

AN ABSTRACT OF THE THESIS OF

Hyun-Kyung You for the degree of Master of Science in Human Development and Family Studies presented on June 9, 2003. Title: Korean American Mothers of Children with Disabilities: Adaptation Process and Positive Transformation.

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Abstract approved: \_\_\_\_\_

Sharon E. Rosenkoetter

This study examined the experiences of five Korean American mothers in Oregon and California who have children with disabilities using qualitative research analysis. The mothers' adaptation processes were individually analyzed, and these mothers' overarching experiences were discussed with three major themes: (a) caring for family cohesiveness, (b) needs for social and professional support, and (c) positive transformation of life through religion

Adaptation to the children's disabilities was a process for these participants. All mothers had their own demands, resources, and subjective interpretations of their situations. Analysis of the qualitative data disclosed that these five Korean American mothers transformed the negative life events of having children with disabilities into meaningful opportunities to grow personally and spiritually. These immigrant mothers' care-commitment for their families' cohesiveness strengthened their life long coping process. Several married mothers perceived emotional support from their husbands. Most of the mothers expressed the need for social support due to their immigrant status. These five Korean American mothers tried to adapt to their situation of raising a child

with a disability within their intact family members. Two mothers from California utilized emotional and informational support from Korean parent support groups, which are more readily available in that state due to the large number of Korean American families with children with disabilities. Despite the lack of social and professional support, many of the mothers perceived their experiences of having children with disabilities positively through their religious beliefs. Raising a child with a disability reportedly strengthened the mothers' religious faith, and their strong religious beliefs gave them courage to successfully adapt to their situations. Several of the mothers stated that their worldviews were also changed.

Although this study was limited to five participants, it yielded an enhanced understanding of Korean American mothers who have children with disabilities and provided direction for future research and practice. The findings suggest that special education providers should emphasize and support the strengths of a child's major caregiver.

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Korean American Mothers of Children with Disabilities: Adaptation Process and  
Positive Transformation

by  
Hyun-Kyung You

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Hyun-Kyung You, Author

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# Korean American Mothers of Children with Disabilities: Adaptation Process and Positive Transformation

## CHAPTER 1

### INTRODUCTION

Centuries ago, Sir Francis Bacon explained two conflicting sides of parenthood:

The joys of parents are secret; and so are their griefs and fears. They cannot utter the one; nor they will not utter the other. Children sweeten labors; but they make misfortunes more bitter. They increase the cares of life; but they mitigate the remembrance of death.

Most parents, including those with children with disabilities, experience both delights and difficulties from raising their offspring. Parents who have children with disabilities might experience the extreme emotional range between joy and sadness in their parenthood. Medical and educational conditions related to children's disabilities challenge parents emotionally and physically, in addition to witnessing their children's differences in everyday living. Parents may become worn out psychologically and physically from the care they provide for their children with special needs. On the other hand, what their children with disabilities have achieved may be very meaningful to parents.

A ray of hope along the way, sometimes, guides some distressed parents into an unexpected direction of life. Just like that, some parents transform their worldview positively and change their life according to their children's disabilities. How do parents who emigrated with a dream of building a life in a new country adjust to experiences of raising children with disabilities? This study explored how Korean

immigrant mothers perceive their parenting children with disabilities and their own adjustment to this unexpected challenge.

Korean Americans have the reputation of working hard to help their children achieve educational success (Goldberg, 1995). In fact, the desire to provide the best education for their children is considered to be one of the major motivations for some Koreans to emigrate to the United States. However, the parents' desires and efforts to provide appropriate education for their children to succeed in the new culture might be sabotaged from the moment they discover their children's exceptionality. Such immigrant parents might then feel pressure to investigate special education systems as well as a new culture. Special education services have to hear what these immigrant parents say about their experiences of raising children with disabilities in the United States. Here, I attempt to provide stories from such Korean immigrant mothers.

Researchers (Hill, 1949; McCubbin & Patterson, 1982, 1983a, 1983b) have been interested in individual, familiar, and social coping processes in response to various stressors. Having a child with a disability is an unexpected life event for most parents. This particular event of giving birth to a child with a disability or discovering a disability in a young child brings changes within the family and outside the family. Stress and demands do not solely originate from a single event. It is rather a process, in which one action leads to another (Montgomery, 1982).

Previous studies (Bailey & Simeonsson, 1988; Blacher, 1984; Dyson, 1993; Floyd & Gallagher, 1997; Glidden, 1993; Seligman & Darling, 1997) have expanded our knowledge about parental stress, difficulties, and needs related to raising children

with disabilities. Some (Bristol & Schopler, 1984) have been interested in the relationships between different types of disabilities and parents' levels of stress or depression. Over the years, researchers (Garwick, Kohrman, Titus, Wolman, & Blum, 1999; Skinner, Bailey, Correa, & Rodriguez, 1999) have also captured positive and meaningful changes that parents experienced in their lives through this nonnormative life event. Researchers have reported that having a child with special needs is a wake-up call for some parents. Studies about different voices and experiences from ethnically diverse populations (Cho, Singer, & Brenner, 2000; Park & Turnbull, 2001; Skinner, Bailey, Correa, & Rodriguez, 1999; Smith & Ryan, 1987) have broadened the depth of knowledge in the field.

Bridging past and recent studies, the purpose of the current study was to learn more about how Korean mothers cope with their unexpected life event of having children with disabilities using an in-depth qualitative approach. This exploration was based on Korean mothers' perceptions about their families and social networks. Research focused on (a) the coping processes of Korean American mothers with children with disabilities, (b) these mothers' perceptions of other family members' adaptation, and (c) the mothers' interpretations of social support and professional support. Three research questions were asked: (a) How do Korean American mothers of children with disabilities cope with their situation? (b) How do they perceive their own adaptation and other family members' adaptation? (c) How do they interpret social and professional support? These research questions were based on the family system approach in Special Education (Turnbull & Turnbull, 1997), the Double

ABCX model (McCubbin & Patterson, 1983a, 1983b), and the ecological perspective (Bronfenbrenner, 1979).

## CHAPTER 2

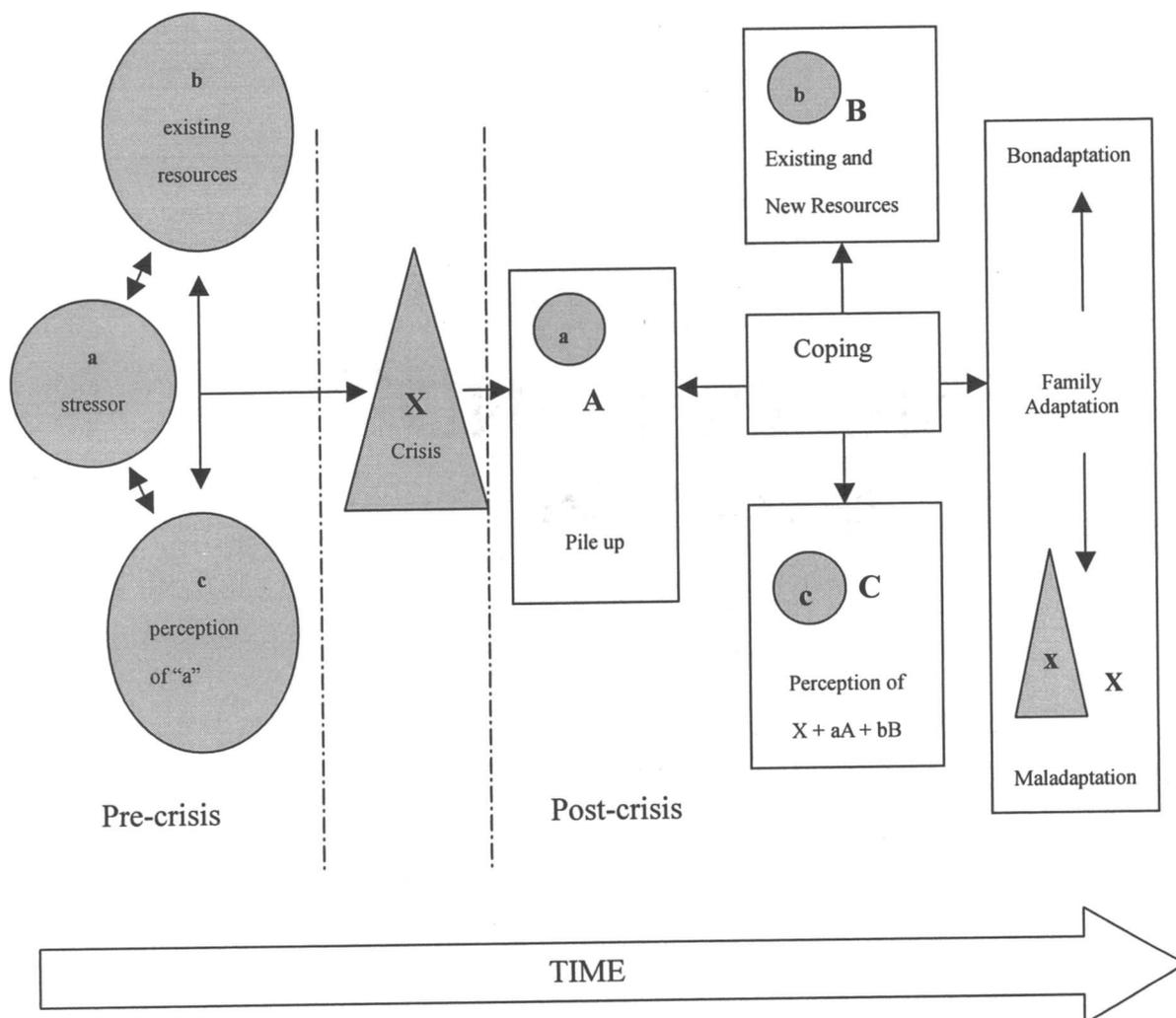
## LITERATURE REVIEW

Boss (1987) raised this question: Why do some individuals and families cope with their severe stresses, while others do not? Asking the same question to mothers who have children with disabilities, why do some mothers survive the crisis and successfully adapt, while others do not? Over the decades, researchers have tried to understand an individual's and family's coping process over a stressful event. Some events are developmentally expected and others are situational or unexpected. For practical implications within individual, familiar, and social contexts, disability researchers also have contributed to an understanding of mothers who have children with disabilities. In both the fields of family sciences and disabilities, recent approaches to families are also taking into account diverse ethnic backgrounds.

*Theoretical Frameworks*

Double ABCX Model. The double ABCX model has its conceptual foundation in Hill's (1949, 1958) ABCX family crisis model. In the ABCX family crisis model, A (the stressor event) interacts with B (the family's resources). Family resources also have an interaction with C (the family's interpretation of the event), which produces X (the crisis). Hill (1958) classified four stressors in family life. Families experience changes through "accession" (e.g., birth of a child), "dismemberment" (e.g., death of a child), "loss of family morale and unity" (e.g., alcoholism, substance abuse), and "changed structure and morale" (e.g., desertion, divorce). A stressor (A) can be normative and within the family's developmental transitions (e.g., marriage,

Figure 1

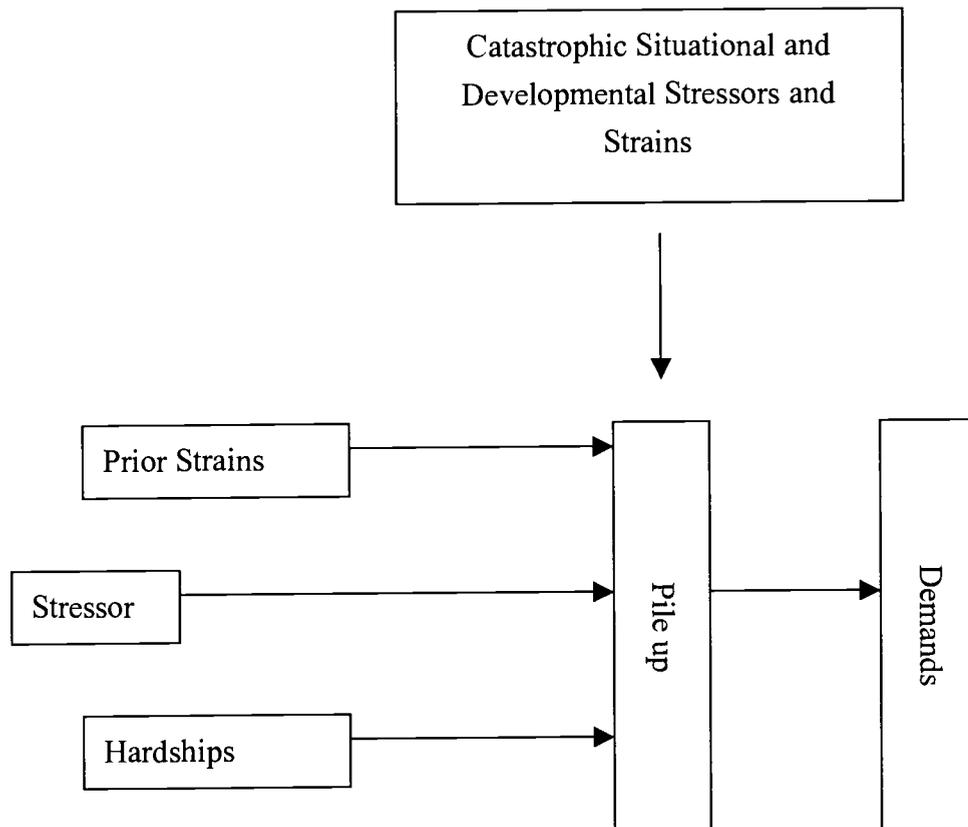
*The Double ABCX Model*

Source: McCubbin & Patterson (1983a)

parenthood, adolescence). Having a child with a disability is nonnormative and out of its developmental transition. The family's resources (B) (e.g., coherence, unity, and a sense of economic interdependence) are its ability to prevent a normative or nonnormative event from turning into a crisis. What a stressor means to the family (C) has two sides: the objective cultural definition and the family's subjective definition. The family's values and previous experiences influence construction of its subjective meaning. When there is imbalance between the family resources and the demands dealing with a stressor, the family feels stress. When the family is unable to use its resources and thus, perceives the situation negatively, the situation turns into a crisis in this ABCX model.

McCubbin and Patterson (1982, 1983a, 1983b) expanded Hill's original ABCX model, adding post-crisis variables. The Double ABCX model (see Figure 1) is a dynamic model that includes additional life stressors and changes. It also emphasizes the process of coping. Another crucial point of this model is that the demands are constantly piling up (see Figure 2). *Hardships* (e.g., increasing financial difficulties from covering a child's medical bills) are demands that the family unit experiences that are specifically associated with the *stressor* (e.g., discovering a child's disability). *Prior strains* are ongoing family events or roles such as being a parent or a spouse. *Stressors, hardships, and prior strains* pile up along with other friction and create *demands* with which the family copes (McCubbin & Patterson, 1982). A study about the Army family by Lavee, McCubbin, and Patterson (1985) supported this notion of a pile-up of demands. McCubbin and Patterson (1982)

Figure 2

*The Double ABC-X Model of Family Stressors and Strains*

Source: McCubbin & Patterson (1982)

distinguished three units of analysis: (a) the individual family member, (b) the family unit, and (c) the community unit. The family's adaptation can be achieved through the interactive relationships among these three units.

The Double ABCX model (see Figure 1) also focuses on the xX factor (adaptation) rather than a stressor. The central concept of family adaptation involves a continuum ranging from *bonadaptation* (positive) to *maladaptation* (negative). The family's demands (aA factor) change constantly. They are also multiple and tend to pile up rather than facing a single stressor at a time. The authors defined five types of stressors and strains: (a) the initial stressor and its hardships, (b) normative transition, (c) prior strains, (d) the consequences of family effort to cope, and (e) ambiguity, both intrafamily and social (1983, p.14). The family's adaptive resources (the bB factor) include the family members' individual resources, family system resources, and social support. Social support provides families with emotional support, esteem support, and network support through various social networks. The cC factor is the family's definition and meaning of the crises. This step is necessary to clarify the related issues, manage responsibilities, decrease emotional stress, and encourage other family members. It is a critical component of family coping.

