienced the disadvantages of having a lower income, being unemployed, and lacking access to health care services. Low socioeconomic status would limit access to proper health services and nutrition.

Immigrant families of children with DDs face a lack of access to services such as health care and social services, a lack of understanding about the health care and special education systems, a lack of information, languages and communication barriers, different cultural views and beliefs, and financial hardships (Welterlin & LaRue, 2007; Al-Hassan & Gardner, 2002). Their challenges are affected by their environmental contexts as well as their cultural contexts. Cultural factors include their religion such as Buddhism, Taoism, and Confucianism and cultural values and beliefs such as collectivism. These cultural factors affect how an immigrant family perceives their child with DDs, how they define their stressful situations, which coping strategies they use, and their use of available resources and formal services.

Confucianism has the most influence on the culture, history, and government of Asian countries such as Korea, China, Japan, Taiwan, and Singapore (Ghosh & Magana, 2009). Confucianism values harmony and order within family, community, and society. Also, Confucianism values respecting older persons, filial piety, loyalty, trust, and cooperation as well as education and hard work (Yan, Accordini, Boutin, & Wilson 2014). Males and elders hold strong authority in the family structure, so males and females have distinct gender roles. Collectivism is evident in Asia and Latin America. Immigrants from collectivist societies might consider the in-group and fulfillment of social roles as important (Ghosh & Magana, 2009).

Individuals fall along the spectrums between individualism and collectivism, but European Americans lean more towards individualism than do Asians and Latin Americans. Families from cultures that embrace collectivism and Confucianism might be less likely to utilize services and explore the needs of their children with DDs because they try to solve their problems within their own families.

Perceptions toward Children with Disabilities

Religious beliefs have a considerable impact on attributions of the causes of children's disabilities and perceptions toward children with disabilities. In one study, over half of Latino mothers of children with DDs who were affiliated with Catholic churches believed children's disabilities were a sign from God (Skinner et al., 1999). Another study that compared Hispanic families to non-Hispanic white families on adaptation to having a child diagnosed with mental retardation revealed that Hispanic families perceived raising a child with disabilities as a religious duty and as less burdensome than non-Hispanic families (Markwardt, Rowitz, Farber, & Heller, 1994).

Muslim immigrant parents of children with DDs addressed that Allah sent these children to their families, because they were capable of dealing with it, and they believed in "never questioning, only accepting" (Jegatheesan, Miller, & Fowler, 2010). In contrast, Chinese families considered having children with disabilities as more shameful than Australians and Germans (Westbrook, Legge, & Pennay, 1993), so families resist bringing their children with disabilities out in public, which reinforces negative perceptions toward children with disabilities.

Research about the cultural differences in attitudes toward people with disabilities has found that Asians are more likely to have negative attitudes than Americans (Westbrook & Legge, 1993; Chan, Lee, Yuen, & Chan, 2002). Families of children with disabilities in

collectivist cultures experience greater stigmatization (Westbrook & Legge, 1993). For immigrant families from collectivist cultures, public responses and attitudes toward people with disabilities are highly influential when it comes to how immigrant parents of children with DDs perceive their children with disabilities; this can also be a source of stress. However, their perceptions toward children with DDs can be changed depending on their acculturation. Ghosh and Magana (2009) suggested that acculturation affects cultural beliefs about disabilities among immigrant families. The more acculturated families are, the more they hold Western beliefs regarding the causes and perceptions of disabilities.

Access to Social Services

Nationally representative data showed that compared to non-Hispanic whites, immigrant families of children with DDs reported underutilization of formal health care services (Lin, Yu, & Harwood, 2012; Beccerra et al., 2014). Lack of service use in immigrant families can be explained by environmental factors, including lack of service information, uncoordinated systems (e.g. transportation), lack of culturally relevant services as well as racial disparities within institutional budgets (Bogenschutz, 2014). In terms of culturally relevant service, service use can be facilitated by culturally and linguistically competent providers who are competent in disability specific issues and in respect to different cultures (Bogenschutz, 2014). Racial disparities within institutional budgets were found as the California Department of Developmental Services (DDS) spent an average of \$11,723 per white child and \$7,634 per Hispanic child for intervention services (Cohen, Holloway, Dominguez-Pareto, & Kuppermann, 2014).

However, culture also affects the use of social services in immigrant families of children with DDs. Parents of children with DDs, especially those who are Asian immigrants, do not use

psychotherapeutic services due to cultural beliefs about what they should do when they experience mental health problems. For example, the ethnic groups rooted in collectivism such as Asian or Latino cultures are more likely to solve their own problems within the family unit than people in a more individualistic culture. As a result, they are less likely to seek support. Also, Asian immigrants may not consider formal counseling and psychotherapeutic services as a first option to deal with family and individual problems due to stigmatization (Su-Je & Kwang-Sun, 2010). Moreover, different goals for treatment and interventions for their children would limit their use of social services. For example, the primary goals of TEACCH (Treatment and Education of Autism and Communication-handicapped Children) are to achieve independence skills, but East Asian cultures put less value on the independence of children with disabilities (Welterlin & LaRue, 2007).

In addition, lack of services can be accounted for by low self-advocacy skills among immigrant families. Huang (2004) examined self-advocacy skills among Asian American parents of children with DDs. Some Asian Americans have difficulties expressing their needs and opinions. They reported that Asian Americans had significantly lower assertiveness scores and lower request help scores than non-Asian-Americans. Parents who received higher levels of social support reported higher advocacy skills (Huang et al., 2004). The number of years the Asian immigrants have been in the United States affected their levels of advocacy skills (Huang et al., 2004).

Adaptation to Stressors

DeLambo (2011) compared the parental stresses between Asian American families of children with DDs and non-Asian American families. He found that Asian American families of children with DDs experienced higher levels of stress related to children's behavioral problems

than non-Asian Americans. Another study compared the family well-being of Latino Americans and white parents (Blacher & McIntyre, 2006). There was no difference in parenting stress between the two groups, but the Latino-American parents of children with an ID reported higher depression and lower morale than the white parents. Also, the Latino American parents experienced a higher positive impact of having children with an ID than the comparison group.

Chun and colleagues (2006) provide explanations of different coping strategies by cultures. Individuals from collectivist cultures are more likely to avoid stressors and modify internal cognition because they have a greater tendency to attribute having children with DDs to external controls. In order to control their inner feelings, they are more likely to use avoidance or cognitive coping skills. On the other hand, individuals from individualist cultures would commonly confront stressors and directly deal with them.

Evidence supports the assumptions of Chun et al. (2006) that the most dominant coping strategy for Chinese families of children with DDs was avoidance (Lam & Mackenzie, 2002). The study that compared coping strategies of Asian American families of children with DDs with Caucasian families of children with DDs revealed that Asian Americans had a higher score when it came to reframing coping, and Caucasians had a higher score when it came to passive appraisal (Twyo, Connolly, & Novak, 2006). As the literature shows, culture may be a critical factor that affects how parents of children with DDs perceive their children, their burden of care, informal and formal supports, responses from public attitudes toward their children with DDs, and their selection of coping strategies.

Korean American Families of Children with Disabilities

Following a comprehensive search of the literature, five studies focusing on Korean immigrant caregivers of children with disabilities were identified. Three studies adopted

qualitative methods, and two used quantitative methods. You and Rosenkoetter (2014) explored the meanings that Korean immigrant mothers of children with DDs attribute to their experiences caring for their children. The five participants were from Oregon and California, and their lengths of residency in the United States ranged from 5 to 22 years. The participants explained having difficulty accepting their children having disabilities at first and finding dealing with their behavioral problems to be challenging (You & Rosenkoetter, 2014). Although all participants spoke English, they had difficulty understanding the jargon and specialized terms that were used by special educators or medical practitioners. Also, they were unfamiliar with the United States' special education system which helped them with providing adequate services for their children with DDs (You & Rosenkoetter, 2014). One parent said, "If my daughter had met her case manager earlier, she might have become better. I think most Koreans don't know about having a case manager and can't advocate for their children" (You & Rosenkoetter, 2014, p. 36)

The mothers described caring for their children with DDs as their primary career, and they described their husbands as "supporters" or "listeners." One mother wished that her husband would help her more (You & Rosenkoetter, 2014). However, mothers described their relationships with family members, especially their relationships with their partners, as becoming closer after having their children with DDs. Since they moved, they did not have close friends or extended family members, so mothers told their husbands everything, and the husbands in turn provided emotional support (You & Rosenkoetter, 2014). The study found that child behavioral problems, communication problems with educators and medical practitioners, and accessing services for their children with DDs were factors that challenged the KA mothers. Their husbands and Korean churches provided significant emotional support. The participants positively perceived the impact of having children with DDs on their families as increasing

family coherence and changing their beliefs about life. They also described becoming more humble.

Kim and colleagues (2007) interviewed 10 KA parents residing in California in order to understand their expectations for their adolescent children with DDs and their perspectives about the transitions of their adolescents. What parents expect for their children with DDs' futures is highly affected by parents' perceptions toward their children. Parents appeared to have either positive or negative perceptions toward their children's future. Some parents negatively perceived their children's futures, because they would not expect children with DDs to have jobs due to the severity of their disabilities, while other parents focused on their children's strengths and preferences. The parents who had positive perceptions of their children's futures advocated for a post-education system and employment. They advocated for their children with DDs' potentials.

The parents felt stressed because of the need for long-term care, lack of community services and support, and health problems in family members; therefore, many of them considered sending their children to group-homes after they graduated from high school. They received emotional and financial support as well as information and disability services from the Korean community and Korean ethnic churches. Language barriers were a factor as to why these parents did not participate in school meetings or conferences regarding their children's education as well as passively accepted professionals' opinions (Kim, Lee, & Morningstar, 2007). Interestingly, they pointed out professionals' lack of commitment to their jobs and decreased response to their requests, and they emphasized that professionals who work with children with disabilities should have "special hearts."

Cho's (2000) qualitative study compared adaptation and accommodations among KA parents and Korean parents of children with DDs. Sixteen parents in each group participated in the study. Both sets of parents were highly distressed when they first learned of their children's diagnoses. Forty percent of the parents had suicidal thoughts at that time. However, they were able to solve their negative emotional feelings over time. Interpretations of causes for the disabilities were different between the two groups. Korean mothers attributed the causes for these disabilities to their behaviors during pregnancy or their children's early development, while KA parents considered children's disabilities as God's plan (Cho, Singer, & Brenner, 2000). Both types of parents reported that their children's behavioral problems caused emotional distress, and they intended to avoid situations with strangers. The problem behaviors also made it difficult for these families to find respite care services.

KA parents assessed public attitudes toward disabilities more positively than Korean parents. Issues for KA parents included language barriers, which lead to difficulties in obtaining information and public services, but they were dissatisfied with translators due to their lack of special knowledge and condensed translations. KA parents (69%) indicated an increased amount of spousal emotional support over Korean parents (38%). Also, more KAs mentioned receiving practical support such as help with transporting family members, emergency child care, and translating than Korean parents (70%). Although KA parents experienced communication difficulties with service providers, they responded positively to formal support.

KA families of children with DDs employed more religiously-based coping strategies, because a large portion of KAs are affiliated with Korean ethnic churches, and these churches provide strong support for immigrant families and children with disabilities. Many KA families become religious after moving to the United States, and subsequently, they reported viewing

their children with DDs through religious principles (Cho, Singer, & Brenner, 2000). Overall, KAs strongly agreed that the United States is a better place to raise children with DDs than Korea.

Cho and colleagues (2003) confirmed their qualitative findings about the adaption of KA parents of children with DDs and Korean parents by using a quantitative method. The Korean parents reported significantly higher depressive symptoms than the KA parents. Problematic behaviors by their children were predictors of depression (Cho, Singer, & Brenner, 2003). The association between behavioral problems and depression was stronger in Korean parents than in KA parents.

Su-Je and Kwang-Sun (2010) quantitatively examined the effectiveness of journaling intervention on reducing psychological distress among KA mothers of children with DDs. Forty-four percent of the total 52 participants fell beyond clinical cutoff scores of depressive symptoms measured by the CES-D (Cho & Blair, 2010). This result corresponds with the meta-analysis that found that 30-50% of mothers of children with DDs go beyond clinical cutoff points of depression (Singer, 2000). The study found that KA mothers with low economic resources, low English proficiency, and whose children had been diagnosed with DDs within the last 2 years were more vulnerable to psychological distress.

Five studies' findings illustrated negative aspects of raising children with DDs from the first age of diagnosis to adulthood such as stress, depression, concerns about the future, and negative aspects of the future. However, it is unsure how parents deal with their difficulties of raising their children with DDs and what resilience factors are present that help them move forward even though caring for children with DDs is challenging.

Theoretical Framework

As reflected in the literature, some families have experienced significant psychological distress with numerous sources of stress, while others are better at adapting to stressful situations. This phenomenon can be explained by the stress and coping theory (Lazarus & Folkman, 1984). More specifically, scholars elaborated the process of adaptation to stressors found by the stress and coping theory, and they proposed the Double ABCX model. In this study, the Double ABCX model is applied as the theoretical framework to guide research questions.

The Double ABCX Model

The Double ABCX model suggests that family adaptation to a stressful situation is related to components such as available resources, the perception of stressful events, coping strategies, and the interplay of the components (McCubbin & Patterson, 1983). In other words, a stressful situation would not lead to stress as long as families appropriately utilize their resources, have adequate resources, apply effective coping strategies, and perceive the stressful situation as positive (see Figure 2). Also, the possible factors that have an effect on components include spirituality, values, beliefs, and culture (McKenry & Price, 2005). In this process, lower case letters refer to factors during the pre-crisis time and changes in those elements over time are characterized with capital letters (ABCX).