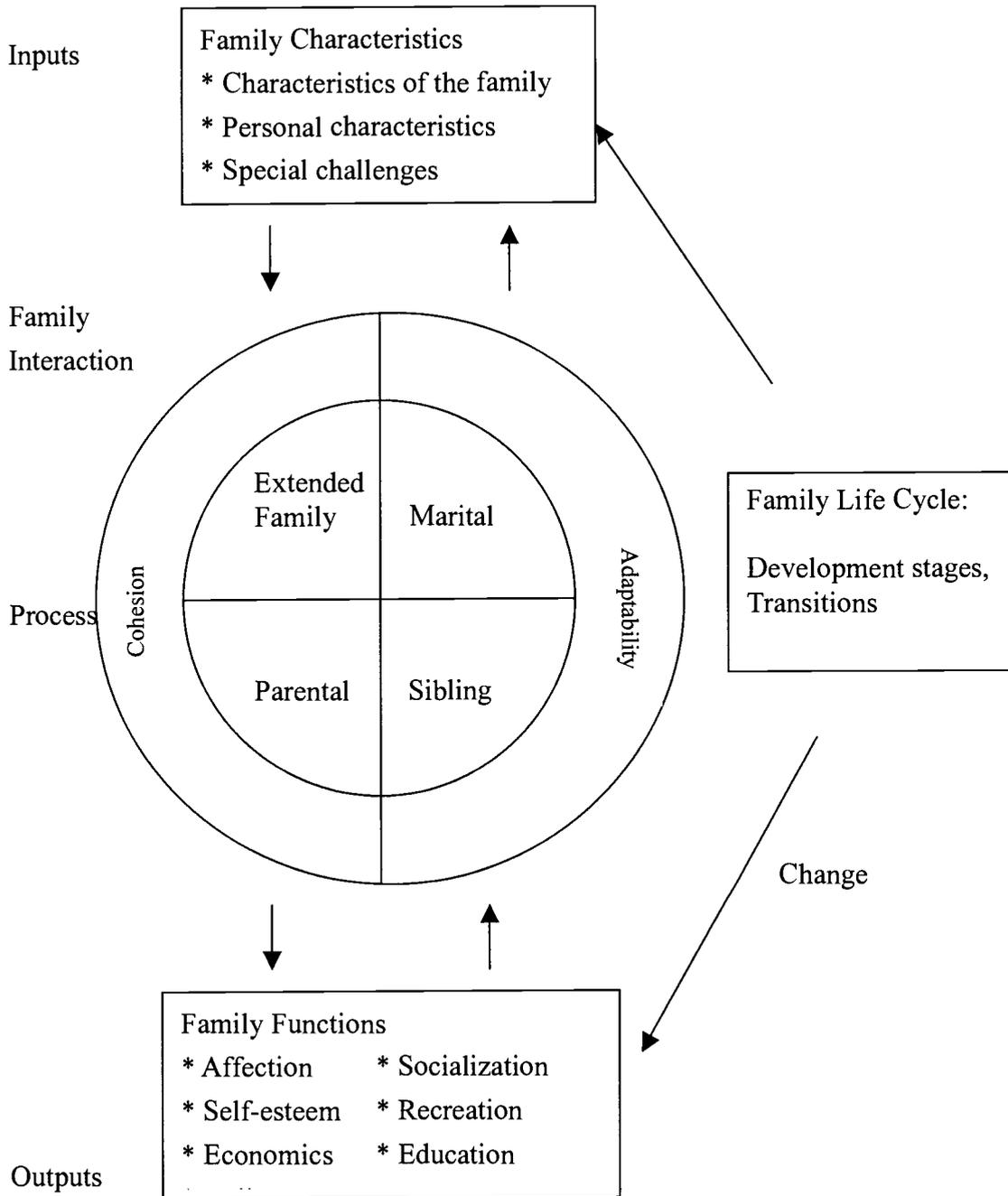
Patterson (2002) concluded that attribution of positive meaning to the situation is a central process in adaptation. Applying this process to family resilience, she specified three levels of meaning construction: (a) about a particular stressful event, (b) about the family's identity, and (c) about its worldview. Understanding and applying these meaning making processes to an individual, each family member has

to make his or her subjective appraisal of the stressful experiences. Changing the way an individual thinks about the situation may help him or her to cope with the event better. An individual's identity within the family can also help the family to create and sustain the shared family identity. In the third level, an individual's worldview outside of the self and the family contributes to the attribution of adaptation process.

Family Systems Theory in Special Education. Whitchurch and Constantine (1993) proposed that general systems theory (GST) drove modern systems theories about families to explain complexity, organization, and relationships among family members and other various community and larger systems. Turnbull and Turnbull (1996, 1997) adopted the family systems theory to explain the dynamics of families of children with disabilities. A family system is described as a mobile. The family subsystems, comprised of marital relationships, sibling relationships, parental relationships, and extended family relationships, are balanced through the family's characteristics, function, and life cycles (Figure 3). Another important concept in the family systems framework is input, which occurs when parents discover their child's disabilities. How family members adapt to their challenging situation will be revealed as their output. The process of family members' interaction for adaptation occurs between input and output in the framework. Boundaries show each family member's interaction within various family subsystems and with individuals, groups, and events beyond the family. Understanding a family's disabilities, systemically. According to Turnbull and Turnbull (1997), *family characteristics* refer to the (a) *characteristics of the family*, (b) *personal characteristics*, and (c) *special challenges* (See Figure 3).

Figure 3

*Family Systems Framework*



Source: Turnbull and Turnbull (1997)

disabilities, systemically. According to Turnbull and Turnbull (1997), *family characteristics* refer to the (a) *characteristics of the family*, (b) *personal characteristics*, and (c) *special challenges* (See Figure 3). Characteristics of the family in this model are its size and forms, cultural background, geographical location, and socioeconomic status. Number of family members and their degree of involvement in care taking influence family interaction and the process of coping. Turnbull and Turnbull explained examples of several family forms including traditional and non-traditional family forms.

Families' cultural background is another characteristic of the family in this theoretical perspective. Turnbull and Turnbull (1997) pointed out the importance of recognizing the family's cultural background in order to understand the family. They explained that the majority culture in the United States is Euro-American, which values individualism, self-reliance, and competition with others. On the other hand, some cultures in the United States are more collective, emphasizing the family's values and cohesiveness. The major principles of special education services are predominantly oriented to the individual. The policies and practices of special education do not reflect all members from diverse cultural backgrounds. Various cultures embrace divergent views of disabilities (Lynch & Hanson, 1992). For instance, seizures are considered to be closely connected with spirits in the Hmong culture, and Hmong people in the United States feel compelled to perform spiritual rituals to cause the spirits to leave a person (Fadiman, 1997). Parents in other non-mainstream cultures may use alternative coping styles due to their religious beliefs,

spirituality, and values.

Other important characteristics of the family are its socioeconomic status (SES) and geographic location. The family SES influences its interpretation of the event of having children with disabilities. The family SES also influences the utilization of resources. Geographic location influences the family's adaptation. Families in urban areas have more access to various services than those in rural areas. Military personnel and migrant farm workers frequently relocate their families, which may influence their access to and utilization of services.

*Personal characteristics* of an individual with a disability contribute to the inputs, along with the characteristics of the family. Types and age of onset of the disability affect the family's coping process. The model also includes other challenges to the family such as poverty, substance abuse, and parents with disabilities.

In the *family interaction* part of the family systems framework (Figure 3), the four subsystems: extended family, marital, sibling, and parental systems are discussed. How these subsystems interact are crucial for the family's *cohesiveness* and its *adaptability*. *Family cohesion* refers to family members' emotional closeness, which varies by cultures as well as individual families. In a highly cohesive family, the boundaries among their subsystems are weak. For example, older siblings take on caregiving roles for their younger siblings in some Asian culture (Chan, 1992). When the family has a low degree of cohesion, the supports within and between the subsystems are more likely to be weak. The family's cohesion should be understood

within its cultural acceptance according to Turnbull and Turnbull. The other crucial concept in the family interaction is *adaptability*, which can be understood as the family's ability to respond to the situation. This concept is also continuously affected by the family's values and cultural background. The more highly adaptable the family is, the more flexible it is so that the family members can collaborate and negotiate with each other when a new situation arises.

The family's cohesion and adaptability within and between its family members produce outputs, as the family functions. The child's disability has an impact on the family's functions including its affection, socialization, self-esteem, recreation, economics, education, and daily care. These effects may be positive or negative, depending on the family's input, interaction, and its life cycle variables. Again, these functions should be considered within the family's cultural values and practices.

The family's input, interaction, and output should be understood within the life cycle perspective. Turnbull (1988) used the concept of a long marathon to explain the life of a family with a child with a disability. The family's successful adaptation is not a quick fix. It is important for the family to anticipate the whole range of time and effort throughout the years. The life cycle transitions of the child with a disability are uncertain and usually developmentally delayed, which creates anxiety and stress for the family members.

The family systems framework by Turnbull and Turnbull (1997) is an overarching and comprehensive model for understanding and empowering families of

children with disabilities. In that sense, the intention of this model is to guide professionals to help families to empower themselves.

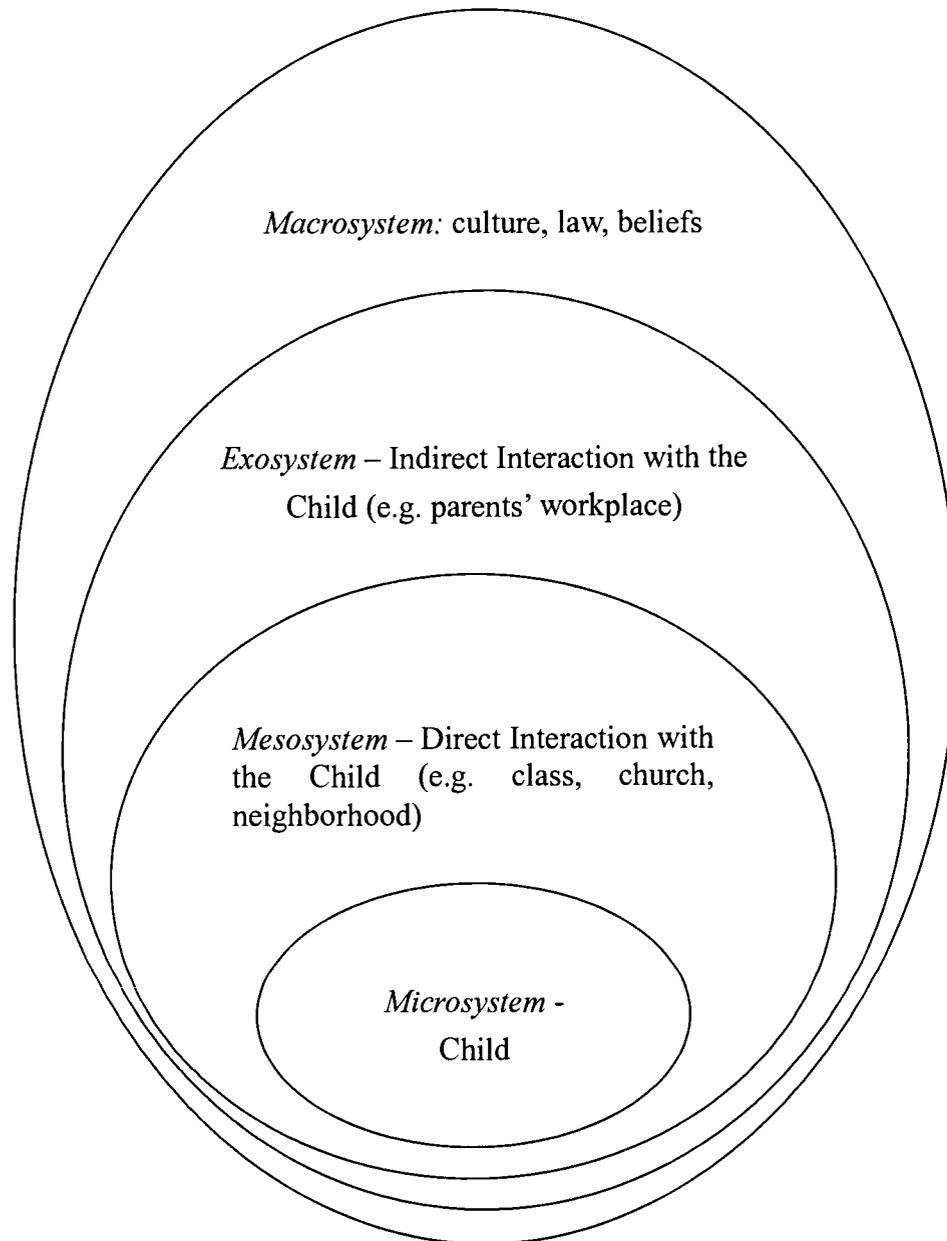
*Ecological Theory.* Human ecology theory considers human beings as both biological organisms and social beings interacting with their environment (Bobolz & Sontag, 1993). The original ecological perspective derived from biology is used to explain human social organization. The key elements of the human ecological perspective are the interaction and interdependence of humans with each other and with their environment. A major tenet of human ecology theory is that as humans adapt to their environment in order to survive, they increase their quality of life and act to conserve their environment (Bobolz & Sontag, 1993).

Bronfenbrenner's (1979) ecological theory describes how the human environment affects individuals and families (Figure 4). This theoretical perspective can be applied to families of children with disabilities. The neighborhood, school, church, parent's workplace, culture, special education systems, and laws as well as the family influence their child's development. The meso-, exo-, and macrosystems (Bronfenbrenner, 1979; 1997) actively transact with the family and their child with a disability. It may be crucial to acknowledge the various systems influencing a child's development in order to maximize the potential of a child with special needs.

Although Bronfenbrenner's initial theory did not address the environments of diverse families, his later work included families of children with disabilities (1997).

Bronfenbrenner distinguished external systems such as meso-, exo- and chronosystems and their effects on a family of children with disabilities in an article

Figure 4

*Bronfenbrenner's Ecology of Human Development*

Source: Bronfenbrenner (1979)

late in his career (1997).

The mesosystem is the context where children are directly involved and interact with others, such as a school or classroom. Exosystem is the environment where children are indirectly affected such as the parents' workplace or their social networks. Children's developmental changes and life transitions constitute the chronosystem. Bronfenbrenner's extended theoretical perspective did not specifically address the reciprocal relationship between a family and the broader context such as the law or cultural beliefs, which were indicated in his early work as the macrosystem (1979). Bronfenbrenner, however, pointed out that a family's "social address" (1997, p.51) –socioeconomic status, ethnicity, and geography—would affect the development of children directly and indirectly through the child's family. Social networks and community can positively influence a distressed family of children with disabilities.

Sontag (1996) suggested a comprehensive theoretical framework for children with disabilities, applying Bronfenbrenner's ecology of human development (1979; 1986). The author pointed out that previous studies in special education have not given much attention to the ecological perspective, that is, understanding the development of children with disabilities in multiple contexts. In applying Bronfenbrenner's (1979, 1986) theory of the ecology of human development to special education, Sontag addressed five features of the framework (1996). First, attention would shift from emphasizing general descriptions of children with disabilities to more detailed characteristics in a study's sample. Second, the

investigation would identify more clearly the environments of children with disabilities, such as family characteristics, teacher characteristics, and school and classroom contexts. Third, observation of the reciprocal interactions of child and environment would maximize the individualized model of early intervention. Fourth, a child's and family's community environment within the broader context of neighborhood, lifestyle, culture, and family resources would be studied to learn how these elements serve a family's and child's needs. Fifth, longitudinal investigations within various contexts would be crucial to capture significant, durable developmental changes in children with disabilities.

#### *Care Demands for Children with Disabilities*

A child with a disability requires parents to provide intensive care and time. These demands begin to pile up, perhaps even before they are told about their children's disability. A journey of searching for answers to their children's special needs places caretakers in a stressful and ambiguous situation.

The characteristics of the children's disabilities and behaviors have an impact on parental stress and care demands. Floyd and Gallagher (1997) compared the stress and care demands on mothers and fathers of children (N=231) with mental retardation, chronic illness, with a nondisabled behavior-problem sample. The authors found that the presence of major behavioral problems had more significant impact on parental stress than the types of disabilities. A population-based study conducted in the Netherlands (Haveman, Berkum, Reijnders, & Heller, 1997) also supported the close relationship between the subjective burdens of parent caregivers and child

characteristics. This study included 2,573 parents of children and adults with mental retardation in the Netherlands. Haveman and others in this study concluded that the significant predictors of caregiving burden were time demands, child behavior problems, child physical health, child adaptive skills, service use, and parent's educational level. A child's behavioral problems seem to be highly related to time demands and parental stress level.

Dyson (1993) examined parental stress and family functions of parents who have children with disabilities compared to those who have children without disabilities through a Questionnaire on Resources and Stress-Short Form (QRS-F) and the Family Environment Scale. The results demonstrated a significant difference in that families of children with disabilities experienced more stress than the other group across two different time points. Parents of children with disabilities rated a great amount of stress related to daily care, pessimism about child's future, and concerns about their children's physical and behavioral characteristics. Another interesting predictor of parental stress was the quality of the family relationship. Dyson found that family relationships actually affect the parental adjustment more than the presence or absence of a child's disability.

The severity of a condition adds stress for mothers of children with disabilities. Severe disabilities may require caregivers' intensive attention, high medical expense, and frequent contacts with service providers and coping with difficult behaviors (Seligman & Darling, 1997). Singer and Farkas (1989) reported a high degree of financial stress along with stress related to care giving from the

mothers (N=27) of infants and children with long-term tracheotomy, which requires the insertion of a tube into the trachea for facilitating mechanical ventilation (Batshaw, 1997). More than half of these mothers felt that they were on an emotional roller coaster, and they worried about their children's future. Physical fatigue was also reported frequently. It is difficult to conclude that the mothers of children with severe disabilities felt more subjective burdens because a control group did not exist in this study (Singer & Farkas, 1989). Stresses that parents of children with disabilities experience vary from emotional problems such as depression, to financial difficulties, to marital problems (Beckman-Bell, 1981). Unalterable physical and diagnostic characteristics of the child may tremendously burden the lives of families who have children with exceptionalities. According to Beckman-Bell (1981), some alterable characteristics such as caregiving demands, behavior problems, temperament, social responsiveness, and rate of child development also demand huge commitments by family members.

Mothers of children with autism need to deal with the ambiguity of the diagnosis, which increases stress. Bristol and Schopler (1984) suggested that mothers of children with autism have an especially difficult time accepting their children's diagnosis because of their children's typical physical appearance and the presence of some age appropriate or developmentally appropriate skills. Children with autism often have difficulties with verbal communication, which possibly leads to mothers feeling rejected. Along with these psychological difficulties among mothers of children with autism, they may also experience physical burdens due to certain

behaviors related to autism (e.g., hyperactive, aggressive, and careless behaviors).

The disabilities' severity, behavioral problems, and certain types of disabilities create care demands and parental stress. According to a study of life span perspectives by Haveman and others (1997), mothers' subjective burden did not differ significantly over all age groups of children (birth to age over 40) except during the adolescence. As adolescent children spend more time in school, parents tended to feel less stress. However, parental subjective burdens were very much consistent over time, and differences across ages were not statistically significant. According to Blaska (1998), parents of children with disabilities reencounter feelings of guilt, anger, devastation, numbness, frustration, and sadness over and over throughout their lifespan. In Blaska's study of 10 parents who have adult children with disabilities, parents experienced these emotional states again and again when their children missed developmental milestones and showed behavioral problems. Care taking demands did not decrease over time and other types of concerns, such as retirement issues, added to parental distress.

Mothers play a significant role in responding to the care demands of their children with disabilities in the families. This fact is highly related to the social and historical context of gender expectations. Women perform more caring and household related work than men regardless of their race, ethnicity, culture, and social class (Walker, 1999). On average, women usually carry out two times more family work than men, according to Coltrane (2000). Traustadottir (1991) portrayed the mother as the final decision maker for matters concerning children with disabilities in the family,

while the father serves as a supporter. This traditional pattern was evident in the interview of 14 families in the study. One mother had a very demanding professional career, but providing care for her child with a disability was also her responsibility. Most mothers perceived their care demands for their children with disabilities as their work, interpreting their caring role as more of a professional career than traditional mothering work. Porterfield (2002) also found that more mothers of young children with disabilities choose not to work outside of the home compared to mothers of young children without disabilities. Married mothers, especially, tended to stay home taking care of their children with disabilities compared to single mothers. This pattern was also evident in a study by Schilling, Kirkham, Snow, and Schinke (1986). Single mothers reported more care demands and time demands than their married counterparts. These demands related to their economic difficulties rather than care taking needs.

### *Protective Factors*

Positive perception of the situation. Although parents, especially mothers have numerous care demands related to their children's disabilities, they do not automatically transform these demands into stress or crisis. Garwick, Kohrman, Titus, Wolman, and Blum (1999) studied how Hispanic, African-American, and European American parents explained the causes of their children's conditions. Individuals had various explanations about their children's disabilities. Through semi-structured interviews with 63 families, Garwick and colleagues categorized these explanations into six groups: (a) biomedical explanations, (b) environmental explanations, (c)

traditional beliefs, (d) fatalistic beliefs, (e) absence of known causes, and (f) personal attributions. Some parents tended to emphasize positive, rather than negative reasons, for the disability and were less preoccupied with the question of why this happened. They also had the ability to move beyond questioning why this happened to managing the needs that ensued. These parents showed the ability to come to a coherent explanation of the cause of the condition, which was consistent with their beliefs. Orr, Cameron, and Day (1991) found that parental positive cognitive appraisal of the situation led to their use of various resources and services.

Along with psychological attribution related to a child's condition, maternal perceptions of hope and social support are protective factors (Horton & Wallander, 2001). In the study of 111 mothers of children ages 5 to 18 who have chronic physical conditions, Horton and Wallander found that both hope and social support were negatively related to maternal distress as measured by the Hope Scale, Social Support Questionnaire-6, Brief Symptom Inventory, and Parents of Children with Disabilities Inventory. Maternal perception of hope also moderated the relationship between disability-related stress and maladjustment.

Maternal perception of mastery in learning to care is an important protective factor. Mothers of infants with disabilities reported a strong sense of mastery in their care taking role, which gave them confidence (Singer & Farkas, 1989). Traustadottir (1991) found that some mothers perceived their caring as an empowering experience. Hartshorne (2002) proposed that key protective factors are the parent's *courage* to meet the basic needs of the child and the family, to love the child unconditionally, to

establish relationships, to take charge and make things happen for the child, and to establish balance in life. Psychological coping strategies are critical in altering human behaviors. An individual's self-efficacy (Bandura, 1982) to deal with situations influences his or her adaptive behaviors (Walker, 1985). Murphy, Behr, and Summer (1990) also found that how parents think about having and raising a child with a disability predicts parental stress. In their study, parents with a lower level of stress made more favorable or positive and less unfavorable or negative social comparisons. These parents also perceived their children as sources of acceptance and family closeness.

Perception of social support. Another possible protective factor is social support. The study by Heiman (2002) revealed hope and social support as protective factors for individuals and families. Parents expressed the need for a strong belief in their child and in the child's future as well as acceptance of the situation as key elements of resilience. Finding some meaning for the situation, could realistically lead to seeking more social support outside of the family and moving toward successful adaptation. Hieman also distinguished three factors that enable parents to function resiliently: (a) an open discussion with family members, friends, and professionals; (b) a positive and supporting marital relationship; and (c) consistent and intensive educational, therapeutic, and psychological support for family members.

Perception of positive support from a spouse or a partner moderated maternal psychological distress in the study by Singer and others (1996). In this study of mothers of very low birth weight infants, perception of general social support did not

related to lower stress levels among the mothers. Stronger partner or spousal support, however, lowered mothers' stress level even when the mothers were insecure about their own parenting competence. Marcenko and Meyers (1991) also found that mothers' perceptions of emotional support from spouses were important. The mothers in the study actually performed most of the day-to-day care for their children regardless of their marital status. A study by Suarez and Baker (1997) also supported the significance of spousal support for parents of children with behavioral problems. Perceived spousal support has the main effect on parental stress. It also had a moderating, or buffering effect in the relationship between the child's externalizing behavior and parental stress. Social support from others might be important for single mothers who presumably experience more difficulties and have less emotional support than married mothers. Floyd and Gallagher (1997) found that single mothers who had children with mental retardation were not actually more stressed than their married counterparts. However, single mothers used more social support services than did two-parent families.

In general, social support from parents who understand the difficulties of rearing a child with a disability is a powerful tool in lowering the daily stress of parents of children with disabilities (Santelli, Turnbull, Marquis, & Lerner, 1993). The Parent to Parent Program is a family support program that helps parents who have children with disabilities by matching one veteran parent with a novice parent in a similar situation (Ainbinder, Blanchard, Singer, Sullivan, Powers, Marquis, & Santelli, 1998; Santelli, Turnbull, Marquis, & Lerner, 1997; Santelli, Turnbull, &

Higgins, 1997). Ainbinder et al. (1998) qualitatively examined the experience of parents involved in this program. They concluded that participating parents benefited from the program through parents' perceived sameness, situational comparisons, and the consistency and mutuality of supports.

Perception about religious beliefs and support. Personal religious beliefs may comfort and strengthen individuals who are going through difficult situations. Religious organizations may provide resources for receiving additional help. The role of religion for parents and families of children with disabilities has received limited discussion. According to Marshall, Olsen, Mandleco, Dyches, Allred, and Sansom (2003), religion provides philosophical and spiritual meaning to the experience of rearing a child with a disability. In their study, 32 parents affiliated with the Church of Latter-day Saints perceived their situation as a spiritual experience and used their faith to cope in their daily lives. These parents' positive meaning making grew from their religious beliefs with support from their religious community.

Religion may also help parents to see their situation as an opportunity rather than a burden (Weisner, Beizer, & Stolze, 1991). Religious parents may find reasons or purposes for their children with disabilities based on their religious beliefs, while nonreligious parents do not. Weisner, Beizer, and Stolze found that religious parents perceived that God gave them their children for a reason. Parental religiosity (religious beliefs) influenced the interpretation of their experiences. The study of African American parents of children with disabilities also showed that their religious beliefs positively affected their adjustment (Rogers-Dulan, 1998). Three positive

themes related to the role of religion among these parents were “(a) the need for assistance and help in the face of challenge and struggle, (b) meaning and a moral/ethical path to good, and (c) a source of hope and peace” (Rogers-Dulan, 1998, p. 99). Some parents in the study, however, had negative comments about the role of religion. Such parents reported (a) lack of support from church members or organizations, (b) lack of desire to attend organized religious services, and (c) feelings of guilt and punishment.

Tarakeshwar and Pargament (2001) examined the role of religion in parents of children with autism. In their study, positive religious coping was related to spiritual growth and a lower level of stress, while negative religious coping influenced greater depressive symptoms and lower spiritual growth. Similar to findings in other studies (Marshall, et. al., 2003; Rogers-Dulan, 1998; Weisner, Beizer, & Stolze, 1991), religious parents of children with autism attributed their situation to God’s will. Some parents also perceived that their religious beliefs saved their marital relationship, which was falling apart after the diagnosis of autism. Some parents in the study, however, felt that religious services were stressful due to children’s disruptive behaviors. The perception of these parents was that fellow church members were annoyed with behaviors caused by the disability.

#### *Studies of Parents from Ethnically Diverse Groups*

Ethnic minority families of children with disabilities have received scant attention from researchers. Conducting well-designed empirical research on an ethnically diverse population requires participation by professionals and researchers

who are bilingual and bicultural in order to achieve validity and credibility (Gabel, Vyas, Patel, & Patel, 2001). Historically, a shortage of professionals from ethnic minority groups has been one of the obstacles in reaching diverse ethnic samples. The number of studies on ethnic minority families of children with special needs has been increasing over the last several years.

Blacher, Lopez, Shapiro, and Fusco (1997) compared depression levels of Latino mothers with and without children with mental retardation. Perception of the child with retardation was moderately related to these mothers' depressive symptoms. Mothers' health status and their perception of family cohesiveness were more strongly related to their depressive symptoms than was the child's disability. A qualitative study by Skinner, Bailey, Correa, and Rodriguez (1999) showed how Latino mothers constructed their identities through their children with disabilities, using cultural and religious explanations of disabilities. Most mothers made sense of the disability and constructed their own identities as good mothers, taking care of their children and family. Roman Catholic theology motivated these Latino mothers to accept their children and sacrifice their lives to care for their children with disabilities. These mothers' perceptions about disabilities through their religious beliefs were similar to those in other studies described earlier (Marshall, et. al., 2003; Rogers-Dulan, 1998; Weisner, Beizer, & Stolze, 1991).

Studies of Chinese American parents of children with disabilities are rare. The study by Smith and Ryan (1987) explored Chinese American parents' reactions to service providers. The language difference between the parents and professionals was

the biggest problem expressed by these Chinese American parents. Not understanding the diagnosis and medical and educational systems made these parents confused, angry, ashamed, and depressed. Cheng and Tang (1995) also found a high level of stress in Chinese parents of children with Down syndrome. The parents in the study reported frequent use of avoidance coping strategies. The study of mothers in China (Huang, Rubin, & Zhang, 1998) found relationships between the severity of a disability and the maternal stress level. Moreover, the level of maternal stress was highly related to perceived negative attitudes of neighbors toward the child with mental retardation. The authors also found a significant negative relationship between the level of mothers' belief in Confucianism and maternal stress. Appraising the children's disabilities as a supernatural force seemed to lower levels of stress and to help these mothers to cope with their situation better. The ethnographic study by Holroyd (2003) showed a slightly different phenomenon of Chinese cultural influence on parental caregiving of children with disabilities. The disability challenged the natural order of cultural expectations concerning caregiving obligations, which is that parents provide care for their offspring, but parents receive care from their children later, as the parents age. This disruption of the natural order plus public stigma toward disabilities added to the difficulties of parenting.

Illustrating the growing Asian population in the United States in 1998, 2% of all preschoolers who received special education were of Asian and Pacific Islander origin, and approximately 1.7% of the total disability population ages 6 through 21 were from these two ethnic groups (U.S. Department of Education, 1998). Asian and

Pacific Islander children and youth with disabilities seem to be underrepresented in special education when compared with the census statistic that Asian and Pacific Islanders are 3.7% of the total American population. Americans of Korean origin numbered 1,077,000 in the United States in 2000 (U.S. Census Bureau, 2001). Approximately 10% of 10 million Asian Americans identified themselves as having Korean ethnicity.

The research conducted by Cho, Singer, and Brenner (2000, 2003) compared Korean parents in Pusan, Korea, with Korean American parents in Los Angeles, California, in order to understand how societal contexts influenced these families' experiences of rearing children with disabilities. Sixteen Korean parents and 16 Korean American parents with similar cultural origins showed different degrees of psychological strain and varied causal attribution to their children's disabilities. Korean parents living in Korea, where special education is in an early stage of development, experienced more challenges from negative social and cultural attitudes toward people with disabilities. They also noted a lack of services to assist their children. On the other hand, Korean American parents evaluated their difficulties more positively, reportedly because they receive various supports from the special education, medical, and case management systems. Korean American parents, however, reported other challenges such as language barriers and cultural differences that Korean parents did not share. The comparative cross-cultural study allowed researchers and practitioners to understand how social structure and cultural tolerance influence families' dynamics and daily adaptations.

Park and Turnbull (2001) conducted an in-depth qualitative study of eight Korean American parents who have children with disabilities. Although the authors' telephone interview procedure did not allow for personal contact, the study indicated that Korean parents of children with disabilities were mostly satisfied with the services they received and felt grateful for privileges given to them. Most parents in this study voiced comments similar to those of parents in the other study regarding difficulties in exchanging information with professionals because of their limited English proficiency. Desire to know more about their children's school life reportedly competed with feelings of being overwhelmed by too much information (Park & Turnbull, 2001). The authors pointed out that Korean parents of children with disabilities living in the United States showed a passive communication style with authority in which they did not interrupt professionals by asking many questions. Korean parents in the study suggested the need for a mediator, who is bilingual, bicultural, and familiar with the special education system.

Difficulties arising from limited English proficiency were foreseen by the researchers in their studies of Korean parents in the United States with children who have disabilities (Cho, Singer, & Brenner, 2000; Park & Turnbull, 2001). Even if some parents were comfortable communicating in English daily, they had difficulty understanding special education jargon and medical terms (Park & Turnbull, 2001). Translators often lacked knowledge about disabilities and legal entitlements, which frustrated and dissatisfied these parents who were attempting to make sense of the American system (Cho, Singer, & Brenner, 2000, 2003).

Approximately 62% of Korean American parents reported a great amount of emotional support from their religious group compared with only 6% of Korean parents in Korea (Cho, Singer & Brenner, 2000). Along with emotional social support from religious groups, the Korean American parents of children with disabilities in this study gave spiritual attributions to disabilities. The important role of Korean churches among social and cultural institutions in the United States has been recognized in other studies (Chan, 1992; Hurh & Kim, 1990). According to Hurh and Kim (1990), 69.9% of the Korean residents interviewed in Los Angeles and 76.8% of the Korean residents interviewed in Chicago reported attending Korean ethnic churches regularly. The authors also noted that while the Korean ethnic church continues to play an important role for Korean Americans, this is especially true for recent immigrants.

#### *Chapter Summary*

This review has shown three broad lines of research relevant to the present study: (a) care demands for a child with a disability, (b) protective factors of adaptation, and (c) studies of parents from ethnically diverse groups. As the previous research revealed, parents of children with disabilities encounter various kinds of stresses in their lives. Despite stress associated with care demands, some reframed the attribution of their children's disabilities more positively through supports from their spouses and religion. Although studies of parents from various cultures were scarce, the findings shared some aspects of similarity with the main line of the research. Several studies on Korean American families of children with disabilities provided

insights for the present study.