Family Stressor Event/Pile-up (aA)

Boss (2002) defines a stressor event as “an occurrence that is of significant magnitude to provoke change in the family system” (p. 47). With an initial stressor event, families experience an additional stressor as the crisis evolves over a period of time. Collecting stressor events is called a stress pile-up. For example, after children are diagnosed with ASD, which is an initial stressor event (a), demands on money and time to care for children with ASD can be a pile-up

stressor (A) for KA immigrant parents. The stress pile-up does not necessarily have to be related to an initial stressor event, but it can come from outside factors such as job loss or illness (Drahota, Wood, & Dyke, 2011).

Resources (bB)

McCubbin and Patterson (1986) placed family resources in three categories: 1) individual members, 2) family unit, and 3) the community. Individual resources include traits, characteristics, or abilities of individuals such as financial, educational, physical and mental health, and psychological resources (i.e. self-esteem) (McKenry & Price, 2005). Family unit resources refer to families' internal characteristics that prevent them from stressor events or make it easier to adapt to the stressor events (McKenry & Price, 2005). Community resources are "those capabilities of people or institutions outside the family on which the family can draw when dealing with stress" (McKenry & Price, 2005, p. 12). Informal and formal social support are forms of community resources. The degree to which KA immigrants have the resources can be different.

Family Perceptions (cC)

McCubbin and Patterson (1983) defined the first "c" factor as the perception of initial stressor events and the second "C" factor as the perception of a "total crisis situation" (p. 97), including stress pile-up and existing and new recourses (McCubbin & Patterson, 1983). A Double ABCX model emphasizes perception and considers it as the most powerful variable when explaining outcomes. Families often view initial stressor events and total crisis situations differently. For example, some KA immigrant parents might consider that their child's behavior problems are controllable while others do not. When families have positive perceptions or

definitions of stressor events, the families are more likely to initiate coping strategies and eventually adapt.

Coping: The Interaction of Resources, Perceptions, and Behavior

Despite parental stress, families cope with their stressful situations. Lazarus and Folkman (1984) defined coping as “cognitive and behavioral efforts to manage specific external and/or internal demands, that are appraised as taxing or exceeding the resources of a person” (p. 14). Employing effective coping strategies results in parents’ positive growth (Minnes, 2015). Researchers have taken an interest in investigating coping strategies that are more effective than others to reduce psychological distress among parents of children with DDs. Several studies concluded that problem-focused coping was more effective than emotional coping in reducing parental stress (Hasting et al., 2005; Lyons et al., 2010; Smith, Seltzer, Tager-Flusberg, Greenberg, & Carter, 2008).

It has been suggested that coping mechanisms should be assessed within the context of a situation such as socioeconomic status, child’s age, parents’ education, and severity of symptoms, because none of the coping efforts are inherently good or bad (Folkman et al., 1986). The Double ABCX model shows that coping is a bridging concept in which resources, perceptions, and behavioral responses interact to achieve a balance in family functioning in response to an initial stressor and crisis.

Family Adaptation (xX)

Family adaption is an outcome of the Double ABCX model which describes achieving a new level of “balance in family functioning” as a result of the crisis. This adaptation consists of a continuum in which the positive end of the continuum of adaptation is called bonadaptation and the negative end of the continuum is called maladaptation. Families who do not achieve balance

as a result of a crisis are more likely to experience negative results (McCubbin & Patterson, 1983) while families whose outcomes are adaptive experience less or manageable levels of stress (Xu, 2007). For example, KA immigrant parents experience high levels of stress but at the same time, they enjoy taking care of their children because of their experiences of joy and happiness.

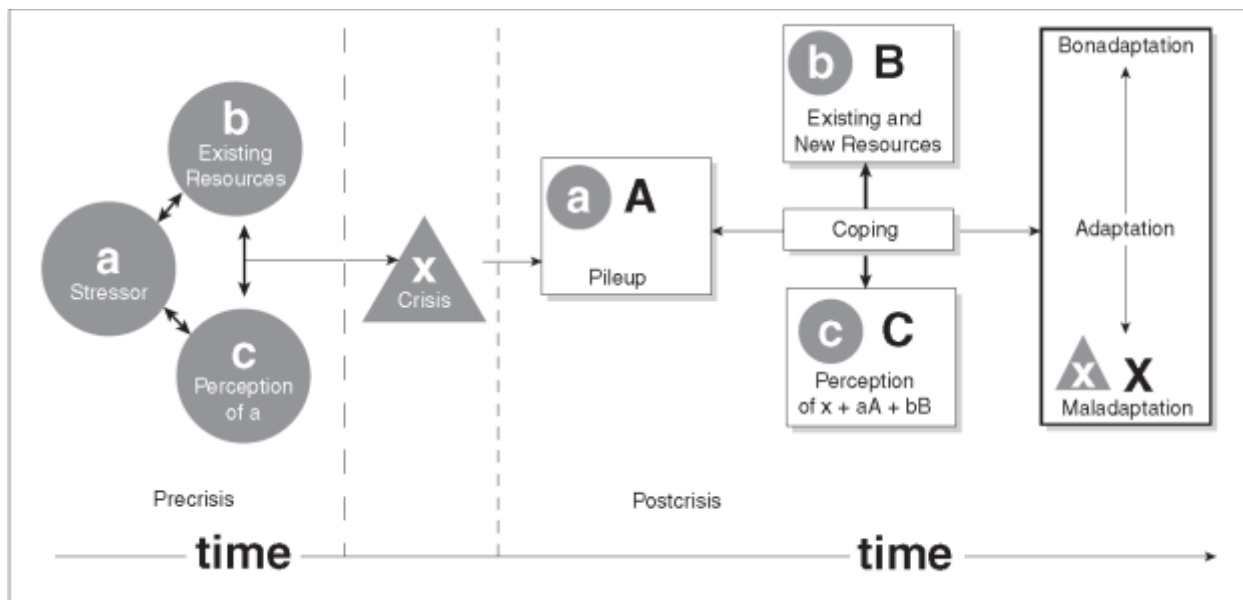


Figure 1. The Double ABCX Model
Source: McCubbin & Patterson (1983a)

Summary

In this study, the Double ABCX model is used as a guide for the development of research questions aimed toward discovering the adaptation methods of KA immigrant parents who have children with DDs. According to the Double ABCX model, it is assumed that KA immigrant parents have stressors in relation to caring for their children with DDs as well as other stressors. However, they could successfully adapt to their caregiving stress by using resources and positive appraisal. The factors among resources and positive appraisal that affect successful adaptation of KA immigrant parents are unknown.

Stoneman (2007a) highlighted methodological issues in research on disabilities that showed that low-income and ethnic minority families were less likely to participate in research studies. As a result, our knowledge may be biased toward specific populations. Although there are three qualitative studies that help to understand experiences of KA parents of children with DDs, no studies specifically provided factors that affect successful adaptation and the process of how to deal with parents' caregiving difficulties. Also, as the Double ABCX model suggested, cultural and environmental factors might affect the process among KA parents of children with DDs.

Additionally, in previous studies, the majority of the participants were mothers. Although Kim's study (2007) included three fathers' voices, their partners (mothers) were not recruited. Rather than recruiting fathers separately from mothers, it would be better to hear parents' voices together to compare their experiences in the same situation; this is so because the literature review indicated that mothers and fathers have different experiences in raising children with DDs. The current study recruited KA parents including both fathers and mothers.

Lastly, although there are three qualitative studies focusing on KA parents of children with DDs, all existing studies were conducted on the west coast (i.e. California) or east coast (i.e. Maryland), and no study was conducted in the southeast. This study recruited participants from the southeast region. I assume that different locations result in different experiences for KA parents of children with DDs because available services and support systems for KA parents may be different.

CHAPTER 3

METHODOLOGY

The current qualitative study seeks to understand the process of how the KA immigrant parents manage parental challenges that they experience in raising their children with DDs. The three primary research questions of this study are as follows:

1. How does caring for children with DDs affect KA parents or family members?
2. What resources and strategies do the KA parents use in managing their challenging experiences?
3. How do cultural and environmental contexts affect their caring experiences and coping strategies?

The following five subsections will be discussed to provide a detailed framework for this study: (1) research design; (2) data collection; (3) data analysis; (4) trustworthiness; and (5) researcher subjectivity.

Research Design

In this study, a grounded theory approach was employed (Corbin & Strauss, 2008). Grounded theory is a specific methodology that aims to build a theory using data gathered from participants (Corbin & Strauss, 2008). Creswell (2013) broadly defines *grounded theory* (GT) as “a qualitative research design in which the inquirer generates a general explanation (a theory) of a process, an action, or an interaction shaped by views of a large number of participants” (p. 83).

GT was originally developed by Glaser and Strauss in 1967; they claimed that systemic qualitative analysis provided logical results and could generate a theory. Despite their initial work, they professionally and methodologically diverged from the original GT because Glaser

criticized Strauss's approach as too structured (Glaser, 1997). Later, Charmaz (2006) fashioned a new approach to grounded theory. She focused on GT within the social constructionism paradigm, which stresses social contexts, interaction, sharing viewpoints, and interpretive understanding.

This study followed Corbin and Strauss' (2008) structured approach to grounded theory because the philosophical assumptions that they use for qualitative studies align with my approach to research. The philosophical assumption that I have for research has been identified as following postpositivism, which is characterized as having "the elements of being reductionistic, logical, empirical, cause-and-effect oriented, and deterministic based on a priori theories (Creswell, 2013, p. 24). In qualitative research, Corbin and Strauss' structured process of grounded theory exemplifies the postpositivist approach.

There are general features of grounded theory. First, it focuses on *process*. Although it is hard to understand the concept of process, Corbin and Strauss (2008) describe process "as sequences or a series of "actions, interactions, and emotions" taken in response to situations or problems, or for the purpose of reaching a goal as persons attempt to carry out tasks, solve certain problems, or manage events in their lives" (p. 99). A process is not only delineated by developmental terms such as *stages* or *phases*, but it can also be chaotic, which means it is not always linear or progressive but possibly up and down or circular. Thus, researchers try to discover the dynamic quality of "actions, interactions, and emotions" (Corbin & Strauss, 2008).

Second, the researchers are interested in building theory. The definition of theory varies according to philosophical assumption. The positivist perspective views theory as a statement of the relationship between abstract concepts in order to explain and predict a particular phenomenon, while pragmatist perspectives support that the theory is an interpretation that

provides abstract understanding of actions or meanings (Charmaz, 2006). Therefore, a theory could be substantive, middle-range, or formal (Corbin & Strauss, 2008).

Finally, there are several distinct methodological techniques unique to GT. It emphasizes concurrent data collection and analysis as well as specific procedures such as *theoretical sampling, coding, constant comparison, saturation, and memo writing* (Glaser & Strauss, 1967; Kenny & Fourie, 2014). Using those techniques helps data to be coded, sorted, and organized into abstract categories, and it then leads to the building of a theory. The theory is refined by combining new raw data.

Researcher Subjectivity

In qualitative research, it is important to acknowledge the identity that I bring to the research process. My identity has an influence not only on all processes of the study including interview questions, interpretation of interviews, and so on but also on participants' view of the researcher. Because I adhere to a positivism philosophy that believes in the existence of an objective reality, I am more familiar with and skillful in conducting quantitative research compared to qualitative research. However, for my dissertation, my research question led me to choose qualitative research methodology. Although I started the project planning to utilize a qualitative method compatible with a constructivist perspective, it soon became clear that my post positivist perspective was still present in terms of the way I was thinking about the data. With this realization, I chose to continue the project basing my work on a qualitative method more compatible with post positivism. Thus, I structurally interpreted interviews and tried to find cause and effect relationships. For example, I asked myself why a situation happened, or why the parents thought or behaved in certain ways.

My research interest and work experiences have been associated with children with DDs and their families. I have gained much knowledge about the population from academic literature and media, and I have close relationships with parents who raise their children with DDs. As a result, I bring significant knowledge to this process, which can be beneficial to understanding parents' daily caregiving process; however, it could prevent me from opening my eyes to new concepts or knowledge shared by participants.

I believe that my identity as a Korean female and Christian had a significant impact on the interview and analysis process. I am from the same ethnic Korean origin as the participants, which helped me understand when they talked about Korean culture. Because all participants prefer to speak Korean and have limited English proficiency, they liked to talk about their children in Korean. Although my third research question is about how Korean culture affects their experiences in raising their children with DDs, I did not explicitly ask questions about the culture. However, because I am Korean and understand Korean culture, I assumed and was implicitly aware of how culture affected participants' experiences based on what they said. Also, participants were involved in a Korean-ethnic church and significantly talked about their religion when I disclosed that I am a Christian, too.

Korean culture also affects the researcher-researched relationship. In Korean culture, age is important, because language reflects who is younger and who is older. As such, Koreans usually ask about age when they first meet before they continue communication. Koreans respect people older than themselves, even if they are only 1 year older. Older people are more likely to have authority over younger people. The age gap between the participants and me is over 20 years, which would make participants feel uncomfortable when talking about their life with a young researcher. However, during the interview, they seemed to respect me and were willing to

help me with anything that was related to their children with DDs. Also, I mainly recruited participants from the Wheat Mission organization where I have volunteered for several years, and I have known the same participants—but have not had a close relationship with them—throughout this time. It is possible that participants could be more open and show trust in me during the interview while they might not want to openly share their experiences with someone they know well because of their fear of losing face.

Data Collection

Procedure

The study was approved by the Institutional Review Board of the University of Georgia. Before I conducted the interviews, participants were given the opportunity to read and sign a consent form that states the research purpose and potential risks, and it also includes a section explaining their right to withdraw from the study at any time. The confidentiality of participants was safeguarded by eliminating identification information and using pseudonyms in the transcripts. In addition, the interview data were stored in a database that is inaccessible to others.

Initially, I contacted a leader of the “Korean Coalition,” which is sponsored by the Georgia Council of Developmental Disabilities (GCDD), and the director of the Wheat Mission organization, which provides services to KA children with disabilities and is located in Georgia. They allowed me to recruit research participants through their email listserv, but no one contacted me. I was then told that there is a Saturday worship service for children with disabilities, and that the Korean Coalition meets every first Thursday of the month. Consequently, I went to the Wheat Mission organization and the Korean Coalition’s meetings to recruit participants. Parents who participated in the interview received a \$30 Mega Mart gift card.

Participants

In this study, snowball and theoretical sampling were utilized to select participants. Participants who were interested in participating in the study were recruited from two groups, and I was introduced to other KA parents who met the inclusion criteria but may not have been involved in either group by KA parents who were involved in those groups. Also, the participating mothers were asked if their partners were available for the interview. In grounded theory, data should be gathered until each theme is saturated. Saturation refers to the point at which no new categories or relevant themes are emerging (Corbin & Strauss, 2008). Thus, theoretical sampling was employed during the interview process. Theoretical sampling means “seeking and collecting pertinent data to elaborate and refine categories in your emerging theory” (Charmaz, 2014, p. 192). The inclusion criteria for the participants are as follows: (1) first generation immigrant parents from Korea (2) who are currently parenting children with DDs in their homes and (3) who have children with developmental disabilities such as ID, ASD, and DS. Those who met inclusion criteria were invited for interviews.

Twenty KA parents (five fathers and 15 mothers) out of 16 families participated in the interviews. Table 1 reports the demographic characteristics of the participants’ children with DDs. Six out of 16 are females. The ages range from 6 to 35 years. Their diagnoses include ASD, intellectual disability, and Down Syndrome. Table 2 shows the demographic characteristics of the participants. The ages range from 49 to 63, and the number of years in the United States ranges from 4 to 41. The reasons for coming to the United States include family immigration, looking for better education opportunities for their child with DDs, studying, and marriage. Only one mother out of 20 participants has a student visa, and the others hold either citizenship or permanent residency. Two families (one father and two mothers) were recruited

from Florida. They were introduced by one of the participants who lived in Florida before and who still has a connection with them. The rest were recruited from Georgia.

Table 1. Demographic characteristics of individuals with DDs

No.	Gender	Age	Diagnosis	Age at time of diagnosis	Place of diagnosis
1	Male	23	ASD	3	U.S.A.
2	Male	35	Intellectual disability	3	U.S.A.
3	Male	24	ASD	5	U.S.A.
4	Male	22	Intellectual disability	4	Korea
5	Female	30	Intellectual disability	5	Korea
6	Female	23	ASD	3	U.S.A.
7	Male	19	Down Syndrome	5	Korea
8	Female	24	Intellectual disability	3	Korea
9	Male	11	ASD	2	U.S.A.
10	Female	16	ASD	2	Korea
11	Male	6	ASD	5	U.S.A.
12	Female	8	ASD	3	U.S.A.
13	Male	11	ASD	4	U.S.A.
14	Male	8	Down Syndrome	Birth	U.S.A.
15	Male	10	ASD	6	U.S.A.
16	Male	15	ASD	2	U.S.A.

Table 2. Demographic characteristics of KA parents

No.	Family Unit	Caregiver	Age	Years residing in U.S.	Reason for immigration	Employment status	Number of children	Citizenship status
1	A	Mother	52	25	Marriage	Self-employed	2	Citizen
2		Father	51	27	Family immigration	Employed	2	Citizen
3	B	Mother	63	37	Family immigration	Homemaker	2	Citizen
4	C	Mother	48	10	Education for child with DDs	Homemaker	2	Permanent resident
5	D	Father	63	18	Education for child with DDs	Self-employed	2	Citizen
6	E	Mother	53	27	Marriage	Homemaker	3	Citizen
7	F	Mother	48	10	Education for child with DDs	Homemaker	1	Permanent resident
8	G	Mother	50	23	Husband's studies	Employed	3	Citizen
9		Father	55	23	Student	Employed	3	Citizen
10	H	Mother	39	12	Husband's studies	Homemaker	2	Permanent resident
11		Father	44	12	Student	Employed	2	Permanent resident
12	I	Mother	45	7	Education for child with DDs	Homemaker	2	Permanent resident
13	J	Mother	40	18	Student	Homemaker	1	Permanent resident
14		Father	40	21	Student	Self-employed	1	Permanent resident
15	K	Mother	38	15	Family immigration	Homemaker	2	Citizen
16	L	Mother	42	23	Family immigration	Homemaker	2	Citizen
17	M	Mother	41	24	Family immigration	Homemaker	2	Citizen
18	N	Mother	42	9	Student	Homemaker	2	Student visa

19	O	Mother	60	41	Family immigration	Self-employed	1	Citizen
20	P	Mother	48	4	Education for child with DDs	Homemaker	1	Permanent resident

Interviews

Whether they were face-to-face or on the phone, in-depth interviews were conducted in the parents' native language, Korean. The data were collected for approximately 5 months in total. Before conducting the interview, the participants were given the opportunity to read and sign a consent form and fill out basic demographic information. This study used semi-structured interviews; as semi-structured interviews provide flexibility, they allowed the parents of the children with DDs to elaborate on important information that may not have been discovered otherwise (Gill, Stewart, Treasure, & Chadwick, 2008). The face-to-face interviews were conducted either at their home or at other places such as church, the Wheat Mission organization, or a restaurant that they selected.

Demographic questionnaires were filled out by parents before the interview. In order to develop rapport with the participants, I started asking basic questions based on demographic information that they filled out (Appendix B). The interview questions are in Appendix C. Based on the interview questions, probe questions were continually asked throughout the interviews. The interviews lasted approximately 50 to 60 minutes, and they were tape-recorded with the permission of the participants and transcribed verbatim. The parents sometimes continued to talk after the recording was turned off, so I made substantial field notes about what they were saying and the characteristics of the children if I met the individuals with DDs. The interview was transcribed in Korean within a week of the interview. As I transcribed, I was able to get an overall sense of what the participants have experienced.

Data Analysis

For data analysis, qualitative software, Nvivo 10, was utilized, and the grounded theory analysis method (Corbin & Strauss, 2008), which includes two data coding methods (i.e., open and axial coding) was applied. Before starting coding, I read the data from beginning to end several times to gain insights about what the participants experienced. At this time, I did not hurry to label raw data or my notes, but remained open to all potentials and possibilities in the data.

Open coding refers to labeling blocks of raw data with interpretive conceptual names (Corbin & Strauss, 2008). I broke the data apart and named the block of raw data conceptually to best describe what the data indicated. This was the process of identifying concepts, their properties, and their dimensions. The open coding process was repeated to find key concepts in the data. Axial coding attempts to make connections between concepts. In fact, dividing the analysis process into open and axial coding has only an explanatory purpose (Corbin & Strauss, 2008). During my analysis, the two processes did not occur separately. While I was delineating concepts, I automatically put the concepts together to make a connection.

During each stage, two analytic strategies were utilized—*asking questions* and *constant comparison*—when working with data. Asking questions enables the researcher to probe, develop provisional answers, think outside the box, and become acquainted with the data (Corbin & Strauss, 2008).

Asking questions and thinking about the range of possible answers helps us to take the role of the other so that we can better understand the problem from the participant's perspective. Any answers to the questions are only provisional, but they start us thinking about what ideas we need to be looking for in the data, both from this participant as well as future ones. (Corbin & Strauss, 2008, p. 70)

The second strategy is constant comparison. Each incident is compared with other incidents in the data for similarities and differences as the researcher proceeds with the analysis (Corbin & Strauss, 2008). This type of comparison allowed me not only to distinguish each theme from others, but to identify properties and dimensions in each theme.

Memo and Diagram

From the beginning of the data analysis, I kept writing memos in Nvivo as well as my notes. I wrote down all my thoughts because Corbin and Straus (2008) emphasized that writing memos and doing diagrams move the analysis forward, and they are as important as other aspects of the research process such as data collecting. Those memos helped me organize my thoughts and avoid missing important concepts. Because I did not remember everything, writing memos helped me keep a record of the analysis. I repeated the reading of my memos while I was coding. The first time, I did not have any particular structure when writing memos; I just tried to write down everything that seemed interesting to me. As I analyzed the data, key concepts were raised. I created memos named after each raised concept and then wrote down the properties and dimensions on each concept memo. In addition, diagrams helped me to visualize the concepts and to connect each concept. The diagrams kept getting modified based on the analysis. The diagram allowed me to have a broad picture of the findings. Examples of memos and diagrams can be found in Appendix E.

Validity and Reliability

Creswell (2013) defines *validity* in qualitative research as the “attempt to assess the ‘accuracy’ of the findings as best described by the researcher and the participants. This view also suggests any report of research is a representation by the author” (p. 249). This study employs

multiple strategies to ensure the validity of the research, including investigator triangulation, clarifying researcher bias, member checking, and thick description.

Investigator triangulation refers to involving more than one investigator in the research process. The KA parents' data were collected as Korean and non-English data, but reports or publications were written in English, so it is possible that some meaning could be lost in the translation. Translation involves interpretation as well, but the interpretation and representation of meaning are more complicated when cultural contexts differ (van Nes, 2010). I did not translate whole interviews into English, but rather I translated segments into English that are used in findings of this dissertation. I asked a Korean bilingual graduate student to review the translation. We met and discussed the translation together. Based on this step, some modifications were made.

The clarification of researcher bias helps readers understand how the researcher shapes the interpretation (Creswell, 2013). I included a subjectivity statement that explicates past experiences, biases, and orientations that affect interpretations at the end of this chapter.

Member checking in qualitative studies involves "taking data, analyses, interpretations, and conclusions back to the participants so that they can judge the accuracy and credibility of the account" (Creswell, 2013, p. 252). I briefly introduced the findings to a participant via a phone call to make sure that nothing was missing or different from their accounts. She agreed with the findings.

Rich, thick description was used to enhance external validity. Merriam and colleagues (2002) noted that while internal validity deals with questions that ask how congruent one's findings are with reality (p. 25), external validity deals with the transferability of the findings to another context. I described in detail the participants and provided a thorough description about a

theory and each concept within the theory. Rich, thick descriptions allow readers to transfer findings to other settings due to shared characteristics.

Bogdan and Biklen (2007) define *reliability* as “a fit between what they record as data and what actually occurs in the setting under study, rather than the literal consistency across different observations” (p. 40). Reliability can also be safeguarded by several strategies used in ensuring validity.

CHAPTER 4

FINDINGS

From rich and illustrative descriptions provided by KA immigrant parents who raise children with DDs, the hope for development theory was developed in relation to experiences in caring for children with DDs (Figure 2). The theory explains how parents can continue their endless caregiving loads across the course of their life even though they have experienced physical and emotional burden and distress. I will explain the overall theory first and then describe each component within the theory.

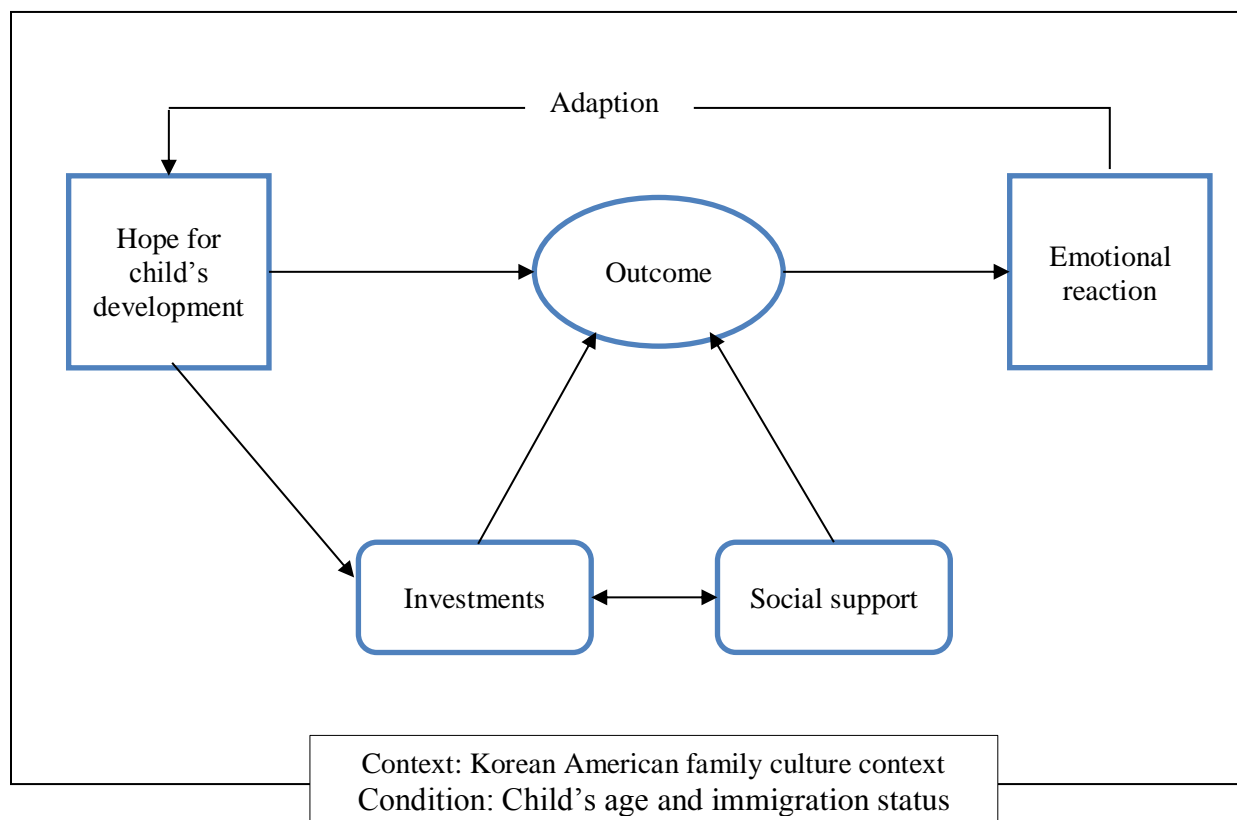


Figure 2. Hope for Development Theory

Hope for Development Theory

Parents who raise children with DDs explained that they have feelings of frustration even though having a child with DDs brought feelings of happiness. From the time their children were diagnosed, the parents have paid attention to their child with DDs. They were aware that their caring for their child with DDs might be endless and would require tremendous efforts and energy. In everyday life, parents encountered challenges due to a wide variety of reasons which made them feel overwhelmed. Nevertheless, they have continued caring for their child. What makes KA immigrant parents keep moving forward while some parents become depressed and stuck? Parents having hope for their child's development in any aspect can be their fuel in their long journey.