## CHAPTER 3

## METHODS

This study examined the questions: (a) How do Korean American mothers of children with disabilities cope with their situation? (b) How do they perceive their own adaptation and other family members' adaptation? (c) How do they interpret social and professional support? A qualitative research approach was proposed to address these research questions because qualitative methods allow researchers to focus on meanings, concepts, definitions, characteristics, metaphors, symbols, and descriptions of phenomenon (Berg, 1998). Denzin and Lincoln (2000) defined a broad and comprehensive meaning of qualitative research:

Qualitative research is a situated activity that locates the observer in the world. It consists of a set of interpretive, material practices that make the world visible. These practices transform the world. They turn the world into a series of representations, including field notes, interviews, conversations, photographs, recordings, and memos to the self. At this level, qualitative research involves an interpretive, naturalistic approach to the world. This means that qualitative researchers study things in their natural settings, attempting to make sense of, or to interpret, phenomena in terms of the meanings people bring to them. (p.3)

Gilgun (1992) also explained that the common thread of diverse qualitative research is construction of meaning. Qualitative research is an inquiry process to render and understand human behaviors and the world (Creswell, 1998, 2003; Denzin & Lincoln, 2000). The process of qualitative research starts from a researcher to interpretive paradigms, to strategies of inquiry, to methods of data collection and analysis, to presentation, and it continues full circle (Denzin & Lincoln, 2000).

To capture the essence and ambience of the lives of Korean American mothers who have children with disabilities, this study used the mothers' narrative stories with sufficient details (McWilliam, 2000) and open-ended interviews. A qualitative research approach also shows promise of eliciting in-depth information about a very sensitive subject (Berg, 2000). Due to a lack of previous research on Korean American parents of children with disabilities, this study was exploratory in nature and is partially taking the form of a collective case analysis (Stake, 2000). As Stake (2000) noted about the purpose of a case report, this study is not to represent all Korean American mothers of children with disabilities, but to represent an individual case. The current study particularly focused on individual cases as well as the collection of these cases qualitatively.

### *Participants*

Recruitment. After the approval (Protocol No. 1797, Appendix A) from the Institutional Review Board (IRB) at Oregon State University, I contacted Korean ethnic churches, parent support groups and professionals through electronic mail and phone calls in order to locate Korean families of children with disabilities in Oregon, California, and Washington. Brief information about the current study, including a flyer (Appendix B) and an informed consent form (Appendix C) were sent to various organizations in these three states through electronic mail, fax, or mail. The format of the flyer and informed consent form employed both English and Korean in order to convey respect for the subjects' native language. Korean mothers who are in the United States and who have children under age 18 with disabilities were asked to

participate.

The contacts to the researchers who have previously worked with Korean parents of children with disabilities were made to gain suggestions for recruiting participants. Service providers and researchers were asked to help recruit participants by explaining the study and distributing fliers during their regular contacts with Korean mothers. Mothers were asked to contact the researcher if they were interested in gaining more information about the study in order to decide whether they were willing to participate in the project. If mothers chose to participate in the study, they gave permission to a family service provider who forwarded contact information. This procedure was followed in order to ease mothers' concern about a direct contact. Participation was voluntary, and subjects were told they could withdraw from the study at any time. Participants were informed that collected data would be kept confidential at all times.

Following the described procedure, two mothers from Oregon were recruited through contacts with the ministers of Korean ethnic churches. Another mother from Oregon was signed up for participating in the study through a referral from Early Intervention. Two mothers from California were recruited through snowball sampling (Berg, 2001). An individual who was involved in Korean parent support groups introduced these two mothers to me. It is uncertain whether these two participants knew each other. Attempts to recruit participants from Washington State did not succeed. Thus, five mothers from Oregon and California participated in the interviews.

Characteristics of participants. The participants in this study consisted of five Korean American mothers of children with disabilities: three mothers from Oregon and two mothers from Los Angeles, California (Table 1). These mothers are the first generation to live in the United States either as permanent residents or in the process of immigration. Asian immigrants who were born in other countries and emigrated to the United States are generally considered the first generation in the United States (P. Sakurai, personal communication, October 15, 2002). (For European immigrants, their offspring who were born in the U.S. are considered as the first generation.)

The participating mothers' averaged 12 years spent in the United States, but they ranged from 5 to 22 years of living in this country. The ages of their children who were receiving special education included 4 1/2, 7, 10, 16, and 18 years old at the time of the interview. The wide variation in children's ages was necessary due to difficulty in locating this small special population. These children with disabilities have been receiving special education services from a minimum of one month to a maximum of 13 years. One mother has a daughter with multiple disabilities, including mental retardation, hearing impairment, speech delay, and autism. Three of the boys were diagnosed with autism. One boy was recently diagnosed with speech delay. All five children shared a common condition of communication delays.

The children's diagnoses and their degrees of need vary in this study because the main focus of the research was the experience of Korean mothers who are rearing children with exceptionalities in a new culture. In the current study, four mothers who previously worked are now taking care of their children at home. For example, one

participant, who was a preschool teacher for over 20 years, decided to quit working in order to spend more time with her son with autism. One mother was working outside the home at the time of the interview. She resumed working a couple of months before her son's diagnosis.

Table 1  
*Description of the Participants*

State	Oregon			California	
Mother's					
pseudonym	Young-Mi	Kyung-Hee	Jung	Mi-Hwa	Hyun-Ja
Marital Status	Married	Married	Married	Divorced	Married
Years					
in the U. S.	22	16	5	12	17
Child's diagnosis	Autism	Multiple disorders <sup>a</sup>	Speech Delay	Autism	Autism
Child's age	16	18	4 1/2	10	7
Child's					
pseudonym	Chan-Ho	Hae-Jin	Jin-Su	Chul-Hee	Ki-Chul

*Note.*  $N = 5$

<sup>a</sup>Multiple disorders including mental retardation, speech delay, hearing impairment, and autism.

Except for one participant who lives with her parents and her son with autism, the other four mothers live with their husbands, child or children without disabilities, and the child with disabilities.

Mothers were selected for interviewing because in Korean culture mothers provide more direct caregiving to children than fathers do (Cho, Singer, & Brenner, 2000). Mothers are usually more in tune with their children's developmental condition and care more about the details in their children's education than fathers. Although there have been many changes in social structure, mothers in Korea typically stay home with their children rather than working outside of the home environment, while fathers play the role of breadwinner (Cho, Singer, & Brenner, 2000). Most participants in this study fit within the traditional role of mothers.

#### *Data Collection*

After lists of potential participants were received from service providers or mothers, informed consent forms written in both Korean and English were sent to the Korean mothers, who might participate in the study. Additional information about the project, written in Korean and English, was also sent to them. Participants could read the explanations in their preferred language. An approval document (Appendix A) from the Institutional Review Board (IRB) was sent to these potential participants along with the informed consent forms.

During the initial contact with the mothers, the purpose of the study and the plan for conducting the study were explained in Korean. Prior to interviews, the participants were informed about benefits and risks from participating in the study. The

participants might benefit emotionally from talking about their situations with someone from the same country of origin. They received a gift certificate of up to \$25 from a local grocery store before the interview began. The participants received information related to their children's disabilities or parent support groups upon request. The participants were also informed that, in the long run, the study would be beneficial to Korean families, an underrepresented population, by creating and supporting culturally and developmentally appropriate special education and family services in the United States.

The research participants were notified about potential risks prior to interviews. Potential risks to the participants from this study were the emotional discomfort of disclosing their family story to an outsider, the researcher. Other foreseeable discomforts were emotional distress from remembering a previous emotional state. In order to minimize or reduce emotional discomfort and distress, the participants were given time to reflect on memorable and helpful experiences they had had while rearing their children with disabilities. Moreover, additional resources such as parent support groups and informational web sites were shared at the end of the session, upon the participants' request.

The questions used to facilitate the interviews were developed through a review of the literature on culturally diverse families of children with disabilities as well as multiple discussions with the major advisor. The semi-structured protocol covered four major areas: (a) the mother's and her child's characteristics, (b) the mother's transition after discovering her child's disability, (c) the mother's social

networks and informational resources, and (d) the mother's satisfaction with provided services and their perception of unmet needs. These questions were modified and additional questions were asked as needed to clarify responses during the interviews. The open-ended interview questions are attached in Appendix D.

Two participants were interviewed in their home, which allowed me to observe them in their natural settings. In both cases, their children with disabilities were introduced. One interview was conducted in the local library. The other two interviews were held in restaurants for their convenience. Interviews were conducted in the mothers' and my native language, Korean. It was comfortable for both the mothers and myself to be able to converse in Korean. Speaking in the native language helped the interviewees to reflect personal thoughts and to generate thoughts more easily than speaking in a second language. Conversing in Korean also seemed to help these mothers feel confident about their stories and themselves without worrying about making grammatical mistakes. At the beginning of each interview, casual small talk gradually led the mothers to move on to more specific and intense conversation (Fontana & Frey, 2000). During the interviews, I tried to make a connection with the mother by expressing an empathetic understanding of her situation. An average interview session was approximately two hours in length. Each entire interview was tape recorded except for one interview where the participant wished not to be. In that case, notes were taken instead.

#### *Data Preparation and Analysis*

The original interview content was transcribed initially in Korean and then translated into English. Another Korean native speaker who was a former graduate student in Human Development and Family Studies at Oregon State University translated 10% of the interview content, using the Korean transcription. A third native Korean, a graduate student from the same department, compared the two versions for reliability of translation. The two translations were highly related to each other in terms of the meaning of the content. Modifications of words or order of sentences were made when necessary for easier understanding in English.

Any information obtained from interviewing these mothers was kept confidential to the extent permitted by law. Code numbers were used to identify any interview results or other information the participants provided. Neither the subjects' real names nor any personal information was used in any data summaries, presentations, or publications. The original copies of the interview content were also held in confidence. The participants were not identified by their names but by their code numbers throughout data analysis. The instructions, details of procedure, audiotapes, notes, coding systems, and analyses used for the study will be retained for at least five years after any publication (American Psychological Association, 2001).

The analysis process required a constant attaching and detaching from the data; I immersed myself in the data and periodically pulled back from them in order to process. Immersing myself the data allowed me to examine these mothers' narratives line by line. Sometimes, pulling myself away from the data was necessary to see an entire picture of each story. In qualitative research, a researcher is often

described as an instrument rather than a conductor; a researcher herself becomes a tool. A researcher seems to be in a vulnerable position, needing to feel and go through similar stress that participants have gone through to reflect their situation (McGraw, Zvonkovic, & Walker, 2000). As Denzin and Lincoln (2000) described a qualitative researcher as a bricoleur, quilt maker, jazz musician, and montage maker, putting pieces together with a researcher's own interpretation was a necessary step.

First I read the entire transcripts and developed main codes from the data. I went back to each interview to disassemble the data. During this process, additional codes and sub codes were revealed. After initial coding of the data, the major advisor and a special education teacher coded 25% of the translated transcripts separately. We discussed the codes and categories and refined them together through multiple meetings. During the meetings, agreement and disagreement on coding were also recorded. The agreement rates were 81% (between the major advisor and the investigator) and 90% (the special education teacher and the investigator). The total agreement rate was 86% among the three coders. In order to answer the stated research question, several main themes derived from theoretical perspectives were anticipated. These guided the process of analysis.

The codes and interview transcripts were entered into the WinMax qualitative software program. WinMax did not analyze the data, rather it facilitated in the organization of the data. It also allows the investigator to anticipate the overall frequencies of the main themes and sub themes. Use of computer software was

preferable to the “cut-and-put-in-folder” approach (Bogdan & Biklen, 1998), which would have involved handling multiple copies of data.

Through discussions with other researchers, the adaptation process of each mother was examined through the Double ABCX model in order to analyze each individual case more precisely. Each mother used her personal and social resources to resolve the tension created by the stressors (i.e., a child with a disability, immigrant status, and other related challenges) in her own way. Some common threads weaved throughout their stories. Each mother’s perception of the situation was another key variable in her adaptation process. After each case was examined, the major themes from the entire data were analyzed.

## CHAPTER 4

## RESULTS

*Individual Adaptation Process*

The adaptation process of each mother has been analyzed below based on the Double ABCX model by McCubbin and Patterson (1983a, 1983b). All names are pseudonyms.

The first mother: Young-Mi. During the initial contact with Young-Mi to schedule an interview, I could sense her enthusiastic personality. Young-Mi repeatedly confirmed that she was not embarrassed about her son, Chan-Ho with autism, and that she liked to talk about herself and her son. A few weeks later, I visited her home in Oregon to conduct the interview. We began talking about ourselves casually over: what town in Korea we came from, what schools we attended before coming to the United States, where our parents were, and how many siblings we have. Young-Mi came to the United States 22 years ago with her parents after graduating from high school. She met her husband in the United States 17 years ago.

The event of discovering the oldest son's disability (a stressor) was beyond Young-Mi's expectations, although she had some early suspicions due to her son's slow language development. Signs of lag in Chan-Ho's language development made this mother seek professional opinion:

Chan-Ho couldn't talk when he was two and a half years old. So I went to see a doctor, and they said he had autism. After he was diagnosed with autism, I didn't know what it was so I started studying about autism. And I met some mothers, and I took him to a famous child psychologist. It was the same diagnosis, autism. They said there was no cure. There was no known cure or

operation yet...How can I say this? When I found out that he had autism, I felt numb. I didn't know what autism meant and I thought it was a neurological disorder and a disability, so I cried a lot.

The official diagnosis brought doubts and fear from the word "autism." The event had a psychological impact on Young-Mi. Similar to the Chinese Americans who experienced confusion and frustration about their children's condition (Smith & Ryan, 1987), not being able to comprehend what autism meant placed Young-Mi in a very vulnerable position.

The stressor (a) of having a child with autism became intensified through negative interactions with Young-Mi's existing resources (b). Young-Mi's ability to make the transition to life with a child with autism involved her perception of family integration. Young-Mi recalled her husband's longer denial period. Breaking the traditional Korean order of family heritage (Holroyd, 2003) was difficult for her husband; this child, although he is the oldest son in the family, would not be able to take care of Young-Mi and her husband later in life. Young-Mi stopped working after she found out about her son's disability. What was the subjective meaning (c) of the event to Young-Mi? She had never seen anyone with disability before. She felt frustrated and hopeless. Imbalance and tension escalated the level of stress and the stressor turned into a crisis (x) (McCubbin & Patterson, 1983a).

Demands began to pile up (aA). Some were related to the characteristics of autism. Some were from Chan-Ho's own characteristics. New family members (younger children) joined the family. As Chan-Ho grew up, his aggressive behaviors became worse. He also exhibited typical autistic behaviors such as resistance to

redirection, anxiousness, routine-orientedness, restlessness, and limitations in communication skills (Bristol & Schopler, 1984; Mauk, Reber, & Batshaw, 1997). Turnbull (1988) mentioned that parenting a child a disability would require marathon skills (i.e., strength across the life course). Reflecting a marathon view of life long adaptation, Young-Mi had to make constant efforts to adjust to new challenges and concerns. Young-Mi reported that she followed the detailed changes in Chan-Ho's combination of medications very carefully. During the interview, Young-Mi received several phone calls from Chan-Ho's class assistant related to his new medicines. Attention had to be shared with Young-Mi's other two children. When the demands of caregiving escalated to a point that Young-Mi could not handle, her body responded to her psychological distress:

I used to be transferred to the emergency room by ambulance about twice a year a while ago. Stress just exploded after piling up over and over. I didn't know what it was at that time, but when I think about it now, it was stress. The built up stress turned out as a high fever. My condition did not even have a name. I just had a very high fever. My teeth were hitting against each other. Then I went to an emergency room and was tested with all kinds of examinations. And the doctor didn't find anything wrong specifically and said that it was some kind of virus. And I was given some antiviral medicines. I felt okay a few days later.

Young-Mi's resources (bB) were analyzed on three levels: (a) personal, (b) her perception of family system resources, and (c) social supports. On the personal level, personality characteristics, financial security, English fluency, and spiritual beliefs were present. Ever since Chan-Ho was diagnosed with autism, Young-Mi had stayed at home. Providing care to her children and taking care of the house was her major role,

similar to many other mothers of children with disabilities (Porterfield, 2002). One of the most significant personal resources seemed to be her personality in dealing with problems (McCubbin, & Patterson, 1983a). Young-Mi briefly talked her strong self-esteem and her feeling that she did not want to complain about her situation to others. These characteristics helped her confidence grow in taking care of the child with autism. Her husband's business was also operating successfully, which meant that Young-Mi and her family were financially secure. She did not need to worry about medical bills or costs for additional therapies. Over the years of living in the United States, Young-Mi became fluent in English. Interaction with professionals and teachers did not seem to be difficult for her, although she had to learn about autism specifically. Most of all, Young-Mi believed that her religious beliefs gave her strength and courage. Similar to other studies about religious parents (Marshall, et. al., 2003; Rogers-Dulan, 1998; Weisner, Beizer, & Stolze, 1991), Young-Mi described her spiritual connection with God as her most important protective factor.

The second level of resources included Young-Mi's interpretation of her family's cohesion and adaptation. Young-Mi's husband gradually accepted his son's condition after he began attending church. Her husband supported Young-Mi's decisions on matters of the children's education. Traustadottir (1991) described this pattern in families of children with disabilities. Young-Mi was particularly proud of her other two children without disabilities: how mature they were, how thoughtful they were, and how well they behaved at both school and home. She also felt sorry for

them: how they had to understand their older brother's disability and how strictly their behaviors were regimented at home.