Once parents had hope for their child's development, parents investigated their time and finances and tried whatever they could do to fulfill their hope. Depending on the degree to which they obtained their desired outcomes, parents experienced different emotions ranging from positive to negative. If their child showed development, changes, or achievements in any degree, parents felt pleased. On the other hand, if their child had no development or fewer changes than they expected, they felt disappointed and distressed. Social support can affect investments, outcomes, and emotional reactions. Then, parents adjusted their hope for their child based on achieved outcomes. This caring management process seems to be repeated across their life course.

Also, the process is highly affected by the child's age, cultural family values, and family and social contexts. Parents who raise a young child were more likely to have hope that focused on the normalization of their child. Their child can develop as a normal child while parents who care for adolescents or young adults with DDs tended to acknowledge limitations to growth and

focused on different expectations and hope. Korean cultural family values and immigration status appeared to affect each component of the hope for development theory.

Categories and Themes

Table 3 shows each category of the theory and themes. I will give more detailed explanations for the categories below.

Table 3. Categories and Themes

Categories	Themes
Having hope for their child	Type of hope Hearing from others
Investment	Time Money
Social Support	Family support Parent-to-parent Available community services
Outcomes	Developments No changes
Emotional reaction	Positive Negative
Adjustments	Fit with their child From parents' desires to child's desires
Condition and Context	Cultural Family Values Language proficiency Citizenship

Having Hope for their Children

Type of Hope Parents had hope that their child would change for the better in terms of their development. The kind of hope they had varied, and the child's age appeared to be a significant factor. Parents who had a young child with DDs had high or sometimes unrealistic hopes, for example, that their child would become normal if they educated them a lot or used some medications; they believed some miracles could happen. Although parents acknowledged that their child's diagnosis was chronic, they had hope for significant development when their child was young. Mothers of young children with DDs demonstrated hope for their children's development as follows:

This depends on parents. Getting diagnosed with autism is not a death sentence. We should keep educating them. Who knows what might happen after 10 years. There are a lot of people who blossom after 21 years old. Now, I am teaching him to type on an iPad. Apple sells the program #375. The app includes 'I want ice water' and you can add words. He started with 10 words at first, but now he can use 20 words. He typed 'go home.' He is nonverbal, but can type with the iPad. He also remembers food names and typed rice soup. He did not look stupid. I will teach math and normal classes at home.
(#17)

I have searched and found that children with ASD can go to college, too. There is a college where autistic children can attend. I copied the link and brought it to the MT teacher and told the teacher that I will let him attend college, and they said, "I am sure he can attend the college if you prepare for it as of now." The teacher gave positive words. I will. (#13)

On the other hand, as children were getting older, parents were more likely to accept their child's symptoms and acknowledged limitations regarding development, so mothers who have young adults with DDs appeared to give up the hope they had before and no longer even hoped for their young adults with DDs' development. Parents who have adolescents or young adults expressed their feelings as follows:

That was when he was 3 years old; now we cannot do what we did before. At that time, I had hope that there would be a bigger change if I did something. I was caring with that hope, but not many changes happened. (#16)

I had a dream that she could go to regular class if she received extensive training...I believed that if she received extensive training, she would be cured or better. Now, I gave up a lot, but when she was young, nothing happened, and she was not cured. It made me give up a little bit about making Anna into a normal child. (#6)

I thought my child became normal. I had hope when the child was young. But now I don't have that kind of hope. I came to acknowledge the reality by hearing from professionals who said that disabilities are not diseases so they are not curable. I was in shock, but I was more aware. (#2)

There is no plan. I just live [day by day], just live together. I occasionally think about what would happen to her if we die, but we just live. There is nothing I can do and no alternative ways. So we just live. (#9)

Not all mothers of young adults with DDs are hopeless in terms of their child's developments. A mother of a young adult with ASD expressed hope for her son's future.

I had hope that he can live independently, and Peter is good at drawing, so we want to make a space for him to paint or draw pictures. He is swimming. I hope he can participate in the Special Olympics someday. (#1)

In addition, parents made decisions for immigration with hopes that their child would receive better educational services, that they would receive less negative attitudes toward their child with DDs, and that they would get better disabilities services in the United States. However, the reality was different from what they hoped for. Mothers who made the decision to come to the United States stated that:

I decided to come to the United States to experience a haven of social welfare services where people normally say it's good. But, there are pros and cons. We thought everything would go well if we went to America, but the reality is not like that. (#20)

A decisive factor to go to America was that I heard that America is like heaven for people with disabilities. I did not know anything about what benefits or services existed here. Life here also is very tough. I didn't know the reality when I was in Korea. I thought going to America is all [I had to do] to achieve my dream. That's why I came here. (#7)

Hearing from Others KA parents were willing to hear positive stories about development from senior parents or professionals. They were disappointed or became hopeless when hearing about a negative future in terms of children with DDs. KA parents showed strong parent-to-parent connections, and they helped each other. However, parents tended to interact often with parents of children who are a similar age as their children with DDs. KA parents who raise

young children with DDs were not willing to interact with KA parents who have an adolescent with DDs or adults with DDs because they felt that parents of adults with DDs have relevant experiences but sent negative messages and were not hopeful in terms of their child's future.

Mothers of young children with DDs described these experiences:

I went to the GCDD meeting and there are mothers who care for young adults or adolescents with DDs. I am willing to try anything for my child's development whether it works or not. They said that's a waste of your time. That seemed to not be hopeful for someone like me who is raising a 4- or 5-year-old child. I want to be around people who are positive and diligent in doing things for their child. (#13)

Another parent expressed how she was encouraged by hearing positive stories from other parents who already went through the same process. She stated that,

I depend on parents who raised a kid with autism to receive comfort and to be consoled. I am encouraged by parents who have already gone through what I am experiencing now. A couple of days ago, I heard that a kid with severe autism at a young age got better in middle school, and now the kid is like a normal child in high school. That kind of news gives hope to me that if I consistently put effort towards my kid without giving up, my child can be like that kid. (#16)

A KA parent who heard about the possibility of a negative future for their children from professionals felt hopeless and upset. She stated that,

Before I came out of the hospital, a doctor told me all negative things like his muscles are weak, his skin is very dry, blah, blah, blah. It is good to know the information, but I was more shocked [when I heard] and thought about how I could raise my child. (#15)

Investment

Having any hope made parents invest their time and money towards their child. For example, parents immigrated to America at the cost of their life in Korea. However, parents who do not have any hope or expectations for their child's changes or development may not even move forward. Also, parents believe some changes would happen. A father of a young adult with ASD stated that, "[We did a lot of things for my children] we repeated countlessly. There were few changes, but I believe there would be changes little-by-little as time went by."

Time In order to fulfill their hope of their child's development, parents spent their time studying to know more about their children with DDs and taking care of their children all day. Parents work to find training programs, therapies, or education that best fit their children with DDs. Parents believe that educating themselves regarding autism is necessary. For example, parents searched the Internet, read books, and watched movies that related to individuals with DDs. A father of a son with ASD stated that, "His mother made a great effort to find any information that was related to our child. I think that information helped him a lot." Parents described their studies or findings as follows:

Mothers of children with ASD got together, learned about autism, and shared about education and other things. Also, I searched the Internet and watched movies. I think that no matter whether a child has disabilities or not, parents should educate themselves and share information because we do not know a lot. (#10)

I studied a lot. At first, I started searching YouTube. I think mothers should research a lot of information about a child. Mothers research information, and then it leads to the

child's education. At Marcus [research institute], they educate mothers first before addressing the child's behavior. (#16)

Based on their studies, searches, or what they heard from others, parents made decisions about where to invest their time and finances. While the child was young, it appeared that parents tried everything possible for their child or had a strong desire to make their child better. After having greater understanding and studying about developmental disabilities, parents had their child receive education, therapy, and try whatever they can to help their development. Educating children with DDs was the basis for all that the parents were doing for their child, but ways to actually carry out the education varied by parents. Most parents depended on the public education system, but some parents sent their child to private school or did homeschooling. A mother who homeschooled her child was against the public special education system. She shares her views below:

My son is in fifth grade and a stupid IP class had repeated kindergarten level [words]. But in my opinion, there is no need for repetition. Children with autism have good memory function, no repetition needed, and must move forward. They should teach them as a normal child. They do not have a slow brain, and professionals misunderstand. They wanted him to push DOLPHIN every time, and the child was irritated. He already knew the word! I think there is no need for repetition. I went to an RPM conference and they have the same thoughts as me. They said do not consider children with ASD as stupid because they are nonverbal. Do not underestimate them. They have good memory function. Don't repeat, but keep teaching. The child will remember everything. So I brought that method into my home. (#17)

In addition to education, parents focused on treatments to improve child's symptoms such as social relationships, language, movements, and physical health. The child with DDs received speech therapy, occupational therapy, physical therapy, musical therapy, and participated in exercise activities such as swimming, taekwondo, soccer, gymnastics, painting, or piano. Also, for treatment, parents used alternative medicine such as acupuncture and herbal medicine in addition to medication. It appeared that parents and their children were very busy doing all those things:

When he was young, I tried everything that I heard is good. If I heard acupuncture was good, I went and tried. (#20)

Anything I can do, I tried. In addition to taking medication, if David can be cured with prayer, I did that; no matter where it was, I didn't care. And to anything I heard that can be good for David I said, "Really? I will take it. Expensive? I don't care. Get a loan." I looked like a crazy woman and went all around the world until David was 20 years old. (#3)

Because of my dream, my house became a private school until she was 10 years old. Tutors were with Anna 24 hours, 7 days, 365 days a year. There were no holidays or breaks...Parents want to do anything they can do for their children with autism if there is something that looks like it will help their child. If someone hears that using headphones for 2 hours every day would help to cure children with autism, they would try to buy it and practice it with their kids. This is a parent's mindset. Sometimes a miracle, a real miracle happens. I tried letting her use headphones for 2 hours, and she listened to some

music. I paid \$5,000 for 2 weeks. I did anything or everything I could do for her from when she was 2 or 3 years old to when she was 10 years old. When I heard that a kid took some kind of hormone and then became a normal kid, I tried to find out which hormone and went to New York to find it. (#6)

Ashely was very busy after school from Monday to Friday. She was going to therapy three times a week and another day she went to piano lessons, gymnastics, or swimming. The whole week is very busy. (#12)

I cured my son's atopic medication. Completely got rid of atopic medication so he can sit down [for long periods of time]. I did this for several years. Did cage free and had him have probiotics, vitamin b6, 12 and mineral supplements along with biomedical treatments. I stopped using atopic medication. It works after 5 years. Detox works. He sleeps well. (#17)

In order for parents to focus on and put tremendous efforts into raising their child, a majority of mothers have stayed at home and did not even consider finding a job because of the sheer amount of time they have spent on their child:

We went to speech therapy, participated in many education programs, et cetera. Anyway, I spent entirely everything on Daniel...I never worked. There was child therapy and coming and going to school frequently due to Daniel's problems. There is no time to think about being a working mom. I cannot imagine working because caring for a child was overwhelming and exhausting. (#19)

I bring him to a swimming lesson [and wait] about 4 days a week and spend 5 hours per day. So, I think if we focus our time on Peter for 5 days a week, I believe it affects him.

(#1)

Money Not only did parents invest their time but they also spent tremendous amounts of money on their child's education and treatments. Insurance can cover therapies for a limited time, but parents wanted to provide more therapies for their child, other activities, and other forms of education in addition to public school—however, all costs had to come out of pocket. Mothers explained how huge their expenses were as follows:

I spent my own money. It was like an after school program in my home. I built it only for Anna. My friends would tell me that I spent a great deal of money on her: "The total amount of money you have spent on her is almost the same as the price of a house."

Because the tutoring program was not included in the public education system and that was extra education for her, I could not receive any financial support from the government. (#6)

It cost a lot of money. Four times more expensive for gluten free, and he has to have a special probiotic...also for therapies, too. Therapies cost a lot of money. We have insurance, and it covers 20 therapy visits. If people use speech therapy 20 times, they can choose either physical therapies or occupational therapies along with speech therapies. In the case of my son, he needs both PT and OT. I cannot give one of the two, so he receives both PT and OT, and I pay one portion of the cost. (#10)

The basic things like ST and OT are covered by insurance, but other types of education like camp or swimming is paid out-of-pocket. Georgia family support provides some amounts of money per year, so I use that money for music therapies. After spending all of that money, we have some breaks. The cost of therapies is expensive. It is two or three times more expensive for music therapy than music lessons. Calling something “therapy” makes it expensive. (#18)

More financial burdens were placed on parents who have an adult with DDs. The mandated public services are no longer available to adults with DDs. Although the Medicaid Waiver covers adult day care programs, due to a limited budget, it has a long waiting list. It is too expensive to pay for the adult program for all 5 days per week. Mothers stated the following:

I cannot send my son to an adult day care program for 5 days due to our limited budget. So he just goes to the program 2 days a week. (#7)

The cost of a day care program for 5 days from 8 to 6 is around a couple of thousand dollars, I heard--\$72 per day. I cannot afford a full month of payment so I tried to send him twice a week. (#19)

Immigrant parents who do not have citizenship could not even receive offered therapies covered by Medicaid, and low income families could only rely on public systems even though they were willing to give additional education and treatment to their child. A mother who immigrated for her child with DDs stated that,

We need to educate children with DDs and try everything you can to do so that you won't have any regrets. I did try [everything] when I was in Korea, but after coming to America, putting my child in public school is the only thing I did for my child with DDs

because I did not know [what to do], I couldn't speak English well, and I did not receive an education here. So it is such a shame. (#7)

Also, for households where both parents had to work, they felt sorry about not spending all of their time on their child and expressed regret that their son or daughter might get better if the right amount of time could be dedicated to them.

Social Support

Family Support There appeared to be two types of fathers in terms of assisting with care: One type actively helped the mother by sharing care responsibilities, and the other type was indifferent in caring for his child and turned all caring responsibilities over to the mother. The KA parents emphasized how important it is that the parents collaboratively care for their child when they have a child with special needs. Observations revealed that mothers who received spousal support seemed to be relatively satisfied with caregiving demands and welcomed the chance for me to interview their spouse when I asked for permission, while mothers who complained about their spouse's indifference regarding caregiving spoke with agitated voices and hesitated to ask their spouse to participate in the interview. A mother stated, "The families have a child with special needs, [so] the parents must work with one accord."

Also, it was found that all four fathers who participated in the study believe that sharing care responsibilities with mothers for a child with special needs is necessary. Parents of a child with DDs stated the following regarding partner support:

Like for children with typical development, the roles of both mother and father are important in terms of nurturing the kids with DDs. It is not just division of labor, but we should work together in every aspect. My wife spends the most time with my kids, so my

role is to directly take care of my kid with DDs during the weekends and do things such as educating, playing, having meals, sleeping, and bathing. (#11)

I think there are two types of couples who raise children with disabilities. One type of couple is where only the mother takes care of the child and the husband does not care about it. The other type of couple includes those who share care responsibilities. I think we are the second case. I tried helping with care responsibilities. I was told that only one parent's efforts are not good enough, but the couple should make an effort together. (#2)

The fathers not only provided physical help in terms of caring for a child with DDs, such as playing with them, doing house chores, and driving the child to places like schools, etc. but also emotional support. A mother said, "When I complain that I cannot live like this, my husband always tells me not to worry too much about the future, just live day by day." Also, spouses who were flexible managing time at work were able to assist with caring demands: "I sometimes feel up and down and my husband has many available paid vacations, so he takes over my work. I tell him 'I need your help' like a crybaby."

Some families who decided to immigrate to the United States in order to provide better education opportunities for a child with special needs were separated from their spouses for several reasons. They were supposed to come together, but the mothers came alone with their children, and the fathers only provided financial support from Korea. These kinds of single mothers expressed the hardships they face in raising a child with DDs alone.

Because my husband is in Korea, there are big differences between when he is with me and when he is not. I have to do everything alone, which is very difficult. I am taking care of two kids, so I am very busy. I go to work, pick up the first kid, and then pick up the

second kid, and also I am doing house chores. This is not easy, and it is time consuming.

(#18)

Besides spousal support, extended family members such as grandparents also provided emotional and instrumental support such as financial assistance and childcare in raising a child with DDs. Parents who lived close to their extended family could receive help, but families who did not have extended family in the United States could not receive those kinds of support. After the grandparents passed away, parents were much more aware of how helpful they were.

My father gave us a lot of help. He drove a lot for my kids. After he passed away, I became aware of how helpful he was. He was very passionate in helping my child with DDs. He was a big helper. (#1)

When my mother was alive, she took care of my child although she was old and it was difficult for her to do so. With her help, I was able to have a full-time job. After she passed away in 2010, I became very busy. The family on my side lived in Georgia. (#17)

A mother who did not have extended family members in the United States mentioned, “My husband and I have no relatives here, so we said to each other that if one of us is sick, one should go to Korea alone to get treatments because we cannot go together due to Daniel.”

Parent-to-parent KA parents interacted with other parents in the same situation and benefited from sharing information, experiences, and emotions. It seemed that connections between parents of children with DDs were well-developed and strong. Each parent provided emotional support and resources. A mother stated, “I knew about the insurance system and helped another Korean parent, and also another Korean parent helped someone.” They showed

deep sympathy toward each other—parents had many things in common in terms of caring experiences, so it was easy to sympathize with others. A mother of a child with ID stated that:

We understand each other when I talk about difficulties. I only told them small things, but they understood everything. I think mothers who do not raise kids with a special need might not understand what I experienced in terms of difficulties, but the parents [of children with special needs] experienced similar things. (#7)

However, sometimes KA parents limited their social interaction only to parents in the same situation and gradually avoided interactions with other parents.

I cannot hang out with parents without a child with disabilities because they talk about their child's education and other things; I have nothing to say about those things. So I avoided meeting them. When I talk with parents of children with disabilities about my difficulties, they understand what I am saying with just simple words. How can others understand? We depend on each other. (#8)

Available Community Services It is important for the community to provide sufficient services that fulfill parents' needs. It appeared that the KA parents were more likely to utilize services in the Korean-based community rather than mainstream services due to language proficiency and culture differences. So, a high number of the KA parents of children with DDS among the study participants were involved in the Korean church, which provided significant services to their child with DDs; these parents received support from faith leaders and church members. Having people take care of their child with DDs in Sunday school was also a huge help for parents. Parents of a child with DDs described getting help from their church:

When there was a camp in the church, they took my son with DDs for 3 days. On Sunday, church members take care of my son for a couple of hours. I had a church member who

was my neighbor. Their sons are twins, and they came to my home to play with my son as volunteers. I was very thankful for them. (#4)

I did not know about the early childhood program at the time my son was young. A pastor in my church helped me a lot. He was knowledgeable and old. He had studied in Canada at a young age. He let us know about the early childhood program, and then I investigated it. (#3)

I am not a Christian, but I go to church every Sunday. I hate participating in the church small groups, but I go due to my child with ASD. There are three children with autism in total in my small group. The parents are educated, and I can get information for my son as fast as possible. (#14)

A mother of a young adult with ASD stated the following about culture differences:

I go to the Wheat Mission Center 2 days a week. The reason I go to the center run by Koreans is that mothers of children with disabilities prepare lunch for kids. So mothers feel comfortable enough to send their children to the center. They know each other very well, and they know which kids like or dislike which types of foods. Americans just leave them alone if children with disabilities do not want to eat. They learn that way. That is their culture. However, Koreans are not like that. Korean parents try to feed them by any means. The parents know my kid likes some kinds of food, and they strive to feed my her with those foods. When I come to pick up my child, the parent thoroughly describes what

she ate and what she did that day or what she disliked. So I feel very comfortable sending my daughter to the center. (#6)

In addition, the region of the country is a factor that profoundly influences services available for KA parents. Although Georgia has the fastest growing Korean population in the United States, there are fewer services for the Korean population compared to services available in L.A. or NY, which have the largest Korean populations. Also, parents who live in a state where the Korean population is not high, like Florida or South Carolina, encounter a lack of services. The parents who stayed in Los Angeles for 10 years and moved to Atlanta reported that there was less formal support for Korean parents of children with DDs in Atlanta compared to L.A. The mother stated the following:

There is a huge difference between L.A. and Atlanta. Lack of services. Funding is good in L.A., I understand. I received respite care services there, but here there is nothing. There is family support, but limited support. The state government said they do not have enough funds, so they can only assist urgent cases and children with severe DDs. (#16)

A father of a young adult with intellectual disabilities who immigrated to Georgia and has lived there for 20 years stated the following:

As you know, many Koreans stay in Georgia, but not many organizations for Koreans exist. Like in L.A., where the most Koreans reside, I heard that many Korean-focused organizations for disabilities exist. But in Atlanta they do not. I hope they can build more Korean organizations here in the near future as the Korean population is growing. (#5)

A mother of a child with ASD who has lived in Florida for 7 years stated the following:

I am living near Miami, Florida. Not many Koreans reside here. Florida does not have a high Korean population, but the city I live in has a higher Korean population than other

cities in FL. I want to have an opportunity to share information with Korean parents who have a child with disabilities, but I do not have them in my church. It would be good to share information with other Koreans. (#12)

Outcomes and Emotional Reactions

Two categories will be explained together because they appeared to have a cause and effect relationship in the data. Parents' emotional reactions seemed to be directly affected by the outcomes of their children with DDs, but not directly by their hopes for their children.

Development Parents were joyful and delighted and had energy to keep going when seeing and hearing about at least a little development or positive changes or achievements of their child. For example, when physical health was getting better, typical symptoms such as speech or movements developed, or they made a new achievement, mothers of young adults with ASD were delighted about their child's new achievements:

The first time he started swimming, he was not able to place his head inside the water, but one day he was able to put his head in and out of water, which I was delighted about. If parents don't give up, a child has many changes. Keep going. (#1)

He likes painting animals and dinosaurs, so I got some ideas that he can enjoy painting 'Noah's ark' so I asked a teacher that for 2 hours, let him draw what he likes for an hour and try Noah's ark the other hour, so he completed it within a month, which was much more pleasing than any other [activity that was] completed because I have been dreaming about that and the dream came true. (#16)

Another mother of a child with ASD stated that, "I am very happy if my child made a little progress. I heard from others that he is better, and I know he is changed through therapy."

Also, severe symptoms that made parents feel exhausted such as challenging behaviors and wandering gradually lessened as children with DDs get older. Parents who have adults with DDs stated that:

When he was around 9 years old, the tantrums disappeared, so I think I was able to bear it. If the tantrums kept on for over 10 or 20 years, I would be exhausted and then something might happen. But after [he was] 9 years old, it was much easier. (#17)

Although it is a very slow process, my daughter has become better. Now, when we go to McDonalds, she is able to sit down for long periods of time. She can wait after ordering food. She was not able to wait before. But now whenever we go for food, she is able to wait until the food is ready. She improves very slowly, but it is less difficult to live with her than when she was young. (#9)

No changes It was not always the case that a child had positive changes or developments. Parents were disappointed when they could not see development corresponding to countless investments in money and time. A father of a child with ASD stated, “Daniel receives various treatments and services with countless investments of time and money, but he did not have progress corresponding to the investments, which was the biggest disappointment to me.”

It appeared that their distress and frustration negatively affected their psychological well-being. A mother of a child with DS described her experience:

No matter [if they] have surgery or not, it is hard. When having surgery or accepting a diagnosis, it was very difficult. [I was] always fighting with myself. I felt good, but

suddenly I would become depressed, [I] felt like there is no life in the future. It is hard to express, but I was depressed unexpectedly. (#15)

Also, parents expressed they could not control their emotions, and their frustration negatively affected their child with DDs by causing them to physically and verbally abuse their child unconsciously. A mother of a child with DS expressed that:

I was so mad so sometimes I pinched him. I could not hit him in front of people, but at some time I unconsciously slapped him in a split-second. I was scared of myself when I hit him or got extremely angry, or cursed at him in a split-second. I don't know other mothers like me. And then I thought I am becoming crazy because I was really stressed out from my son, and I blamed myself. I do not know if this kind of emotional fluctuation is normal or not. (#15)

Adjustments

The data suggest that hope for developmental progress is circular. As a result of a child's development and emotional changes, parents had time to adjust the hope they had. If a child showed any development or changes in relation to their hope, they seemed to rebuild hope for more developments or changes. On the other hand, when they could observe little change or achievements, they began having more realistic or doable expectations.