The third level of resources consisted of Young-Mi's perception of social support from her relatives and social networks. Although most of Young-Mi's extended family members lived in the United States, she felt some limitations in their practical and emotional support. Young-Mi expressed it this way:

Helping has a limit, even though you are a close brother or sister. They can pray for us and support us emotionally, but they don't know what we are going through. Only we know for sure. Only the immediate family members and I know about how it is... Sometimes my sisters come and see me. They can guess how frustrated I am, but they don't know how I truly feel. They don't know. I tell my sister what medicine my son is taking, but they don't know anything about it because they never used it.

Perception (cC) of the situation interacted with the crisis, pile-up of demands, and resources described earlier. Over the years, Young-Mi gave new meaning to the situation. She began realizing how this experience became a chance to grow spiritually and personally:

There weren't many difficulties around me. My family was not rich, but we didn't have financial problems. There was no one with a disability around us when I grew up in Korea. If my child didn't have a disability, I would not have cared about them at all. Those people just live by themselves, and I just would live by myself, not caring about them at all although we live together on the one earth. Because of my son with autism, I think about people with disabilities... I feel more and more that this is 'the life.' My life has been changed absolutely.

Young-Mi's adaptation (xX) to a stressor of having a child with autism included various components and interactions among them. Her personal and family resources made demands manageable although she did not perceive much social support. Positive perception of the situation was an important factor supporting her continuous adjustment.

The second mother: Kyung-Hee. Kyung-Hee was a pharmacist in Korea, running her own drug store. Her husband completed his masters' degree at the top university in Korea and was working at a branch office in Oregon. They were an ambitious and hard-working young couple. With two young children, Kyung-Hee followed her husband to Oregon in 1986. A couple of years later, they decided to stay in the United States because of their second daughter, Hae-Jin with mental retardation.

The formal diagnosis of Hae-Jin's condition was a stressor (a). Hae-Jin's mental retardation significantly impaired her intellectual functioning and adaptive abilities (Batshaw & Shapiro, 1997). Later, she was also diagnosed with hearing impairment, communication delay, and autism. Before the formal identification of disabilities, Kyung-Hee was suspicious about her daughter's slow development. Even after the diagnosis, no one gave Kyung-Hee a logical explanation about possible causes of the disabilities.

Kyung-Hee's ability to make the transition into life with this child (resources, b) was limited. On a personal level, Kyung-Hee did not speak English well enough to ask specialists various questions about her daughter's conditions. Although Kyung-Hee and her husband decided to stay in the United States for their daughter's education, the

multiple steps of the immigration procedure distracted them. Kyung-Hee's husband also quit his job and started his own business, which was not very successful. Kyung-Hee recollected those days:

But at that time, the major and the most important concern was how we [her husband and herself] could be financially stable. We didn't know how to care for each other. We were so busy and worked hard. My husband had just finished graduate school and started his job right away. Our life goal and direction were wrong.

Their financially oriented life goal reportedly did not help them to accept their challenging situation.

Along with her existing resources (b), Kyung-Hee's subjective interpretation (c) of the situation was not defined clearly. She wanted to find the cause, not just the diagnosis for Hae-Jin's problems. Kyung-Hee was occupied with the various possible explanations of the diagnosis: biomedical, environmental, absence of known cause, and personal attribution (Garwick, et al., 1999). Kyung-Hee partially blamed her husband who made her work hard during the pregnancy. She also blamed inexperienced doctors who delivered Hae-Jin. As the subjective definition often reflects previous experience (McCubbin & Patterson, 1983a), Kyung-Hee had not previously seen anyone like her daughter. Considering the stressor, existing resources, and definition of the event, having the child with multiple disabilities was a crisis (x).

Kyung-Hee had to pay constant attention to Hae-Jin's difficult behaviors as the characteristics and severity of the disability required (Seligman & Darling, 1997). Although Hae-Jin reached adolescence, care demands did not decrease because of her

severe condition. Hae-Jin turned 18 years old near the time of the interview, and she had not been toilet trained until a few years ago. Care demands and subjective burden did not decline over the years (Haveman, et al., 1997; Turnbull, 1988). Various demands piled up (aA). It was difficult for Kyung-Hee both psychologically and physically to take care of her adolescent daughter. The physical strains of mothering did not seem to ease, as Hae-Jin grew older: "I am getting weaker and weaker, and my child becomes stronger and stronger." Kyung-Hee had tried to apply some strategies that she learned from therapists or trainers, but they did not work very well at home. As other studies have discussed (Cho, Singer, & Brenner, 2000; Park & Turnbull, 2001; Smith & Ryan, 1987), difficulties associated with the language barrier was a prior strain.

Kyung-Hee's caregiving role (Porterfield, 2002; Traustadottir, 1991) and the expected responsibility for family work (Coltrane, 2000; Walker, 1999) were similar to those of other mothers of children with disabilities. Demands and stresses were increased due to limited practical support from Kyung-Hee's husband and extended family members. Professional support was also reported to be insufficient. Kyung-Hee had limited personal resources (bB) to adjust to escalating demands. The most prominent personal resource was her strong religious beliefs that helped her to be courageous and strong. Religious beliefs and spirituality were described similarly in other studies (Marshall, et. al., 2003; Rogers-Dulan, 1998; Weisner, Beizer, & Stolze, 1991). Like many of the other 70% of Korean immigrants who affiliate with Christian

churches (Chan, 1992; Hurh & Kim, 1990), Kyung-Hee interpreted her situation through religious principles.

Perception of the situation (cC) interacted with piled-up demands (aA) and resources (bB). Her strong religious beliefs influenced Kyung-Hee's view of caring for the child with mental retardation. Through religious experiences, she began to see meaning in her life with the child with disabilities. Accumulation of wealth was not the goal of her life any more. She also stopped searching for the causes of Hae-Jin's conditions and began to focus on education, which became Kyung-Hee's perceived family goal. As Garwick, et al., (1999) illustrated in their study, Kyung-Hee gained the ability to move beyond explanation of the disabilities. The ability to define the subjective meaning of the event positively encouraged her adaptation (xX). Without her strong religious beliefs, she might have perceived this situation negatively and maladapted to it. Within the continuum of adaptation (McCubbin & Patterson, 1983a), Kyung-Hee seemed to be gradually moving toward *bonadaptation*. Nevertheless, the process of adaptation might shift to the other direction if she encounters new demands in the future.

The third mother: Jung. Jung's case was different from other mothers in the study. First, she had spent the shortest length of time (five and a half years) in the United States relative to the other participants. Second, Jung's son, Jin-Su was diagnosed with speech delay, which was less severe than the other children's conditions. Third, due to the recent diagnosis, her case could not be analyzed with the full process of the Double ABCX model. However, the data demonstrated intensity and

complexity of the initial stages of adaptation because Jung was going through the pre-crisis and early post-crisis state of the time of the interview. Her case also illustrated that adaptation is a process rather than a fixed stage. Thus, her story was included in spite of the uniqueness in the case.

Jung and her husband came to the United States five and a half years ago to pursue her husband's advanced degree in economics. Jung signed up for the study through a referral from Early Intervention in Oregon. Jin-Su's recent diagnosis with language disorders was a stressor (a) for Jung. At four and a half years old, Jin-Su's receptive and expressive language skills were significantly below the typical language developmental trajectory, according to the formal assessment results. He expressed himself in one or two English words when he was asked to do so, but not consistently. Jin-Su's teachers were concerned whether Jin-Su was understanding English. They asked how Jin-Su's Korean was at home. Jin-Su's Korean was reportedly not better than his English. Jung thought that Jin-Su's receptive language was Korean, but his expressive language was English. Jung had been distressed concerning the previous and present preschool teachers' concerns since Jin-Su started attending preschool. Jung could not accept the negative feedback from Jin-Su's preschool teachers. These stressors, including the event of the diagnosis and previous negative experiences, interacted with her existing resources (b) and her perception of the situation (c).

Jung's personal and family capability (b) prevented the stressor from immediate transition into a crisis (x). Emotional support from the husband (Marcenko & Meyers, 1991; Singer, et al., 1996; Suarez & Baker, 1997) secured Jung's positive

perception of family coherence and unity. Jung portrayed her husband as the decision maker and herself as an implementer. She saw herself as taking care of the details of the children's education and household work. Clear agreement on the roles (McCubbin & Patterson, 1983a) of Jung and her husband allowed her to view the family as coherent. Although Jung financially contributed to the family more than her husband, she did not see her job as a registered nurse as the breadwinner role. Her employment was a necessity for the family to survive. Jung perceived her main role as taking care of the children's education. Like many other Korean immigrants (Goldberg, 1995), her primary motivation for staying in the United States was to provide better education for her children. However, Jung had not anticipated that special education service would be a part of the educational benefits for her child.

The causes of language disorders may be unknown with no clear medical explanation, and the condition may take many forms (Wang & Baron, 1997). Jung perceived several explanations for the causes of Jin-Su's condition: (a) Jung was too busy studying for the national nursing qualification exam to spend quality time with Jin-Su, (b) Jung unequally distributed her time between her two children, (c) Jung had had to work as a major breadwinner for the last couple of months, (d) Speaking Korean at home delayed Jin-Su's English acquisition, (e) English speaking preschool teachers were inconsiderate and unfair to an international student whose native language was other than English, and (f) The validity of the language assessment was questionable for such students. Overall, Jung had arrived two explanations: personal causes and (Garwick, et al., 1999) and cultural attribution.

Jung's perception of her role as the major caregiver interacted with her personal attribution of the situation. Entering the labor market had not change the perception of Jung's primary role in the family, which was taking care of the children. Jung was performing more household work than her husband like other average women in the United States (Coltrane, 2000). Gendered responsibilities of household work and caregiving (Walker, 1999) were not exceptional for Jung and her family. This gendered role influenced Jung's self-blame for Jin-Su's language disorder. Jung had to study hard to obtain the registered nursing license in the United States although she had worked as a chief nurse in Korea for years. Working as a nurse would give her family not only financial stability but also legal eligibility to apply for permanent residency in the United States. However, she also viewed herself as the one who also needed to spend quality time with her children: "When a mom does not have much time and energy, she cannot focus on taking care of a child. I think that I have neglected taking care of Jin-Su and those things."

Jung also perceived that Jin-Su might have been confused and uncomfortable with the pressure to speak in English at his preschool. Jung and her husband spoke in Korean to Jin-Su at home. Jin-Su was expected to speak English at school. Jung did not agree with the educational opinion that most young children have a natural ability to acquire two languages without difficulty. It was upsetting for Jung that Jin-Su was tested with the language assessment developed for English-speaking children, which would not be a valid tool to judge Jin-Su in her opinion. Jung also attributed previous preschool teachers' negative reports about Jin-Su to their cultural insensitivity. Jung

perceived that teachers' selective attention toward boys from other nations (Burt, 1993) was part of reason why Jin-Su had received the referral to Early Intervention. Within this cultural explanation, Jin-Su's diagnosis would be beyond an individual's control. In this sense, the existing social structure and culture interact with an individual's characteristics (Bronfenbrenner, 1979; Walker, 1985).

Regardless of her existing resources (b), Jung perceived that the stressor (a) was a crisis (x) that required her immediate attention. At the time of the interview, Jung was juggling her work and her responsibility for taking care of Jin-Su. Demands were starting to show, but they had not yet piled up. This case clearly illustrated that adaptation is a chronological process followed by the determination of a crisis (McCubbin & Patterson, 1983a).

The fourth mother: Mi-Hwa. Mi-Hwa was energetic and animated during the interview, reflecting her long-time professional career as a preschool teacher. This Korean American mother came to the United States 12 years ago at her parents' invitation. Mi-Hwa's family structure was different from the other participants in the study. She separated from her husband when her only son was 18 months old. Chul-Hee was 10 years old at the time of the interview. Since then, Mi-Hwa had not contacted her ex-husband. She lived with her parents in Los Angeles, California. Another difference was that she did not perceive her situation as a definite crisis (x) for several years. The degree of crisis was less than that of the other mothers in the study due to several reasons.

Mi-Hwa had not encountered any child with autism in her 20 year professional career as a preschool teacher. Mi-Hwa and her parents had thought that Chul-Hee was a late bloomer just like many other boys. Chul-Hee's mild condition explained this misperception. Chul-Hee did not exhibit any sign of aggressive or hyperactive behaviors. His age inappropriate language development and lack of social interaction with other children (Mauk, Reber, & Batshaw, 1997) suggested a possibility of autism during his repeated kindergarten year. After various assessments, Chul-Hee was diagnosed with autism when he was six years old. It was a late diagnosis (a stressor), considering that most children with autism are identified when they are two or three years old (Mauk, Reber, & Batshaw, 1997). Due to Chul-Hee's mild condition and no sign of behavioral problems, Mi-Hwa appeared to be less distressed psychologically and physically than mothers of children with severe externalizing behavioral problems (Floyd & Gallagher, 1997; Haveman, et al., 1997). However, the ambiguity of his disability and his typical appearance (Bristol & Schopler, 1984) made Mi-Hwa feel disappointment in her only son.

Mi-Hwa's existing resources (b) were limited due by her marital status. Being a single mother of a child with a disability prohibited her from receiving emotional support from a spouse (Marcenko & Meyers, 1991; Suarez & Baker, 1997). Not only was Mi-Hwa responsible for taking care of Chul-Hee but she also had had to work full-time for her son and herself until a year ago. She had been unable to quit her job immediately when she learned of her son's disability. This situation is similar to that of other single mothers of children with disabilities who tend to work outside the home

due to their economic difficulties (Schilling, et al., 1986). However, Mi-Hwa had several protective factors that prohibited the stressor (a) from immediately turning into a crisis (x). First, she received social support from her extended family members. Mi-Hwa's utilization of social support was similar to that reported by Floyd and Gallagher's study (1997): Single mothers used more social support than married mothers. Mi-Hwa co-resided and maintained a very close relationship with her parents. This relationship helped her to utilize emotional and practical support from other relatives such as her own siblings, nieces, and nephews. These existing resources (b) interacted with Mi-Hwa's perception of the situation (a).

Mi-Hwa optimistically perceived (c) the stressor of having a child with autism. This was due to her professional background as a teacher believing in education as well as her strong religious faith. Mi-Hwa believed that her child could be educated like typically developing children. The positive role of religion (Marshall, et. al., 2003; Rogers-Dulan, 1998; Weisner, Beizer, & Stolze, 1991) also helped Mi-Hwa to emphasize hopeful sides of Chul-Hee's condition and develop her personal strength. Mi-Hwa's optimistic view of the situation did not stop with herself. It interacted with her existing resources (b) and protected the stressor from instantly shifting to a crisis:

Mi-Hwa: When I was telling this [Chul-Hee's diagnosis] to my parents and relatives, my attitude was not pessimistic at all. I was very optimistic. My relatives, of course, they were sad. After my relatives saw me, they believed that he would grow up well, very optimistically.

Interviewer: What made you feel so optimistic?

Mi-Hwa: Because...maybe because I have faith. It's weird to say that. Most of all, I have faith that God guides me to take good care of Chul-Hee. I have a belief that Jesus will be a special teacher for him. Actually there are many

teachers in my extended family, most of them. They all do good things and support me very much. So I am very optimistic.

Strong religious beliefs guided Mi-Hwa to feel optimistic about the situation. Mi-Hwa's optimism led her extended family members to view Chul-Hee's diagnosis positively and to provide support for Mi-Hwa. This interaction between Mi-Hwa's own perception (c) and resources (b) positively reinforced each other.

Considering this protective interaction, Mi-Hwa's daily life did not change drastically until she read a book about a Korean father of a child with autism. She realized that she should be actively involved in Chul-Hee's special education. This made Mi-Hwa re-evaluate her situation and perceive it as a crisis (x). She recognized her situational needs later. The transition from the stressful event to the crisis took almost three years. Raising a child with a disability is a life-long commitment (Blaska, 1998; Turnbull, 1988) with constant ups and downs. Mi-Hwa could not attend any of the parent support group meetings and Chul-Hee's school events. Physically worn out from her demanding work, she was consequently not able to spend her time and energy with her only son. It was a gradual transition from the stressor to the crisis for Mi-Hwa.

The crisis (x) forced Mi-Hwa to quit her job, which relieved the physical burden of her work but added economic difficulties. Living on \$600/month provided by Supplemental Security Income (SSI) was financially challenging for this family. Then Mi-Hwa's father became very ill, and she had to take care of him. Demands began to pile up (aA). Mi-Hwa's personal and family resources (bB) were similar to those during the pre-crisis period. Mi-Hwa's strong religious beliefs, optimistic

personality, and professional background in education helped her cope. Her extended family members continuously supported her practically, for example, by attending meetings with professionals and by providing translations, as well as emotionally. After Mi-Hwa quit her full time job, she was able to attend several parent support meetings organized by the regional center and Korean religious groups in Los Angeles. Those meetings offered her emotional support and informational support from other parents of children with disabilities (Ainbinder, et al., 1998; Santelli, Turnbull, Marquis, & Lerner, 1997; Santelli, Turnbull, & Higgins, 1997). Social networks such as extended family members and parent support groups, were available and support from those social networks helped Mi-Hwa to manage her situation effectively (McCubbin & Patterson, 1983a).