A child's age was a factor that affected how to adjust and where to focus their hope. As a child grows older, parents figured out that there are limitations that the child cannot overcome in terms of intellectual or behavior development. When a child was young, parents' expectations or hopes came from what mothers wanted to achieve, and they tried every treatment and service no matter if it worked for their child or not. However, as the child got older, parents could figure out areas of possible developments and achievements as well as treatments or services that fit with

their child with DDs. Also, they realized that those trials could be a part of a mother's hope or expectations rather than things that their child with DDs wanted. A mother of a child with DS stated that:

I forced him to do things like “Do, Do, Do,” but as I am looking at my son, his response was worse when I forced him to do something. For swimming, because he did not want to do it, I stopped it for a while and then he did swimming later. So, I think it was my fault that I tried to control my son because of my expectations. (#12)

Parents adjusted their hope from what they wanted for their child to what their child wanted to do. Parents of children with DDs described these experiences:

At my son's age, therapies or other [things] are not very important, but I think it would be better to go with his interests and things. At a young age, I thought he was likely to achieve everything where he was educated, but now I give up things that did not work for him and search more for what my child likes and enjoys. (#19)

At my child's young age, I was confident that my son would be different. If I am diligent in caring for my child, he would be better compared to other child with DS. As I think back, I was arrogant and he is just a child with DS [not a normal child]. When I looked at a child with DS [who has low function], I thought their mom did not work hard for their child, but as my son gets older, I understand [the low function] because of Down Syndrome. I do not have greed. I just have minor hope for him not to get sick and become satisfied with the reality as my son ages. (#4)

When my child was young, I tried to teach him anything in order to get him to get along with normal children and fit within the society...but now after my son is an adult, I think he should be happy and my son may not be happy with normal children. (#6)

I had educated my son a lot since he was 2 years old, so I know what my son needs. I do not want to push him, but I just want to let him be comfortable and happy. I figured out my son cannot have high academic achievement because I tried a lot, but he is happy when he is just listening to music that he likes, so I no longer push him. (#19)

I ended up accepting disabilities. I tutored him at home, and I tried anything for developments. Full inclusion in the class is one of those things, but as my child aged, I gave them up one by one. The academic education is limited because I tried algebra but he couldn't do it. He can do adding and division, but not application [applying these things to real life]. He is good at spelling tests but not writing. That is my greed to teach and achieve, but I gave up once I accepted his limitation...Now I only let him do painting which he likes and go hiking; this is his current life. (#3)

I quit the home tutoring. We did private tutoring for 8 years in our home. But, there was some point where her development no longer improved. She also looked exhausted. She received afterschool tutoring every day for 6 hours after the regular school day for 365 days a year. I ended up not feeling good about it. Next, I gave up on some of her academic improvement. After I gave up, I decided living healthy and happily was more important for her and pursued that. (#6)

Condition and Context

Korean Cultural Family Values The hope for developmental progress is highly affected by the context. Korean culture appeared to play a role in each component of the theory. Specifically, how to frame hope for development seemed to be affected by the Korean cultural family values. Korean mothers appeared to place a tremendous focus on their child, and their emotions seemed more likely to be affected by the child's outcomes rather than their own. Because of a mother and child's close attached relationship, KA parents might have different hopes than other ethnic groups. Mothers of child with DDs mentioned that:

It looked like American people do not really focus on the child, but we do. My husband and I focus on our child, so that's why Korean mothers do not try to find work. (#8)

Americans usually send their children with ASD to residential homes where children stay for 5 days and bring them home for the weekend and then bring them back to the place on Sunday afternoons. This kind of system is common in the U.S. for Americans. Korean-American parents almost never use the service and try to keep their kids at home as a form of protection. In terms of kids, I still think like a Korean, so Korean mothers do not want their kids to live in a residential home, although parents who have children with severe disabilities might be different. (#12)

Our kids are American by law, but they have been raised by Korean parents. They are neither Koreans nor Americans in aspects ranging from food to care. For example, Korean kids are dressed up pretty by their parents and they go to kindergarten, but when I picked up my kid, she looked messy. When kids are not neat after they play, Korean

teachers help the kids dress neatly or comb the kids' hair. But Americans just leave them alone because kids do this by themselves. I think that's why Americans grow up faster than Koreans when it comes to taking care of themselves. But Korean kids are slow to learn to take care of themselves because their parents take care of everything and do everything for them. The Korean kids who were born in the United States are slow in terms of independency because Korean parents raise them that way. (#7)

Language Proficiency Lack of language proficiency is one of the reasons Korean parents were not able to utilize mainstream services and could not get useful information. Mothers of children with DDs mentioned the following about language barriers:

There are lots of American mothers who have a child with disabilities. I was told to participate in a seminar, but in all honesty, I am not comfortable with communicating in English; I was afraid to participate in the seminar or other things. Even in the school, I cannot actively communicate with special education teachers. (#20)

The services my child currently uses are offered by Koreans. Korean-Americans have some limitations to being involved in the mainstream community to get services unless their English is perfect. (#17)

After meeting Americans in kindergarten, I felt that if my English was good and I have service information to help them start at an early age, [she or he] would develop better. (#10)

Willingness to engage in American mainstream services appeared to increase involvement in mainstream society so that they received more information even though they did not speak English fluently. It seemed that KA immigrant parents who live in the United States for a long period of time appeared to have more active attitudes than their counterparts. A father of an adult with ASD described his family's experience:

I think there is a good amount of services or programs, but KA parents did not utilize them. I think my wife also [did not use services]. Language is the first reason. No, no that's second. The first reason is that she was passive so she could not approach others [when my son was young]. (#15)

Citizenship KA parents who have citizenship utilized treatment services and recreational programs and received medical services for children with DDs that are covered by Medicaid or the Family Support Fund in Georgia. The parents of a child with DDs described the situation in this manner:

In the case of my daughter, all services like hospital visits are 100% free. I know health care fees in America are expensive, but all her care is covered by Medicaid, even though the cost is over \$10,000. Like seeing doctors or getting medications is free because of funding by the government. I am very thankful for it. Depending on the level of the disabilities, some amount of money in the form of a stipend is given every month. Food stamps as well. So, no out-of-pocket costs for my daughter. Also, SSI gives \$700 per month, and food stamps provide food that is equivalent to over \$150 in cost. (#5)

She received services from a county counselor the first time [we used subsidized services]. No matter what people's economic status is, insurance covers all types of

children with disabilities. Therapy is very expensive; the cost per hour is expensive, but the insurance unconditionally covered all of it. Fortunately, the county helped us early on and provided these services at an early age. (#6)

There are many types of support that were available only to families who have American citizenship. Immigrant families who do not have citizenship were not able to afford the extra cost of treatment, so they depended only on public education. Mothers of a child with DDs explained:

I tried to have my child receive speech therapy, but Obamacare does not cover it. It costs \$50 per 30 minutes, but I cannot afford it, so we cannot use ST. I hear that Medicaid can cover it. We are waiting to apply for citizenship. We are permanent residents. It has been almost 5 years since we received a permanent residency, so we are going to apply for citizenship. (#20)

We hold permanent residency, so we cannot receive health benefits covered by Medicaid and PeachCare. (#14)

Summary

The hope for development theory explains how KA immigrant parents keep continuing caring for their children with DDs even though they have experienced caregiving challenges in everyday life. Having hope is fuel for KA parents to move forward. In particular, their hope leans toward their child's development, changes, or achievements. With their hope, KA parents invest their time and finances, and then expect to have positive outcomes. Social support affects parents' investment and positive outcomes. The outcomes regarding their hopes lead parents to have different emotional reactions ranging from positive to negative. As results of outcomes, parents adjust their hopes to fit with their children.

Each process is highly affected by a child's age, Korean cultural family values, and the family's immigrant status. As a child gets older, their hopes or expectations for them become more realistic, and this moves the hope from what parents desired for their children to what their children actually like to do. Korean family cultural values including interdependency influence how parents frame their hope for their child. In addition, language proficiency and citizenship status affect the way parents take care of their children with DDs.

CHAPTER 5

DISCUSSION

The current qualitative study seeks to understand the process of how KA immigrant parents manage parental challenges that they experience in raising their children with DDs. The three primary research questions of this study are as follows:

1. How does caring for children with DDs affect KA parents or family members?
2. What resources and strategies do the KA parents use in managing their challenging experiences?
3. How do cultural and environmental contexts affect their caring experiences and coping strategies?

This chapter will discuss the findings, implication for social work, limitations, and recommendations for future research.

Discussion of Findings

The present study developed the hope for development theory that explains how KA immigrants withstand their consistent caregiving demands and manage them across their life span even though they have experienced emotional distress and burdens in their everyday life. Also, the findings of this study demonstrated each component of the hope for development theory affected by Korean family cultural values, individual immigration status, and social factors. Experiences of KA immigrants who are raising children with DDs of KA immigrants could be similar across all ethnic groups, but what makes KA immigrant parents unique is mainly influenced by their Korean cultural family values and their immigration status.

The findings revealed that KA parents have experienced emotional distress and frustrations in relation to caring for their children with DDs. This is in line with results of studies in diverse populations where parents of children with DDs reported high levels of parenting stress (Delambo, 2011; Blacher & McIntyre, 2006). Although these parents are faced with stress, the findings suggested that they persist in their caregiving responsibilities because they have hope for their child's development. I believe that hope could be a significant concept when it comes to talking about psychological and physical well-being of parents who take lifelong caregiving responsibilities for their children with DDs. A previous study indicated that hope is a resilience factor for psychological well-being of parents of children with intellectual disabilities (Lloyd & Hastings, 2009).

The current study suggested that specific hope for their child's development, not general hope for parents themselves, may be a factor that affects caregiving challenges because hope made further progress possible in adverse situations. KA parents mentioned their goals, expectations, or hopes toward their children frequently rather than their own or other family members'. Results of a quantitative study (Faso, Neal-Beevers, & Carlson, 2013) support this suggestion that higher hope for their children with ASD's future was associated with less parental stress, but general hope did not predict parental stress.

In my view, it could be possible that child-focused hope came predominantly from this population due to Korean's cultural family values. In contrast to the Western culture of individualism, traditional Korean culture that is affected by the values of Confucianism emphasizes relations and emotions that tie individuals together (Park & Kim, 2006), and it values interdependency, authoritarian structure, and family loyalty (Kim, Kim, & Rue, 1997). Parent and child relationships are considered as a basic unit to develop the self. Thus, Korean mothers'

self is extended to their children, so they are closely and intrinsically attached to them. Korean mothers consider children's accomplishments as their own (Park & Kim, 2006). Previous research indicated that Korean immigrant parents had the highest educational expectations for their children among other immigrant and native groups (Hao & Bonstead-Bruns, 1998).

Another key finding of this study was that a child's age is a significant indicator of how to structure and adjust parents' hopes for their child with DDs. The findings illustrated a difference of a degree of hope between parents raising a young child with DDs and those with adolescents and young adults with DDs. A young child's parents had high hopes for their child's development or changes, while young adults' parents showed modifications of their hopes relative to when their child was young after various trials and encountering their developmental limitations.

Because young children with DDs are in an earlier developmental stage, their parents showed hopes that their child would present a greater amount of change even though some parents had unrealistic hopes that their child would become developmentally typical. However, their unrealistic or high hopes made them feel despair because the hopes were unattained. A study conducted by Rasmussen, Wrosch, Scheier, and Carver indicated that realistic hope led to positive psychological outcomes while people with unrealistic hopes experienced decreased subjective well-being (2006).

The findings in this study showed that, at the very least, it is significant to have hope, but the hope should be attainable and realistic. Hope would help parents cope with caregiving challenges. Having hope that is realistic and achievable could lessen parental stress and help parents persist in their continuous caregiving responsibilities. Because KA parents' selves are extended to their children, children's achievements would have huge effects on their parents'

emotions. Realistic and achievable hope could provide more positive outcomes, which might in turn lead to positive emotions for parents.

In terms of young adults' mothers, a majority of them did not show positive hope for their child's changes in the future which stopped them from making efforts towards their adult children with DDs— they believed that it was not possible for their children to make any further progress. They were more likely to pursue children's happiness rather than development or changes. Research indicated that Korean-American parents showed an authoritarian parenting style which is characterized by high control (Otto, 2016; Vinden, 2001). KA parents of children with DDs also showed authoritarian parenting styles that controlled their children so that they could achieve what they wanted for them, but they adjusted their hope for their children to what their children really wanted to do as they got older.

The previous research has demonstrated that a child's age is a factor that influences parents' experiences. Studies found that parents' subjective well-being increased with age (Begeer et al., 2016), and a child's age was negatively correlated with levels of stress (DeLambo, Chung, & Huang, 2010). When it comes to examining hope for parents of children with DDs, the child's age should be considered.

The findings of this study suggested that their hope motivated KA parents to do something. It was noted that a majority of KA parents have tried everything they can do in order to fulfill their hope for their child's development. KA parents have been continually involved in seeking information related to their children with DDs and educating themselves since their children were diagnosed to find education and treatments that maximize their child's development and change symptoms of developmental disabilities. This is consistent with the

findings of another study that reported that information seeking is an ongoing part of life for parents of children with DDs (Reinke & Solbeim, 2015).

Based on collected information, parents tried things that work for their children with DDs including private school, homeschooling, private tutoring, various therapies, medications, alternative medicines, and activities. The trials require a lot of their time and money. This is consistent with findings that Korean parents actively pursued special education at great economic cost and structured their day based on their child's schedule (Cho et al., 2000).

It was noted that KA parents go to extreme measures and are overeager for their children with DDs by trying everything they can do. I believe it is likely that KA parents can be even more extreme or overeager than other ethnic groups, because Korean parents have higher expectations for their children compared to other ethnic groups (Otto, 2016; Vinden, 2001), and they view sacrifice and devotion to their children as their basic role (Park & Kim, 2006). However, it is questionable whether their actions for their children are associated with more positive outcomes for their children, and this is something that should be examined in the future.

Their investment and outcomes can be affected by social support. Previous research indicated that social support was identified as a critical factor that leads to positive family outcomes such as adaptation to having children with DDs, family functioning, self-esteem, and child development (Ekas et al., 2010; Canary, 2008; Bishop et al., 2007). More support may increase more chances for investment in their children with DDs and more outcomes on child development.

KA parents emphasized how important it is to have family support, in particular spousal support, when raising children with special needs. A study by Ekas and colleagues (2010) found that partner support was positively associated with maternal outcomes such as depression,

psychological well-being, and life satisfaction. Some KA mothers complained about lack of partner support and that their husbands did not share the childcare responsibilities at all.

Confucianism created a patriarchal family system where the wife is viewed by the husband as a mother and housekeeper (Brettell, 1999), and the fathers who adhere to a patriarchal family order may display a lack of sharing childcare duties.

The findings illustrated that KA parents interacted with other parents in the same situations and received emotional and resource support. The findings concur with a study that demonstrated that parent-to-parent support helped parents realize they are not alone and helped them meet someone who truly understands them (Kerr, 1999). It has been suggested that parent-to-parent support, which is defined as support found by contacting people in similar situations, exerts powerful stress and buffering effects (Kerr, 1999), and it is a source for managing family life effectively (Wilgosh et al., 2004).