This Korean American mother's subjective definition of the situation (cC) interacted with resources (bB). Mi-Hwa perceived her own strength to deal with this situation drawn from her religious beliefs, similar to religious parents in other studies (Marshall, et. al., 2003; Rogers-Dulan, 1998; Tarakeshwar & Pargament, 2001; Weisner, Beizer, & Stolze, 1991). Meeting this challenge was an empowering experience (Traustadottir, 1991) and a humbling experience. She had to be courageous to locate resources and advocate for Chul-Hee's needs. At the same time, Mi-Hwa began to recognize other people who were in difficult situations.

Mi-Hwa reached *bonadaptation* (e.g., successful adaptation, xX) of the crisis of having a child with autism. Although the piled-up demands (aA) did not entirely disappear, she utilized various resources within and beyond herself. Positive

interaction between the resources (bB) and perception (cC) of the situation influenced Mi-Hwa's successful adaptation (xX).

The fifth mother: Hyun-Ja. Hyun-Ja was the mother of a seven-year-old boy, Ki-Chul. This family lives in Los Angeles. She came to the United States 17 years ago at her father's invitation and married her husband 10 years ago. The initial phone conversation with Hyun-Ja indicated that she was stressed by the various care demands related to Ki-Chul, who was diagnosed with autism three and a half years ago.

In Hyun-Ja's case, the stressful event (a) of the formal diagnosis of Ki-Chul's disability rapidly turned into a crisis (x). Ki-Chul's condition explained this. Ki-Chul's typical appearance and some high-functioning behaviors delayed the diagnosis of autism. Just as other mothers of children with autism experienced difficulties with accepting the diagnosis due to the ambiguity of the disability (Bristol & Schopler, 1984), Hyun-Ja could not accept the diagnosis at first (c), but the diagnosis of autism was the only logical explanation for Ki-Chul's strange behaviors. According to Hyun-Ja, Ki-Chul memorized the alphabet and numbers when he was two and a half years old. Ki-Chul was very good at puzzles and using computers. However, Ki-Chul showed age inappropriateness in his language development and social interaction. He was aggressive, restless, and hyperactive, which made Hyun-Ja physically very tired. Hyun-Ja reported that she was stressed psychologically due to Ki-Chul's externalizing behaviors. Other studies also confirmed a positive relationship between the mothers' stress level and problematic behaviors (Floyd & Gallagher, 1997; Haveman, et al.,

1997). Hyun-Ja made personal attribution to the diagnosis (Garwick, et al., 1999) recollecting her difficult pregnancy.

Hyun-Ja's existing resources (b) were limited. Hyun-Ja viewed her husband as a supporter as did other mothers of children with disabilities who reported spousal support (Marcenko & Meyers, 1991; Singer, et al., 1996). However, practical caregiving for Ki-Chul was her responsibility. She was the final decision maker on matters of the children's education (Traustadottir, 1991), and she implemented those decisions. Clear role agreement in the family (McCubbin & Patterson, 1983a) did not protect her in the event of having a child with autism. The diagnosis rapidly turned into a crisis (x). Hyun-Ja's extended family members' reaction to the situation made her feel less supported. Other factors (e.g., Ki-Chul's externalizing behaviors, care demands, and perception of the situation) strongly led the stressor to a crisis.

Care demands related to Ki-Chul's special needs have not decreased over the years. From a life perspective of caring for a child with a disability (Blaska, 1998; Havemen, et al., 1997; Turnbull, 1988), Hyun-Ja had just started her life-long journey of taking care of her son with autism. Demands began piling up (aA). Although Hyun-Ja did not have much difficulty conversing in English, she had to learn English words for the medical and educational terms related to Ki-Chul's special needs. Hyun-Ja also became pregnant with her second child. This pregnancy of the second child was particularly difficult due to Ki-Chul's increasing hyperactive and restless behaviors. Having another child was considered a normative transition, but it added extra demands.

Hyun-Ja's personal, familiar, and social resources (bB) interacted with her perception (cC) of the situation and coping process. She reportedly did not receive much emotional and practical support from her extended family members. However, her strong self-esteem and sense of family cohesiveness helped her integrate other resources (McCubbin & Patterson, 1983a). Hyun-Ja's extroverted personality helped her to advocate for her son's needs. Her strong religious beliefs were another significant factor. Hyun-Ja perceived that her husband was supportive of her emotionally (Marcenko & Meyers, 1991; Singer, et al., 1996). Her husband also helped her practically. He often provided care for the children while Hyun-Ja attended support group meetings. Shared understanding of care demands in the family reduced Hyun-Ja's stress. Hyun-Ja began attending parent support meetings organized by the regional center and Korean religious groups. The meetings with other mothers of children with disabilities gave her useful information (Ainbinder, et al., 1998; Santelli, Turnbull, Marquis, & Lerner, 1997; Santelli, Turnbull, & Higgins, 1997) related to Ki-Chul's condition. These resources (bB) interacted with Hyun-Ja's subjective definition of the situation (cC).

Hyun-Ja gradually understood that various therapies might help Ki-Chul. Hyun-Ja's strong religious beliefs and information from parent support groups helped her to see hope in Ki-Chul's future. Ki-Chul's hyperactive and careless behaviors still required Hyun-Ja's constant attention, but Hyun-Ja considered future medical treatments that might reduce such behaviors. Hope was a significant protective factor (Horton & Wallander, 2001). Hyun-Ja and her family began to adapt (xX) through

various resources and their positive interpretation of the situation. She did not reach *bonadaptation* yet, juggling many obstacles and protective factors, but she was moving toward the positive end of the continuum.

Case study summary. Each mother's adaptive process was analyzed above with the Double ABCX model (McCubbin & Patterson, 1983a, 1983b), pertaining to the event of having a child with a disability. Discovering a child's disability or receiving a formal diagnosis was considered as the initial stressor (a). The stressor (a) interacted with the mother's existing resources (b) that shaped her ability to make the transition into life with her child with a disability. The mother's existing resources (b) interacted with her subjective definition of the event (c). The interactions among the components determined the transition of a stressor into a crisis (x). In the post-crisis, demands of taking care of the child with disability piled up (aA), and other challenges emerged. These piled-up demands interacted with resources (bB): (a) personal resources, (b) family system resources, and (c) social support. A mother's perception (cC) of piled-up demands and resources and the interactions among these components determined her successful adaptation.

Adaptation was process (Montgomery, 1982), in which everyone had different demands, resources, and perceptions. As their children's needs were various, mothers' care demands varied. Immigrant status was shared by all five mothers, but their utilization of personal, familiar, and social support was unique to their circumstance and history. The positive role of religion was strongly supported by four of the five

mothers. The interactions among different components of the Double ABCX model were evident, supporting the complexity of the adaptive process.

### *Caring for the Family's Cohesiveness*

Mothers' subjective burdens of care. Mothering is not an easy task in general, but for these five mothers, taking care of a child with disabilities requires special attention to the child's unique characteristics. All five mothers had to learn about their children's special needs through reading related books and asking specialists. As previous literature indicated (Floyd & Gallagher, 1997; Haveman, et al., 1997), behavior problems of children with disabilities increased several mothers' stress and their care demands. Certain caring styles were required for each child's unique characteristics and disability. Young-Mi had to focus her whole attention on her son, Chan-Ho, who recently had become very aggressive: "Caring for Chan-Ho is like caring for five children all together. Even more." Another parent, Hyun-Ja, had to monitor her son's hyperactive behaviors whenever the family left home. Kyung-Hee had to clean her teenage daughter Hae-Jin's diapers far beyond the early childhood years. At the time of the interview, Kyung-Hee was trying to teach Hae-Jin not to throw her hearing aids away. These three mothers provided detailed examples of their challenges in caring for their children with special needs. The physical strains of mothering did not seem to ease as their children grew older.

Hyun-Ja remembered her frustration with her lack of information about how to care for Ki-Chul:

I was frustrated at not knowing what to do, not because how I was going to accept this situation, but because I wanted to do things in the right way to help him. How was I going to do things right and practical things for him without wasting time?

Hyun-Ja needed to learn about autism and the specific characteristics within the autism spectrum that pertained to her son, Ki-Chul. She also had to constantly monitor her son's hyperactive and restless behaviors. Learning about autism was emotionally difficult for Hyun-Ja: "I didn't study about this... At first I didn't even want to hear the word, 'autism.' I hated it so much. In those books, there are so many things that my child fits into so I hated it." Young-Mi had a similar experience when she found out about her son's disability and did not know what to do.

Some mothers even questioned their parenting styles. They had to find answers from everyday interactions with their children. Jung was puzzled: "I can't really push him, but at the same time, I cannot just let him be like this either." She was not sure whether to speak in Korean or English to her son, Jin-Su, who was diagnosed with a language disorder. Another mother, Kyung-Hee expressed the fear that she might be too protective, blocking opportunities for her daughter, Hae-Jin. As the children with disabilities grew older, some mothers reported that they became less stressed psychologically. However, their physical burdens seemed to grow. Both Young-Mi and Kyung-Hee expressed how physically demanding it was to care for teenage children with special needs.

Mother as a front-runner. All participants interpreted the role of the mother in the family as managing the details of the children's education. These mothers

perceived that caring for their children with disabilities was their primary responsibility on top of other household demands. These five women lived in traditional families where they were primarily responsible for both domestic labor and child rearing. These mothers were the “front-runners,” physically involved with making family decisions and implementing them everyday. Three out of four married mothers perceived their husbands primarily as the “listeners” or “supporters” for the children’s education, similar to other fathers of children with disabilities (Traustadottir, 1991). Hyun-Ja described her husband’s role and her own:

Often, I don’t have anyone with whom I can talk about things other than my husband. So I tell my husband most things: What happened today, Ki-Chul [child with autism] did something to me, and I was very frustrated... Definitely, I tell him those things. If I don’t tell my husband those things, I will get stressed. My husband doesn’t give much practical help any way other than he listens to me. He will take care of Ki-Chul from time to time or take him to buy some yummy foods... but all the things related to education, I have to do them.

Jung saw taking care of the children’s education as her major responsibility although she was also working as a major breadwinner in the family. Kyung-Hee complained about her husband’s lack of educational involvement due to his demanding business. Mi-Hwa did not inform her ex-husband of her son’s disability after divorce. It was her responsibility to take care of the child with autism. Regardless of their marital status, these mothers perceived themselves as a “front-runner,” caring for a child with a disability and other household work.

Mother's perception of family cohesiveness. All mothers perceived that their family had the picture of "happy family" in their minds. Family cohesiveness was a tool to live successfully with a child who has a disability. The family's cohesiveness was also an ultimate goal for these mothers to achieve. In order to do so, a few mothers had to overcome some challenges related to other family members' reactions toward a child's disability. Both Young-Mi and Kyung-Hee, each married for over a decade, looked back over their marriages and realized how strong their marital relationships had developed throughout the years. They noticed that when the family had strong cohesive values, beliefs, and goals, the adversity of having a child with disabilities turned into an opportunity for a stronger and closer relationship among the family members. It seemed to be possible to reach a cohesive state through understanding the situation of having a child with a disability (Turnbull & Turnbull, 1997). Their status as immigrants strengthened their marital ties. Three mothers who did not have their own family members in the United States particularly mentioned how much they trusted their husbands and relied on them for emotional support. Jung described her relationship with her husband:

I don't have anyone here... I tell him everything regardless of how many mistakes I have made. And my husband tells me everything, too. The only way my family will survive here is to focus on the reality in order to overcome this situation.

Jung's perceived that she and her husband mutually supported each other, which would help them to go through difficulties emerging every day. Spousal emotional support was reported in other literature (Marcenko & Meyers, 1991; Singer, et al., 1996).

Spousal support was important for the married mothers to perceive their family's cohesiveness.

A few mothers also described the importance of other family members' cooperation in living with a child with a disability. They perceived that some adjustments were necessary to sustain or create their family's cohesiveness. Young-Mi promoted the idea of taking their whole family vacationing in the winter:

We even take vacation during winter. So-Eun and Byung-Ho [children without disabilities] don't go to school for a week. Studying is important, but one week is not so important... This summer I will take younger ones [So-Eun and Byung-Ho] to Hawaii because Chan-Ho [child with autism] cannot have such a long vacation, so Chan-Ho will be with his father at home. Like this, there are lots of adjustments to make... Winter is a low vacation season... so in order to avoid crowds and difficulties with flights and things like that, we go on vacation during winter. We also need to set every detail of vacation plans.

Young-Mi commented that having fun as a family was an important tool to maintain her family's unity. Shared understanding of the needs of a child with a disability among other family members was a powerful resource helping Young-Mi's adaptation.

Many of the mothers perceived that a child with a disability also influenced the lives of typically growing siblings. Sometimes siblings without disabilities shared in the responsibilities of taking care of the other child who needed extra attention. Kyung-Hee's oldest daughter had to take care of her younger sister with multiple disabilities while Kyung-Hee was away from home. Jin-Young, Jung's oldest daughter, was asked to be a proper model for the younger brother's English acquisition. Both Kyung-Hee and Young-Mi expressed feelings of sorrow for the extra

responsibilities of the typically growing siblings. However, they perceived that without the understanding and cooperation of their children without special needs, family life could not run smoothly.

### *Needs for Social and Professional Support*

Extended family members. Geographical distance led several mothers to feel limited support from their extended family members. Such relationships were closely related to the participants' immigration histories. If these mothers had come to the United States by themselves, their close relatives usually remained in Korea. Although these participants exchanged phone calls with their extended family members regularly, the phone conversations were inadequate to describe the reality of their situations. When the extended family members had limited knowledge about the disability or the child's condition, it was especially hard for the mother to feel connected, even with her own parents. Kyung-Hee recollected her mother's responses:

My mother even thinks that we need to institutionalize Hae-Jin considering her typically growing siblings. She says that parents shouldn't live hung up by their children... My parents were so upset and frustrated when they saw Hae-Jin. They don't want to come here anymore. I cannot take her to Korea, either... [I don't call them often.] Not really. It just hurts my feelings.

Lack of emotional support from the extended family members was present in the interviews with two other mothers. Hyun-Ja did not perceive much support from her mother in Korea: "She knows, but my mom and I have been apart for a long time... and it didn't seem to be a big deal that her grandson has autism." Hyun-Ja did not think that her other relatives truly understood her situation:

Although they are relatives, it's not a matter of their child so they don't seem to care much... We don't see each other very often. When there is a family gathering or birthday or mother in law's birthday... we meet on those occasions. Sometimes we go to my brother in law's place, but Ki-Chul has a hard time staying calm there. He touches everything. Then my brother-in-law's family doesn't like those things. So I don't go there much because it hurts my self-esteem. I take him to other places a lot, but taking him to the relatives is not so easy because they don't seem to really understand us. They are a little bit critical.

One mother mentioned support from relatives other than the children's grandparents. Because Mi-Hwa lived with her parents, she was also able to maintain close relationships with other relatives. Mi-Hwa's niece, who was a middle school teacher, had been attending the IEP meetings with Mi-Hwa to provide both translation and emotional support:

I went to the IEP meeting with her last time... It was much better. More support... So school people listened to things my niece said... With doctors, whenever I went to see them, I went with my nieces or nephews.

Ever since Mi-Hwa divorced her husband, she had lived with her parents in the same household. Mi-Hwa's parents had witnessed what Mi-Hwa was going through and supported her and her son emotionally, physically, and financially. It was also much easier for Mi-Hwa to communicate honestly with her parents about the situation than for the mothers whose parents remained in Korea.

Parent support groups. Differences between social support agents were noticed between the mothers living in Oregon and those living in California where there were many more families of Korean descent. The mothers from Los Angeles were involved

in Korean parent support groups, while the mothers from Oregon were not. Mi-Hwa and Hyun-Ja from Los Angeles said that these Korean parent support meetings provided enormous emotional and informational support for them. Those meetings became the central place to talk with other mothers of children with disabilities. Meeting with other Korean mothers who were in similar situations through the Korean parent support groups helped Mi-Hwa and Hyun-Ja.

There were three major organizations serving Korean parents of children with disabilities in Los Angeles, according to Mi-Hwa and Hyun-Ja. The programs of these organizations varied from parents' prayer meetings to family potlucks, discussion groups, seminars, summer camps, Saturday classes for children, and annual festivals. The Han-Ma-Um parent support group was arranged through the regional center so that any Korean parents of children who were receiving special education services could attend for extra support. Another organization was the Mil-AI Missionary Foundation, which provided the "class of love" every Saturday for children with special needs. While children were participating in various educational activities taught by voluntary teachers and special education teachers, parents congregated for religious services. The Shalom Center, particularly, served all age groups of Korean people with disabilities within the Christian church. These three organizations' major features were summarized in the interviews with Mi-Hwa and Hyun-Ja who regularly participated in the meetings. Hyun-Ja described her experiences from these meetings:

I have been going to the meetings all the time not even skipping once. I wondered a lot at first what I could get from these meetings. I get tips from any meeting I attend. Sometimes I ask them questions that I am wondering

about. Sometimes I can find out answers through seminars or lectures without knowing. So I always attend the seminars.

Mi-Hwa became able to attend these sessions after she quit her job. She gained not only additional knowledge about various services but also emotional support from other Korean mothers who were in similar situations:

It is great. I am very grateful because we can share something in common together... It's great! I love it. I can share with other mothers, and we can give support to each other. For example, there are many programs providing services. There are mothers who know a lot about some special programs. There are some mothers who have gone after those special services since their children were little. I received a lot of help from those mothers. I learned a lot from those mothers about special programs... Basically we give comforts to each other and pray for each other. It has been great! Those meetings have been great! And I can talk about things in detail with the mothers and share things with them so I like it a lot. We not only share information about practical services but also we share our sorrows from our heart.

These meetings also allowed Mi-Hwa and Hyun-Ja to form social support networks with other mothers who had children with disabilities.

Considering all of the comments, the large Korean community in southern California interacted with the needs of these mothers who had children with disabilities. These parent support groups also allowed the mothers to construct social support networks, which provided emotional and informational help. The sparser population of Korean American families in Oregon left the mothers of children with disabilities with a feeling of isolation. The three mothers from Oregon in this study did not attend any particular parent support groups, which might have limited their social networks.

Professional support. Many of the mothers showed some degree of satisfaction for and appreciation toward the various supports their children had received: speech therapy, occupational therapy, behavior modification sessions, free public education, and medical services. These mothers perceived that they needed to advocate for their children in order to receive appropriate services from professionals. Partnership between a mother and professionals (Turnbull & Turnbull, 1997) required a mother's active involvement in her child's special education. After the years of unsatisfactory services from special education, Kyung-Hee finally realized that she should have advocated for her child's needs to professionals. She hired an advocate to request appropriate services for her daughter Hae-Jin's special needs. Continuous advocacy was necessary. Young-Mi asked the school several times to provide an educational assistant for her son, Chan-Ho.

A few mothers pointed out needs for timely, reliable responses from the professionals. Late responses from Special Education or Early Intervention made the mothers feel anxious and irritated. Jung's experience was as follows:

Their [Early Intervention] responses are somewhat late... you have to wait for a week when you leave a message. Of course, they are busy but how they do [late responses] doesn't really go along with mom's concern... It's okay to arrange meetings later but they should respond fast so that I won't worry about it.

Jung's concerns about her son were mounting while waiting for the early interventionist's response. Another mother, Young-Mi, took action: "I need to follow

up rather than waiting for them [Special Education] to call me back... their responses are usually late.”

The need for a qualified translator who is bilingual and also knows about Special Education was discussed. This has often been addressed in other studies as well (Cho, Singer, & Brenner, 2000; Park & Turnbull, 2001; Smith & Ryan, 1987). Kyung-Hee relied on translations from her husband, who lacked knowledge about education. Hyun-Ja from California was frustrated with a translator who did not know much about Special Education. Mi-Hwa attended the meetings with her niece, a middle school teacher who is bilingual and knows about Special Education.

#### *Positive Transformation in Life through Religion*

Religion as personal resource for adaptation. Other studies of Korean Americans (Chan, 1992; Cho, Singer & Brenner, 2000; Hurh & Kim, 1990) reported that 70 % of Korean Americans were affiliated with Christian churches. All five mothers in this study were affiliated with a local Korean ethnic church. The positive role of religion (Marshall, et. al., 2003; Rogers-Dulan, 1998; Tarakeshwar & Pargament, 2001; Weisner, Beizer, & Stolze, 1991) was prevalent among four mothers in this study. Most mothers had been raised in Christian families except Jung who started attending church after moving to the United States.

Strong religious belief was also a personal resource that helped the mothers perceive their situation positively and manageably. Support from religion was distinguished from emotional or practical support from other church members and church organizations. Many of the mothers in the current study shared their religious

perspectives of the situation. Strong religious beliefs guided these mothers to be able to accept their crisis and adapt to it as described previously. Four mothers perceived that their strong religious faith was a significant factor in helping them to accept the current situation and move on to the next level. Religious belief was a powerful cognitive coping strategy. Hyun-Ja's initial reaction to her son's diagnosis was filled with doubts and frustration:

I thought I didn't have any hope. It was really difficult because my child has this condition. But I prayed to God and cried a lot. God, what can I do? Why... I am not able to... It's kind of... I cannot really take this, God! I am not a great parent. How am I going to raise this child?

Hyun-Ja's question, "How am I going to raise this child?" was to God, but also to herself. This kind of conversational inquiry process was a part of a cognitive strategy that allowed her to follow constructive steps. Hyun-Ja found an answer through her spiritual beliefs: "I can just let God take care of everything and pray. That comforts me quite a bit."

Mi-Hwa explained that her optimistic attitude was derived from her faith. In her beliefs, Jesus was the special education teacher guiding and teaching her son with autism. Young-Mi also showed strong religious belief throughout the conversation: "God created him [Chan-Ho with autism] and sent him to this world. I believe the Creator strongly. Although Chan-Ho was born from me, I believe he is ultimately God's child." Young-Mi attributed her total reliance on God as the only sensible choice that she could make for her son: "Personally, religion was the factor because there is no particular treatment... I don't lose the belief that someone will find a

treatment for autism someday.” These statements illustrate that these mothers received emotional support from relying on their religious beliefs. Strong religious beliefs were their personal resources, which positively influenced their hopeful perspectives of the situations.

Having a child with a disability was a spiritual experience for four mothers in this study. The mothers’ children with special needs made their connection with God close and strong. Several anecdotes illustrated how difficult situations became testimonies of God’s love. Kyung-Hee thought that God listened to her prayers and made her daughter, Hae-Jin, become toilet-trained. When Young-Mi was hospitalized with her unknown illness, she desperately asked God for an explanation of her son Chan-Ho’s diagnosis and cried for help from God. She realized that her son was God’s creation not her own. This spiritual experience was viewed as God’s calling, not as a punishment. Religious beliefs assisted these mothers’ cognitive coping with the situation of having a child with a disability. In turn, raising a child with a disability helped these mothers’ religious beliefs become stronger than before.

Humbling but also empowering. Three mothers with strong religious beliefs discussed how humbling the experience of having a child with a disability was. Becoming humble was possible through this nonnormative life event of raising a child with a disability. When these mothers abandoned their high expectations for their children with disabilities, they began seeing others’ difficulties and sorrows. Having a child with a disability was a special lens that allowed these mothers to be able to see things they had not previously seen. This experience also increased their understanding

of others who were going through difficulties in life. Raising a child with multiple disabilities changed Kyung-Hee's perspectives of others:

Our lives have been changed through Hae-Jin from just living for myself to looking after others around us. I looked down on people who were not like me. I pretended to be humble. You know when you look at each individual's life and home, there are always some problems and difficulties. Now living every day through sharing with other people...I think that is love. If you don't have hardships, you don't understand others.

Hyun-Ja described her experience:

I think I have become more humble. I reflect on myself...I didn't like to talk about these kinds of things with anyone. I didn't like it, but now I can talk about it. There were lots of embarrassing moments, but I can bear them now. I am thinking about how to overcome those moments more wisely.

Mi-Hwa also felt that having a child with a disability made her humble, consciously accepting her child's shortcomings and looking after other people. Humbling oneself was highly recognized in the Bible: "Humble yourself before the Lord, and he will lift you up" (James 4:10): "Be completely humble and gentle: be patient, bearing with one another in love :(Ephesians, 4:2): "Finally, all of you live in harmony with one another: be sympathetic, love as brothers, be compassionate and humble" (1 Peter, 3:8). The ideology of Christianity (i.e., Jesus, the Son of God, came down to the human world to sacrifice himself for human beings) was related to these mothers' interpretation of their own experiences. Being humble and understanding others allowed them to be in a morally higher place.

All five mothers mentioned that they became courageous and brave through the experience of having a child with disabilities. These mothers needed to be courageous

to take charge of caring for their children with disabilities. Hartshorne (2002) proposed parents' courage as a key protective factor. All five of these mothers felt that they had to be brave. Young-Mi described that she needed to be stronger physically and mentally in order to survive with her son with autism. Many of the mothers perceived that their strong religious beliefs encouraged them and gave them strength to continue their journey with their children with disabilities.

### *Chapter Summary*

Most mothers perceived that they positively transformed their lives of raising a child with a disability through their strong religious faith. Their religious beliefs were personal cognitive resources that interacted with their personal definitions of the situation. The analysis of these mothers' adaptation process with the Double ABCX model (McCubbin & Patterson, 1983a, 1983b) illustrated adaptation as process (Montgomery, 1982). An individual's adaptation process interacted with her resources and perception of a stressor or piled-up demands. Every mother had her own pace, resources, and strategies. Most of the mothers cared for their children with disabilities in order to achieve family cohesiveness. Both society and the Korean American mothers considered care demands to be the mothers' responsibilities. Several married mothers appreciated their husbands' emotional support, which was highly related to compromised lack of support from their social networks. Social and professional support was needed for these Korean American mothers of children with disabilities to continue their successful adaptation.

## CHAPTER 5

## DISCUSSION

Discovering a child's disability is a stressor, which requires individual family members' attention and adjustment within the social interpretation of a disability. A mother, as a major caregiver of a child with a disability, utilizes her existing resources, which interact with her own definition of the stressor. A mother's adaptation process occurs within a sociocultural frame in which caregiving is often assumed as the mother's responsibility. Failure to create positive meaning from the situation turns the stressor into a crisis that requires on-going adjustment. As various demands pile up, the mother's personal, familiar, and social support intervenes and interacts with her subjective interpretation of the piled-up demands. Tension and balance among these components will determine the mother's adaptation within a range of *bonadaptation* to *maladaptation*.

This qualitative study explored the adaptation processes of five Korean American mothers of children with disabilities. These mothers' lives had some commonalities in that they all emigrated from Korea to the United States and they all have children with disabilities. Their stories helped readers understand Korean immigrants' experiences of raising children with disabilities. Three mothers were recruited from Oregon, which is relatively ethnically homogenous, while the other two were from California, which is one of the most ethnically diverse states in the nation. These mothers' differing adaptation processes provided answers to the current research questions.

This study examined the questions: (a) How do Korean American mothers of children with disabilities cope with their situation? (b) How do they perceive their own adaptation and other family members' adaptation? (c) How do they interpret social and professional support? Using the Double ABCX model (McCubbin & Patterson, 1983a, 1983b), the individual mother's adaptation processes were analyzed. These mothers' stories created coherent overarching themes: (a) positive transformation in life through religion, (b) caring for family cohesiveness, and (c) needs for social and professional support.

#### *Summary of Findings*

The adaptation process of each mother was analyzed based on the Double ABCX model by McCubbin and Patterson (1983a, 1983b). Adaptation is a process (Montgomery, 1982), in which each mother had different demands, resources, and perceptions. As their children's disabilities varied, mothers' care demands also differed. Their utilizations of personal, familiar, and social supports were unique to their individualized circumstances and histories. The strong religious faith of four of the mothers played a large role as their personal resources, which shaped their subjective meaning of the situation. Some successfully adapted to having a child with a disability, and others were working in that direction.

Young-Mi, the mother of an adolescent boy with autism, perceived that her subjective interpretation of the situation was positively transformed through her strong religious beliefs. Although her son's condition required constant attention and adjustment, Young-Mi was able to manage those demands. Kyung-Hee, the mother of

a daughter with multiple disabilities, also discovered a positive meaning for her situation through religious experience. Although she had limited social and professional support, Kyung-Hee's personal religious belief helped her to reflect on her own difficulties, which led her to be humble and understanding of others. Jung perceived her situation as a crisis that required every family member's immediate attention. Due to the recent diagnosis, Jung's adaptation after the post-crisis was not yet obtained. Mi-Hwa, mother of a child with autism, did not perceive her situation as a crisis until a few years after the diagnosis was made. Her strong religious beliefs and support from extended family members helped her to manage the stressor, but later she realized that she had to pay more attention to her only son. Mi-Hwa utilized her personal, familiar, and social supports and successfully adapted to her situation. Her strong religious belief was also a significant factor in this positive transformation. Hyun-Ja, also mother of a child with autism, was working toward positive adaptation. The child's externalizing behaviors added more demands to Hyun-Ja. However, Hyun-Ja's religious belief helped her to perceive the situation positively.

The religious faiths of four of the five mothers interacted with their subjective interpretations of having a child with a disability. Religious belief was a powerful cognitive coping strategy. It gave these mothers hope and an optimistic view of the situation. It made them feel brave and sufficiently courageous to take care of their children. It gave them strength to continue caring for their children. Four mothers perceived having a child with a disability as a spiritual experience. Three mothers also stated that having a child with a disability made them become humble and understand

others with difficulties. Positive transformation in their lives allowed these mothers to manage their challenging situation of mothering a child with a disability.

All five mothers perceived that caring for the child with a disability was their responsibility toward the goal of family cohesiveness. Care demands were related to a child's severity of disability and other circumstances of daily living. Most mothers were "front-runners," making and implementing decisions related to their children's education and household matters. These mothers interpreted their caring role as part of their family's well being. Three married women appreciated their husband's emotional support. Some mothers perceived that cooperation from their other children without disabilities was important to family cohesion.

Several mothers felt little emotional support from their extended family members who were abroad because these relatives lacked understanding of the situation. Being apart for a long time limited their emotional connection with their extended family members. Other mothers, who lived close to their relatives, perceived modest emotional or practical support. The two mothers from Los Angeles shared their positive experiences with Korean parent support groups. They perceived that the sameness of the parents' situations (disability and immigration) made participants comfortable and enabled them to exchange informational emotional support with each other. Several mothers in the study raised the importance of a case manager. Many of the mothers also pointed out that a translator should have basic knowledge about special education.

### *Theoretical Implications*

Double ABCX Model. In the ABCX family crisis model (Hill, 1949, 1958), A (the stressor event) interacts with B (the family's resources). Family resources also have an interaction with C (the family's interpretation of the event), which produces X (the crisis). The diagnosis of a disability was a stressor that could be classified as 'dismemberment' and/or 'loss of family unity' based on Hill's (1958) classification of four stressors in family life. Having a child with a disability was nonnormative and out of developmental transition for the five Korean American mothers in the present study. These mothers' resources (e.g., their families' coherence) interacted with their subjective meaning making for the event. All mothers perceived their situation as a crisis. Three mothers immediately reacted to the diagnosis and defined the event as a crisis. For one mother, transition from the stressor to a crisis took almost three years for her to perceive the intensity of her situation. These mothers' existing resources and the characteristics of their children's disabilities determined the urgency of transition from the stressor to a crisis. The mothers' values and previous experiences influenced construction of their subjective interpretation. The most significant factor was the mothers' perception of the situation.

McCubbin and Patterson (1982, 1983a, 1983b) expanded Hill's original ABCX model, adding post-crisis variables. The Double ABCX model (see Figure 1) illustrated how these five mothers reached adaptation. Adaptation was a process (Montgomery, 1982) in which most mothers were constantly utilizing their resources and influencing their perceptions. Except for one mother who just entered post-crisis, the other four mothers were moving forward to or in *bonadaptation*. Another crucial

point of this model was that the demands on the five mothers in the study were constantly piling up as the model described. New challenges emerged, as the children matured. These mothers' individual resources, family system resources, and social supports interacted with piled-up demands and their definition of demands. Strong religious belief was the most significant personal resource that these mothers utilized. Three mothers perceived their husbands as emotional supporters. Although there was limited social support from extended family members, parent support groups served as important resources. These mothers' subjective definitions of piled-up demands were a significant factor assisting them in coping with the various challenges of raising a child with a disability. These mothers' adaptation was on a continuum ranging from *bonadaptation* (positive) to *maladaptation* (negative). Where they were in the continuum at the time of the interview is not permanent. It is a part of a process that is consistently affected by new demands, resources, and perceptions of the situation.

As Patterson (2002) concluded that attribution of positive meaning to the situation is a central process for adaptation, many of the mothers gave special meaning to their situation of having a child with a disability. Applying this process to each mother's individual resilience, the data indicated three positive meanings: (a) about the event of having a child with a disability, (b) about family cohesiveness, and (c) about her worldview. Most of the mothers perceived that religious beliefs were the most significant factor in their coping, leading them to think positively of the event, family cohesiveness, and their worldview.