KA immigrant parents mentioned that there are many available services for parents of children with DDs in the community, but they have limited access to the services due to language proficiency and cultural differences. This is consistent with previous findings that show that many ethnic minority groups experienced less use of formal support due to language barriers (Canary, 2008). It is noted that KA parents tended to utilize more mainstream social services and have more connections to people other than Korean-Americans as their length of stay in the United States is longer. I believe that KA parents who have lived longer in the United States are familiar with American systems, and they have confidence in communicating in English even though their English is not proficient. Existing literature indicated that language barriers were not a factor that predicted social support, but levels of self-advocacy, assertiveness, and familiarity

with the majority culture were positively associated with receiving social support for Asian-American parents of children with DDs (Huang, DeLambo, & Kot, 2004; Bailey et al., 1999).

However, those who are familiar with American systems and services also want to have services that are culturally competent to Koreans. Cultural differences such as types of food offered make KA immigrant parents less willing to use mainstream services and look for services that are offered by Korean-Americans. Thus, the majority of participants received external support from Korean American churches that provide services to children with DDs and their families. Some parents were not Christians but participated in Korean ethnic churches to get support for their children. Previous research indicated that the Korean American churches have played an important role as a center for Korean American communities (Huh & Kim, 1990).

KA parents devoted a lot of their time and spent tremendous amounts of money on their children with DDs, but their investment and social support is limited by their socioeconomic and immigration status. KA parents who are not U.S. citizens have low incomes, and recently immigrated Koreans reported many more financial strains, limited access to social support, and lack of information. Most of them rely solely on the public education system because they cannot afford other services that are covered by Medicaid or Family Support funds for U.S. citizens. On the other hand, KA parents who have U.S. citizenship reported that they have received financial support from the government that can be used for their child's therapy or activities. Using therapy is not only helpful for a child's development but also functions as a way to give parents a respite.

Also, KA parents who immigrated with their extended families or who are married with a spouse who has extended family in the United States reported that they receive emotional and instrumental support from extended family members, mainly from grandparents; the

grandparents provided childcare and financial assistance. They were very appreciative of their extended families' support. This is consistent with findings that claim that family support was associated with positive maternal outcomes (Ekas, Lickenbrock, & Whitman, 2010). However, KA parents whose spouse or extended family is in Korea reported their desperate need for support from extended family members.

Several other points can be noted. I noted that a child's developmental outcome had extreme effects on parents' emotional reactions. They reported that their children's modest development or changes brought more joy than other children with typical development cannot. This is consistent with previous studies in which caregiving experiences are joyful and happy when children make progress in developmental areas (Nurullah, 2013; Corman, 2009; Fleischmann, 2004). It is worth noting that children with DDs bring negative emotions to parents such as sadness, frustration, and shame, but they also evoke positive emotions such as joy and happiness even though dealing with daily caregiving demands is difficult.

KA parents expressed that hearing success stories or about positive futures for individuals with DDs from other parents or professionals encouraged KA parents to have positive hope for their child's development. Previous research indicated that parents felt a sense of unconditional acceptance when professionals gave words of encouragement (Fox, Vaughn, Wyatte, & Dunlap, 2002). I believe it is important for professionals not only to provide accurate information about children with DDs but to also find their strengths. Identifying children's strengths can encourage KA parents to have positive hope.

Limitations of the Study

Although the findings expand the literature on parenting experiences of parents with children with DDs through an in-depth explanation of the hope for development theory, this

study presents several limitations. Major limitations include the extent to which findings are generalized to Korean-American parents who raise children with DDs due to the qualitative method and the study population in terms of sample size, source of recruiting participants, and the site of research. One cannot assume that the findings represent all KA parents of children with DDs.

The research participants were mainly recruited from two KA parents' groups, and the snowball sampling method was utilized. It could be that most participants who are involved in the two KA parents' groups might be more active than other KA parents who do not participate in the groups. They may have shared perspectives because the participants were introduced by other participants. The experiences of others who do not participate in the groups or are isolated from the community could be different. In addition, only four KA fathers participated in the study compared to 18 KA mothers. The small number of participating fathers makes it difficult to explore various fathers' perceptions.

Another limitation is related to the reliability of the findings due to the translation of findings and conducting limited member checking. Interviews were conducted in Korean and translated into English to report the findings. Although a back-translation strategy was employed, it is possible to lose some of the original meaning during the translation. Also, only one participant participated in the member checking process very briefly. Reliability would have been strengthened if I had received an agreement form during the interview for the member checking process so that I could work with participants who were really interested in knowing about the findings. Otherwise, a focus group session to hear participants' opinions may have helped.

Grounded theory researchers suggest that data collection and analysis should be conducted simultaneously. The analysis generates concepts which in turn lead to questions. Questions require more data collection to learn more about the concepts (Corbin & Strauss, 2008). This circular process continues until the concepts and relationships between concepts are well-defined and explained; this is called theoretical saturation. This data analysis was conducted after completing data collection which limits theoretical saturation. More detailed questions could be asked of participants to fully understand properties and dimensions of each concept of the hope for development theory and relationships between the concepts. Although a child's age played a significant role in affecting the hope parents had, not much data from young parents of children with DDs were collected.

Lastly, I noticed that some of the participants had more genuine conversations after the audio recorder was turned off. There are many reasons for this. They might feel uncomfortable speaking with recorders or be conscious of the records because they do not want to lose face, something that plays a vital role in Korean culture. I wanted to turn it on again to record their speech because it was very interesting, but I could not do it. I tried to take notes right after coming back home but lost many parts. Despite several limitations, the findings of the study provide meaningful explanations of the experiences of KA parents who raise children with DDs.

Implications for Social Work

Some important recommendations for social work practice and interventions emerged from the findings of this study. This study found that hope for their child's development is a resilience factor for KA parents who raise children with DDs. To clinical social work practitioners, the findings suggest a potential entry point for intervention that incorporates elements of hope to reduce parental stress for KA parents of children with DDs. The intervention

programs should focus on developing realistic and attainable hopes so that parents are filled with positive emotional reactions as a result of fulfilling their hopes. In order to provide culturally competent and sensitive intervention programs, the practitioners should be aware of KA parents' cultural family values where a mother's self is transferred to their child, so they have high expectations for them. Their high expectations may cause KA parents to take more time to adapt to their children with DDs, and sometimes they have unrealistic hopes for their children.

The intervention also needs to include contents that enhance KA parents' abilities to find pathways to meet their hopes. The findings indicated that language proficiency is a barrier for parents to overcome when caring for their children with DDs. It was noted that familiarity with American systems and high self-confidence in communicating in English can be a factor that increases likelihood of involvement with mainstream community and services even though parents' English is not proficient. Thus, the program needs to include education to increase their self-confidence, self-esteem, and self-advocacy skills, and it should incorporate components that deal with several facets: the U.S. education system, the health care system, available community resources, disability policy, and ways to achieve human rights.

This study's findings shed light on issues that show that spousal support and collaborative work with partners can be the best social support for primary caregivers. KA immigrant families are more likely to live away from their extended families because most of them remain in their country of origin. It is difficult for them to receive physical support from extended families which indicates that partner support becomes more critical for KA immigrant families in terms of raising children with DDs. Korean culture is based on Confucianism and emphasizes a patriarchal ideology, so the head of the household is more likely to be a male who tends not to care about household work. Therefore, interventions for KA fathers are necessary.

The interventions can include activities that lead KA fathers to be more involved with caregiving work. For example, education for fathers and marriage counseling can be taken into consideration.

The findings of the study indicated that although KA parents of a child with DDs share common experiences, each family has unique experiences based on socioeconomic status, education levels, immigration status, the child's characteristics, and stages of their life course. Thus, an individualized family-centered approach is necessary—it should focus on needs within the context of families. A mother in the participant group pointed out that a program that provides information to KA parents should be divided according to a child's age. She stated that:

The age range is so big. I think that needs to be divided. For example, in the Korean coalition [KA parents group], there are people from infants with DDs to adults with DDs. So, mothers of a young child are not interested in programs for adults. And if the programs focus on children, older mothers are not interested. They already have done that and know. So, the group needs to be divided [according to age] and then get together if the program is good for all parents. But the group does not work like that, so I am in a difficult position.

Because the parents' interests are different, the information they need is also different. For example, parents of a young child with DDs are interested in information education or treatments while those of adults with DDs are interested in vocational programs or community engagement. The findings also indicated that a child's age is a significant factor that affects how to structure and adjust hope. Social work practitioners should consider a child's age when approaching KA parents of children with DDs.

Recent immigration and non-citizenship status limits KA parents of children with DDs to accessing social support. Social workers should note that families who have recently immigrated, are not U.S. citizens, and have no extended family members are more likely to be vulnerable to the challenges of raising children with DDs. Solely introducing available mainstream services is

not the solution for those immigrant families. They need connections and services, so social workers should help them make connections with people with whom they feel comfortable and can interact with.

The KA parents of children with DDs showed strong ties in Korean-American communities, and KA parents in the same situation are strong supporters of each other. Also, it is noted that Korean ethnic churches play critical roles for KA children with DDs and their families. Thus, it might be difficult for mainstream practitioners to reach out to KA parents because of their strong involvement and ties within KA communities, but it would be good to utilize gatekeepers such as pastors to reach out to KA immigrant parents who are affiliated with the church. In order to reach out to KA parents who are not affiliated with churches, KA immigrant parents of children with DDs who are bilingual and competent in both cultures can also be gatekeepers, because parent-to-parent support is stronger and well-interconnected among KA immigrant parents who care for children with DDs.

Lastly, KA parents were sensitive to hearing about positive hopes for their children's future and development. Several parents mentioned that the way practitioners treated them made them feel powerless and hopeless. The practitioners need to show openness and respect towards KA parents and encourage parents by providing correct information in positive and constructive ways.

It is worth noting that each family has the capacity to overcome the challenges they are presented with, and having children with DDs has a positive impact on the families. Also, because each individual's condition is different, individualized approaches are necessary. A mother of a young adult with ASD mentioned that:

All children are different. My sons can do something, but others might not be able to do the same thing. What my child can do is different from others, so parents have to make

efforts to be the best fit for their sons or daughters. For my son, teaching the ABC's is not important at this point, but teaching living skills is more important...But another child might need [to learn their] ABC's.

Recommendations for Future Research

Several recommendations can be made for future research. The theoretical saturation for the hope for development theory and further data collection to better understand each concept is necessary, because the directions and relationship of each component are unclear. Future studies should test the theory as a framework with other populations. The theory that was found should be further confirmed and validated by applying a quantitative research method. It is unclear if the hope for development theory affects both emotional reactions and investment, whether the outcomes play the role of either moderators or mediators or both, and what the relationships between investment and outcomes are. Also, future studies should examine how social support affects the hope for development progress. A large number of KA samples that represent KA parents of children with DDs for generalizability of study findings should be recruited. As the limitations of the study indicated, more KA fathers' perspectives should be considered in the future.

In order to examine the unique experiences of immigrant parents due to different family cultural values and immigrant statuses, a comparison study needs to be conducted by recruiting culturally and racially diverse populations including immigrants and non-immigrants. Testing the hope for development theory for different ethnic or racial groups may show differences between them. For example, it is questionable whether KA parents have higher hopes for their child's development and invest more time and resources in their child with DDs compared to other ethnic groups. Whether or not the KA parents might be highly affected by child's development outcomes is questionable. There is a need to examine differences between other ethnic groups in

terms of parents' emotional reactions as results of what the child's actual development outcomes are. Also, future studies should examine how immigrant status affects families' hope process.

In addition, prospective longitudinal studies would be helpful to have greater understanding of hope for development progress, because each stage of the life course from the initial diagnosis, preschool, school years, and adulthood gives families different experiences. Families of children with DDs try to adapt to stressful situations related to caring for their children with DDs every moment of their life course. However, as a child ages, parents' hope for their child's development simply changes. Taking this perspective into consideration, realistically it can be difficult to conduct a longitudinal study, but it can be possible to examine subgroup populations in a cross-sectional study because different experiences were found within groups. In particular, subgroups are based on a child's age, disability types, socioeconomic status, and immigrant status. For example, subgroups based on a child's age include: diagnosis before preschool, early childhood years, transition to adulthood, young adult years, and old adult years. Subgroups of disability types include autism, intellectual disabilities, and Down syndrome.

In summary, Korean-American parents have experienced challenges and difficulties in terms of caring for their child with DDs. However, they have strengths to deal with the difficult situation by having hope for their child's development. Social support and socioeconomic status interplay and influence how to frame hope for their child. Developing positive and realistic hope can increase parents' psychological well-being and quality of life. To build the hope, appropriate and sufficient support should be offered to the parents.

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APPENDIX A

SCREENING CONSENT FORM

Screening consent form (English)

UNIVERSITY OF GEORGIA

Eligibility screening consent form

Thank you for being interested in the research study and contacting us. Before we move on, we need to check your eligibility for the interview. The purpose of this screening process is to see if you are eligible for the interview. It takes less than 5 minutes. We have three eligibility criteria questions and you can answer 'yes or no' for those questions. If you answer 'yes' all three questions, you are eligible to participate in the research study. All of your answers will be kept confidential. We will not collect any individually identifiable information during this screening process, so if you are not eligible for the study, you cannot participate in the study and we cannot have identifiable information about you at all. There is no risk or benefit of screening. Your participation in this screening is voluntary and you can choose not to participate or to stop at any time without penalty or loss of benefits to which you are otherwise entitled.

If you have any questions about this screening process, you should ask the co-investigator, Irang Kim, MSW. You may contact her at any time at (803)-553-6117 or er0921@uga.edu. You may also contact the principal investigator, Betsy Vonk, PhD, with any questions, at 678-985-6793 or bvonk@uga.edu. If you have any questions or concerns regarding your rights as a research participant in this study, you may contact the Institutional Review Board (IRB) Chairperson at 706.542.3199 or irb@uga.edu.

By answering the questions, you are agreeing to take part in this screening for eligibility.

After agreeing with the screening process, we are going to ask three eligible questions.

- 1) Are you Koreans from South Korea, first generation immigrants to the United States?
- 2) Are you currently parenting children with developmental disabilities in your home?
- 3) Do your children meet the Pervasive Developmental Disability criteria in the DSM-IV?

Screening consent form (Korean)

University of Georgia

(조지아 대학교)

자격여부 확인 동의서

이 연구에 관심을 가져주시고 연락해 주셔서 감사합니다.

인터뷰를 하기전에 연구에 참여하실수 있는 자격이 되는지 먼저 체크를 해야 합니다.

세가지 질문에 모두 ‘예’라고 답하시면 이 연구에 참여가능한 분 입니다.

자격여부의 확인 목적은 연구에 참여가능한 사람을 선택하는 과정의 하나이며 본인에게 위험이나 이득이 없음을 알려드립니다. 자격여부를 확인하는 동안 개인의 신상정보를 물어 보지 않습니다. 혹시나 자격여부가 안 될 경우에는 어떠한 신상정보도 모이지 않음을알려드립니다.

자격여부와 관련되어 질문이있으시면 리서치 팀, 김이랑 에세 연락하시면 됩니다. 803-553-6117 또는 er0911@uga.edu 또는 대표 연구자, Betsy Vonk, 에게 연락하시면 됩니다.

678-985-6793 또는 bvonk@uga.edu 로 연락하시면 됩니다.

리서치 참여 권리에 대한 질문이 있으시면 Review Board (IRB) Chairperson at 706.542.3199

oirb@uga.edu 여기로 연락주십시오.

자격여부 확인에 동의하셨다면 아래의 질문에 대답해 주시기 바랍니다.

1)이민 1 세대 입니까?

2) 현재 발달장애 아동을 기르고 있습니까?

3) 아이가 DSM-IV 에 있는 Pervasive Developmental Disability 조건에 부합합니까?

APPENDIX B

DEMOGRAPHIC PROFILE

Demographic Information Questions (English)**Section 1: Parents**

Participant's Number:

1. Gender: ☐ Male ☐ Female
2. Age _____
3. Marriage status: ☐ Single ☐ Married ☐ Other (Divorced/Widowed)
4. What years did you immigrate? _____ years
5. Why did you immigrate? _____
6. Status in United State: ☐ Citizen ☐ Permanent resident ☐ Student or Work visa ☐ Others
7. Employment: _____
8. Education attainment: ☐ High school ☐ Bachelor ☐ Master ☐ Doctoral ☐ Others
9. Annual household income _____
10. How many children do you have? _____
11. Do you have insurance? ☐ Yes ☐ No
 - a. If yes, what insurance do you have _____

Section 2: Children

1. Gender: ☐ Male ☐ Female
2. Age: _____
3. Diagnosis: _____
4. Years of diagnosis: _____
5. Place of diagnosis: Korea United States Others

6. Status in United States: ☐ Citizen ☐ Permanent resident ☐ Student or Work visa ☐ Others

인적 사항 (Korean)

고유 번호:

1. 성별 ☐ 남자 ☐ 여자
2. 나이 _____
3. 결혼 유무:
 - ☐ 기혼 ☐ 미혼 ☐ 기타 (사별/이혼/별거 등)
4. 몇 년도에 이민 오셨습니까? _____ years
5. 이민 온 이유는 무엇입니까? _____
6. 미국 내 신분은 무엇입니까?
 - ☐ 시민권 ☐ 영주권 ☐ 학생 또는 취업 비자 ☐ 기타 _____
7. 직업은 무엇입니까? _____
8. 귀하의 최고 학력은 무엇입니까?
 - ☐ 고등학교 ☐ 대학교 ☐ 석사 ☐ 박사 ☐ 기타 _____
9. 귀하의 가족 소득은 얼마입니까? _____
10. 자녀의 수는 몇 명입니까? _____
11. 건강 보험에 가입되어 있습니까? ☐ Yes ☐ No

만약 있다면, 어떤 종류의 보험에 가입되어 있습니까? _____

자녀 인적 사항

1. 자녀의 성별: ☐ 남 ☐ 여
2. 자녀의 나이: _____

3. 장애 진단명: _____
4. 장애 진단을 받은 년도: _____
5. 장애 진단을 받은 장소: ☐ 미국 ☐ 한국 ☐ 기타 _____
6. 자녀의 미국 내 신분: ☐ 시민권 ☐ 영주권 ☐ 기타 _____

APPENDIX C

SEMI-STRUCTURED INTERVIEW PROTOCOL

Interview questions (English)

- Tell me about your daily life in relation to your child
- How do you feel about your overall daily life?
- Any challenges in raising your child with DD?
- What parts of your current daily life feel stressful?

Now I am going to ask you questions about how you take care of yourself

- Is there someone you seek support from home when you feel stressed?
- How does this person support you in reducing stress?
- If there is no one you can rely on, how do you handle your stress?
- Is there someone you seek support from outside of home when you feel stressed?
- How does this person support you in reducing stress?
- What are other ways you try to reduce stress?

Lastly, how your children with DDs affect your entire life?

인터뷰 질문 (Korean)

1. 하루 일과 생활에 대해 말씀해 주세요
2. 그 일상 생활에 장애를 가진 아이가 차지하는 부분은 얼마나 되며 어떻게 본인의 일상 생활에 영향을 주나요?
3. 그런 일상생활에 대한 느낌은 어떠신가요? (예, 힘듦, 보람, 기쁨)
4. 장애아이를 키울 때 가장 큰 어려움은 무엇인가요? (그 부분이 본인에게 스트레스를 주나요?)
5. 현재의 삶에서 어떤 부분이 본인에게 가장 스트레스를 주나요?

Coping strategies

6. 그런 어려움 또는 스트레스를 받을 때 어떻게 그 일을 처리하나요? 스트레스 받을 때 어떻게 대처 하나요?
7. 가족 중에 도와주는 사람이 있나요? 아니면 지역 주민 중에 도와주는 사람이 있나요? 주정부에서는 도움을 주나요?
8. 그 사람 또는 정부는 어떻게 도움을 주나요?
9. 그 외에 스트레스를 줄이거나 해소하기 위해 사용하는 다른 방법이 있나요?
10. 마지막으로 아이가 삶에 준 영향은 무엇인가요?

APPENDIX D**INFORMED CONSENT**Informed consent (English)**UNIVERSITY OF GEORGIA****CONSENT FORM**

Parental stress and coping among Korean-American parents
of children with developmental disabilities

Researcher's Statement

We are asking you to take part in a research study. Before you decide to participate in this study, it is important that you understand why the research is being done and what it will involve. This form is designed to give you information about the study, so you can decide whether to be in the study or not. Please take the time to read the following information carefully. Please ask the researcher if there is anything that is not clear or if you need more information. When all your questions have been answered, you can decide whether you want to be in the study or not. This process is called "informed consent." A copy of this form will be given to you.

Principal Investigator: Betsy Vonk

University of Georgia, School of Social Work

678-985-6793

Purpose of the Study

You are being asked to participate in this study because your child has developmental disabilities and you are Korean- Americans. This study will examine the process of stress and coping in terms of raising your children with developmental disabilities.

About 20parents will take part in this study.

Study Procedures

If you consent to participate in this study, you will be asked to participate in an interview. We will ask questions about demographic information for participants and their children. You will also be asked about challenges and stress you have been experienced, and resources and coping strategies you use to deal with your stress. The interview takes one hour to one in half hour, and will be tape-recorded.

Risks and discomforts

There are minimal risks associated with participating in this study. You may experience some unpleasant feelings when participating in this interview. These feelings may result from thinking about your child, your relationship, or your parenting experiences. You can skip the questions when you feel uncomfortable or stop the interview if you wish.

Benefits

Your interview will help us learn more about cultural perspectives about stress and coping strategies. We believe that this information will increase future research, services, and support for developing interventions for Korean-American parents who raise children with developmental disabilities.

Audio/Video Recording

The tape recording will be used for analysis by the research team. The tape recording will not include demographic information. The tape recording will be stored in a password-protected computer file. The recording will be destroyed upon publication of the results of the study.

Please provide initials below to indicate if you agree or disagree with having this interview audio recorded.

You may still participate in this study even if you are not willing to have the interview recorded.

_____ I do not want to have this interview recorded.

_____ I am willing to have this interview recorded.

Privacy/Confidentiality

The information provided by you will remain confidential. Nobody except the principal investigator will have access to it. Your name and identity will also not be disclosed at any time. The only document with your

name on it will be this consent form, and it will be stored separately from your study information. However, the data may be published in a journal and elsewhere without using your name or disclosing your identity.

Taking part is voluntary

Participation in this study is voluntary. You are free to not participate or to withdraw at any time, for whatever reason, without penalty or loss of benefits to which you are otherwise entitled. If I decide to withdraw from the study, the information that can be identified as mine will be kept as part of the study and may continue to be analyzed, unless I make a written request to remove, return, or destroy the information.

If you have questions

If you have any questions, concerns or complaints about this research study, its procedures, or risks and benefits, you should ask the co-investigator, Irang Kim, MSW. You may contact her at any time at (803)-553-6117 or er0921@uga.edu.

You may also contact the principal investigator, Betsy Vonk, PhD, with any questions, concerns or complaints about this research study, its procedures, risks and benefits, at 678-985-6793 or bvonk@uga.edu.

If you have any questions or concerns regarding your rights as a research participant in this study, you may contact the Institutional Review Board (IRB) Chairperson at 706.542.3199 or irb@uga.edu.

Research Subject's Consent to Participate in Research:

To voluntarily agree to take part in this study, you must sign on the line below. Your signature below indicates that you have read or had read to you this entire consent form, and have had all of your questions answered.

Name of Researcher

Signature

Date

Name of Participant

Signature

Date

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

Informed consent (Korean)

조지아 대학교

동의서

발달 장애 이민자 부모의 스트레스와 대처 기술 연구

연구개요

이 연구에 참여에 앞서서 이 연구가 왜 이루어지고 있는지 이해하는 것이 중요합니다. 이 동의서는 연구에 대한 정보를 제공하고 연구에 관해 어떠한 질문도 없을때 연구 참여 의사를 밝힐 수 있습니다.

대표 연구자: Betsy Vonk

University of Georgia, Social Work

678-985-6793

연구 목적

이 연구의 목적은 미국에 살면서 발달장애 아동을 키우는 한국 부모님들이 발달 장애 아동을 키움에 있어 느끼는 스트레스와 그 스트레스 해결 방안이 무엇인 지 알아보기 위한 연구입니다.

약 20 명의 이민자 한국 부모님들이 이 연구에 참여할 예정입니다.

연구과정

연구참여에 동의하시면 인터뷰 날짜를 잡을 것 입니다. 기본적인 인적사항과 함께 아이를 키움으로써 느끼는 고충과 어려움 그리고 스트레스 받을 때 이용하는 자원이나 지원은 무엇인지에 대해 여쭙 볼 것 입니다. 인터뷰는 1 시간에서 1 시간 30 분 진행될 예정이며 인적사항을 제외한 부분이 녹음 됩니다.

위험요소

연구에 참여함으로 위험을 겪지는 않지만 아이의 대한 생각을 나누는 동안 아이에 대한 걱정 등으로 기분이 안 좋아 질 수는 있습니다.

이익

인터뷰 참여 감사의 의미로 기프트 카드 \$20 을 드립니다. 또한 여러분들의 소중한 이야기를 통해 더 많은 연구들이 미래에 실행될수 있으며 아이들과 가족들이 조금 더 편안한 삶을 살 수 있도록 도울 것 입니다.

오디오 녹음

인터뷰 동안 오디오 녹음이 진행 될 것입니다. 인적사항은 녹음되지 않으며 녹음된 파일은 비밀번호가 걸린 컴퓨터 파일에 저장되면 페이퍼 발표 이후에 연구 삭제 됩니다. 오디오 녹음에 동의하시면 아래에 사인해 주십시오.

_____ 오디오 녹음에 동의합니다.

_____ 오디오 녹음에 동의하지 않습니다.

비밀보장

여러분들이 제공한 내용은 비밀이 보장되며 연구팀 외에는 아무도 자료에 접근할 수 없습니다. 여러분의 이름은 절대 문서에 쓰이지 않으며 이 동의서에만 여러분의 이름이 쓰일 것입니다.

자발적 참여

연구 참여는 자발적으로 이루어지며 참여 도중 인터뷰를 중단하는 것도 가능합니다.

인터뷰 중단으로 인한 불이익은 없으며 모든 자료들은 폐기됩니다.

그 외 질문

이 외에 연구에 대한 질문이나 불만이 있으시면 리서치 팀, 김이랑 에게 연락하시면 됩니다. 803-553-6117 또는 er0911@uga.edu 또는 대표 연구자, Betsy Vonk, 에게 연락하시면 됩니다. 678-985-6793 또는 bvonk@uga.edu 로 연락하시면 됩니다.

연구 참여에 관한 권리에 대한 질문이 있으면 리뷰 기관에 연락하시면 됩니다. 706-542-3199 또는 irb@uga.edu

연구참여에 동의하시는 분은 아래에 사인해주시기 바랍니다.

_____	_____	_____
연구자 성함	사인	날짜

_____	_____	_____
참여자 성함	사인	날짜

APPENDIX E

DIAGRAMS