Family systems theory in special education. Family systems theory was adapted to explain the dynamics of families of children with disabilities (Turnbull & Turnbull, 1996, 1997). Discovering a child's disability was an input, and these mothers' adaptation to their challenging situations was the output. This study showed that a child with a disability influenced a mother and her perception of family cohesiveness. All mothers performed as major caregivers for their children with disabilities and other household work. Changes in their family routines were implemented by the mothers. These mothers perceived that those changes and negotiations were necessary to promote their family's cohesiveness. A few mothers acknowledged the impact of a child with a disability on her/ his typically developing siblings. An older sibling often shared the responsibilities of caring for a younger sibling who had disabilities. These stories illustrated that many of the mothers perceived the importance of pursuing family cohesiveness.

According to Turnbull and Turnbull (1997), *family characteristics* refer to the (a) *characteristics of the family*, (b) *personal characteristics*, and (c) *special challenges* (See Figure 3). Characteristics of the family (e.g., size, form, cultural background, geographical location, and socioeconomic status) influenced these five mothers' adaptation. As immigrants, many of the mothers were away from their parents or relatives, living in a mix of American and Korean cultures. Most Korean American mothers in the current study emphasized their family's collective values and cohesiveness. Other important characteristics of these mothers were their geographic location. Some were in a large Korean American community, and others

were in a smaller Korean American community. Characteristics of their child with a disability influenced these mothers' adaptation. Many of the mothers mentioned other challenges that emerged over the years of caring for a child with a disability (i.e., medical changes, work situation, other children without disabilities). This can be understood within the life cycle perspective of the family systems framework. Several mothers illustrated various empowering practices through implementing necessary changes. These efforts allowed the mothers to transform their negative *input* of having a child with disabilities into a manageable *output* of adapting to the situation.

Ecological theory. In this study, the mothers interacted with their environments in various ways. Bronfenbrenner's (1979) ecological theory describes how the human environment influences individuals and families (Figure 2). Many of the mothers had interactions with extended family members, school, church, parent support groups, special education systems, laws, and sociocultural contexts. These environments interacted with these mothers' adaptation process. Two mothers received and exchanged emotional and informational support with other mothers of children with disabilities through their social networks established through parent support groups. Their relatives who lived nearby helped the families emotionally, by praying for the child, and instrumentally, with occasional childcare or helping the mother with translation in IEP meetings. Three mothers did not receive much social support from their extended family members who lived abroad. Two mothers also perceived that their relatives did not understand or provide much emotional or practical support.

All mothers' affiliation with Korean ethnic churches supported the growth of their religious faith. As two mothers expressed, parent support groups were especially helpful in terms of emotional and informational support from interactions with other mothers with children with special needs. Considering the five stories, the interdependent relationships with various *meso- and exosystems* (Bronfenbrenner, 1979; 1997) were obvious in this study. The lives of these mothers were not independent from *macrosystems*, either. Special education law allowed the children with disabilities in this study to receive individualized education. Growing understanding of partnership and practices in special education also made many of the mothers become vocal about advocating for their situations. In the bigger picture of social and cultural context, understanding a disability as a deficit prevented some relatives from providing emotional support to several mothers. All mothers perceived themselves as the major caregiver for their children, a factor that reinforces and is reinforced by the social and cultural construction of caregiving responsibility and gender.

#### *Links Between the Literature and Research Findings*

As the findings of this study illustrate, a child with a disability provides a stressor requiring a parent's constant care and time. The characteristics of the children's disabilities and behaviors have an impact on parental stress and care demands (Dyson, 1993; Floyd & Gallagher, 1997; Haveman, et al., 1997; Seligman & Darling, 1997; Singer & Farkas, 1989). The mothers of children with severe disabilities expressed more difficulties with care demands than those of children with

less severe disabilities. Several mothers of children with aggressive or hyperactive behaviors constantly monitor their children's behaviors. Four children in the study were diagnosed with autism, and their mothers needed to deal with the ambiguity of this diagnosis. Several mothers of children with autism had a difficult time accepting their children's diagnosis due to their children's typical appearance and the presence of some age appropriate skills (Bristol & Schopler, 1984). Along with these psychological difficulties, a few mothers of children with autism experienced physical burdens due to certain behaviors related to autism (e.g., hyperactive, aggressive, and careless behaviors). As several mothers in the study expressed, language differences were strains for communicating with professionals (Cho, Singer, & Brenner, 1999; Park & Turnbull, 2000; Smith & Ryan, 1987).

Although all the mothers were in different states in their adaptation process, their challenges did not seem to decrease over time (Haveman, et al., 1997). All mothers played a significant role in responding to the care demands of their children with disabilities. Four married mothers provided care for their children with disabilities and did more household work than their husbands (Coltrane, 2000; Walker, 1999). As Traustadottir (1991) presented the mother as the final decision maker for matters of children with disabilities in the family, with the father being a supporter, four families in the study showed this pattern. These mothers perceived caregiving as their responsibility. Four out of the five mothers did not work outside the home (Porterfield, 2002).

Perception of the situation was an important factor that helped many of the

mothers to move toward a successful adaptation to having a child with a disability. Some had a coherent explanation of their child's disability (Garwick, et al, 1999). They had the ability to move beyond questioning why this happened to managing their children's needs. Maternal perception of mastery in caring responsibilities (Singer & Farkas, 1989, Traustadottir, 1991) was shown among many of the mothers. As Hartshorne (2002) proposed *courage* as a key protective factor, all of the mothers in the study mentioned that they became courageous through the experience of raising a child with a disability. Several mothers received emotional and informational support from their relatives or parent support groups (Heiman, 2002).

Perception of positive support from a spouse or a partner moderated maternal psychological distress in a study by Singer and others (1996). Three married mothers perceived that their husbands provided emotional support (Marcenko & Meyers, 1991). One single mother in the study was not more stressed than the married mothers partially because she received considerable social support from her relatives and parent support groups (Floyd & Gallagher, 1997). As a few mothers expressed, support from other parents in a similar situation was a powerful tool, providing emotional and information support (Ainbinder, et al., 1998; Santelli, Turnbull, Marquis, & Lerner, 1997; Santelli, Turnbull, & Higgins, 1997).

Personal religious beliefs comforted and strengthened many of the mothers in this study. According to Marshall and colleagues (2003), religion provided philosophical and spiritual meaning to the experience of rearing a child with a disability. These mothers saw their situations as opportunities for personal and

spiritual growth (Weisner, Beizer, & Stolze, 1991). Parental religiosity (religious beliefs) influenced the interpretation of the experiences. Four mothers' positive religious experiences influenced their adaptation to raising a child with a disability (Marshall, et. al., 2003; Rogers-Dulan, 1998; Tarakeshwar & Pargament, 2001). Just as Roman Catholic theology motivated Latino mothers to accept their children with disabilities (Skinner et al., 1999), in this study Christian ideology helped many of the Korean American mothers accept their situations and understand those of others.

#### *Limitations and Directions for Future Research*

Some studies using the grounded theory approach stop collecting data when the researchers no longer find variance from new information (Creswell, 1998). Small sample size might limit the scope of this study. The decision to end collecting new data was made when it was impossible to locate additional participants within a reasonable timeline. Four children had autism. One child had a language disorder. The nature of the disabilities might have influenced the results of this study. It is also important to acknowledge the criticism about the Double ABCX model's unit of analysis (Walker, 1985). The focus on analyzing individual case could prevent a researcher from anticipating social and historical contexts, which are interdependent with each other.

Another limitation emerged from the restricted interviews with one member of the family. Although the major caregivers of these children with special needs were the mothers in the current study, amplifying these mothers' perception of their family cohesiveness might not be the best way to capture the attitudes of the entire family.

Therefore, it should be acknowledged that the findings of the study were from the mothers' perspectives. This limitation prompts future research to consider including other members of the family in order to understand how fathers, siblings, and other family members perceive the situation of having a child with a disability. A longitudinal study on such families will provide an understanding of their adaptation with life span perspective. Future studies can also triangulate various forms of data such as informal notes between a mother and a therapist, formal documents, and family photos.

#### *Implications for Policies*

In this study, many of the mothers addressed their needs for a qualified translator who also knows about Special Education. A novice translator can be educated through a training class or program that teaches the essentials of special education. Prior to the Individualized Educational Program (IEP) meeting, informational brochures about special education or relevant disabilities should be delivered to an individual who is providing translation for the family who has a child with disabilities. This kind of training for a novice translator will be very helpful for establishing successful communication between the parents and specialists.

Special education providers must be aware of various social support organizations in the community and connect mothers with them. Especially when a mother is an immigrant, the social support organizations from her own ethnic group might be the most helpful. Special education providers must introduce various options to her. However, it is the mothers' decision whether or not to participate in those

groups. Other kinds of programs, such as Internet support group, should be considered for mothers in less diverse communities, where ethnic parent support groups are not possible.

Culturally and developmentally appropriate special education must begin by acknowledging each individual family's stories and developing a relationship between specialists and major caregivers (Barrera, Corso, & Macpherson, 2003). The findings reported here must be interpreted within the lives of these five Korean American mothers. Nevertheless, this study suggests useful questions and qualitative frames that researchers and professionals can adapt to their own practice. Special education providers must find their own answers from the mothers and children with whom they work.

Many of the mothers in this study focused on and cultivated their own abilities of raising a child with a disability through their religious beliefs. The Chinese character for the word "crisis (危機)" is composed of two words: "danger (危)" and "opportunity (機)" (Walsh, 1998). Whether a mother chooses to interpret the "crisis" as "danger" or "opportunity" will influence her adaptation to a stressor. Having a child with a disability can be turned into an opportunity for a mother's personal and spiritual growth. According to the mothers interviewed here, this opportunity can also be a channel for a mother to reevaluate her own perspective of family cohesiveness. Professionals must encourage mothers to establish a positive adaptive process in order to provide culturally and developmentally appropriate special education to children with special needs.

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APPENDICES

*Appendix A: Institutional Review Board Approval*



OREGON STATE UNIVERSITY  
**INSTITUTIONAL REVIEW BOARD**  
 312 Kerr Administration Building · Corvallis, Oregon · 97331-2140  
 E-MAIL: [IRB@oregonstate.edu](mailto:IRB@oregonstate.edu) · PHONE: (541) 737-3437 · FAX: (541) 737-3093

**REPORT OF REVIEW**

TO: Sharon Rosenkoetter,  
 Human Development and Family Sciences

RE: Korean Families in the United States with Children Who Have Disabilities (Hyun-Kyung You, Student Researcher)

Protocol No. 1797

The referenced project was reviewed under the guidelines of Oregon State University's Institutional Review Board (IRB). The IRB has approved the application. This approval will expire on 2/5/03. This modification request was reviewed at the Expedited level. A copy of this information will be provided to the full IRB committee.

Enclosed with this letter please find the original informed consent document for this project, which has received the IRB stamp. The original informed consent document has been stamped to ensure that only current, approved informed consent forms are used to enroll participants in this study. All participants must receive the IRB-stamped informed consent document. Make copies of this original as needed.

- Any proposed change to the approved protocol, informed consent form(s), or testing instrument(s) must be submitted using the MODIFICATION REQUEST FORM. Allow sufficient time for review and approval by the committee before any changes are implemented. Immediate action may be taken where necessary to eliminate apparent hazards to subjects, but this modification to the approved project must be reported immediately to the IRB.
- In the event that a human participant in this study experiences an outcome that is not expected and routine and that results in bodily injury and/or psychological, emotional, or physical harm or stress, it must be reported to the IRB Coordinator within three days of the occurrence using the ADVERSE EVENT FORM.
- If a complaint from a participant is received, you will be contacted for further information.
- Please go to the IRB web site at: <http://osu.orst.edu/research/RegulatoryCompliance/HumanSubjects.html> to access the MODIFICATION REQUEST FORM and the ADVERSE EVENT FORM as needed.

Before the expiration date noted above, a Status Report will be sent to either close or renew this project. It is imperative that the Status Report is completed and submitted by the due date indicated or the project must be suspended to be compliant with federal policies.

If you have any questions, please contact the IRB Coordinator at [IRB@oregonstate.edu](mailto:IRB@oregonstate.edu) or by phone at (541) 737-3437.

Redacted for privacy

Date: 4/28/02

 Dr. Anthony Wilcox  
 Institutional Review Board Chair

cc: IRB Coordinator

*Appendix B: Recruitment Flyer***Research Participants Needed**

A graduate student in Human Development and Family Science at Oregon State University is looking for research participants who meet these conditions:

Koreans who are the first generation in the United States, and who are mothers with a child (under age 18) who is currently receiving Early Intervention service or Special Education service.

As a participant, you will be asked to answer some questions related to your experience of having a child with a disability in the United States. An interview will last no longer than two hours.

You will receive helpful information about special education and related services as well as a \$10 gift certificate from your local grocery store.

If you are interested in participating in the study, please contact Hyun-Kyung You at (541) 752-1268 or email her [hkyung2000@hotmail.com](mailto:hkyung2000@hotmail.com)

Any personal information you provide will be kept confidential.  
*Thank you very much!*

## Appendix C: Informed Consent Form

#1797 1

## Korean Families in the United States with Children Who Have Disabilities

Informed Consent Document

Sharon Rosenkoetter, Associate Professor,  
Human Development and Family Science  
Milam 14, Oregon State University  
541) 737-8529, [sharon.rosenkoetter@orst.edu](mailto:sharon.rosenkoetter@orst.edu)

Hyun-Kyung You, Master's Program student  
Human Development and Family Science  
Bates Hall 117, Oregon State University,  
541) 737-1098, [hkyung2000@hotmail.com](mailto:hkyung2000@hotmail.com)

The student investigator's thesis project will explore the experiences of Korean families in the United States who have children with disabilities. The results of this study may enhance culturally and developmentally appropriate services for children with disabilities in the United States.

Participants who are suitable for the study are 1) Koreans who are the first generation in the United States, and 2) mothers with a child (ages 0 to 17) who is currently receiving services through Early Intervention or Special Education. As a participant, during a two-hour interview I will be asked to answer questions related to the experience of having a child with disability in the United States. The interview will be conducted in Korean and audio tape recorded. I understand that only the student investigator has access to the audiotape, which will be destroyed after the study.

I may experience emotional discomfort from disclosing my family story to an outsider during the interview. I may also benefit emotionally and receive helpful additional resources for rearing a child with disabilities. A \$10 gift certificate from a local grocery store will be given to me prior to beginning the interview. This study may be beneficial to enhance culturally appropriate special education and family services in the United States.

Any information obtained from this interview will be kept confidential. Neither my name nor any personal information will be used in any data summaries or publications.

Participation is voluntary and I know that I may refuse to participate, or may discontinue participation at any time without any penalty or loss of gift certificate. As a participant, I may choose to refuse to answer any questions for any reason.

If I have any questions about the research, I may contact the student investigator, Hyun-Kyung You at (541) 737-1098 or email her, [hkyung2000@hotmail.com](mailto:hkyung2000@hotmail.com) or the principal investigator, Sharon Rosenkoetter at (541) 737-8529 or email her, [Sharon.Rosenkoetter@orst.edu](mailto:Sharon.Rosenkoetter@orst.edu). If I have questions about my rights as a research subject, I may contact the IRB Coordinator, OSU Research Office at (541) 737-3437.

*My signature below indicates that I have read and that I understand the procedures described above and give my informed and voluntary consent to participate in this study. I understand that I will receive a signed copy of this consent form.*

OR

*I do not agree to participate in this study.*

\_\_\_\_\_  
Signature of participant

\_\_\_\_\_  
Name of participant

Date: \_\_\_\_\_

\_\_\_\_\_  
Participant's present address

\_\_\_\_\_  
Participant's telephone number

Date: \_\_\_\_\_

\_\_\_\_\_  
Student Investigator, Hyun-Kyung You

OSU IRB Approval Date: 4/26/02  
Approval Expiration Date: 2/5/03

*Appendix D: Parent Interview Protocol*

1) Can you tell me about yourself and your family?

(e.g. How long have you been in the United States? How many children do you have? What does your spouse do for living? Do you work outside of your home? Other demographic information such as age, education, any relatives in the United States? Their location?)

2) Can you tell me about your child's disability?

(e.g. What disabilities does your child have? How did you find out?)

3) What was your reaction to the child's disability?

(e.g. How did you feel? Were you comfortable in telling your relatives or people you knew about it? How did your spouse react to it?)

4) How did your and your family's life change after the child's disability?

(e.g. Marital relationship, finances, religion, family relationship, and daily life?)

5) What kind of difficulties have you had from having a child with disability?

6) How did you cope with those difficulties?

(e.g. What and who were most helpful? Why are they most helpful?)

7) What have you learned or gained as a result of this experience?

8) How did you get information about your child's disability?

(e.g. Through church, Early Intervention, school district, internet, other family members, or parent support group?)

9) What organization or who was most helpful? How did they help you?

10) When and what did you and your family feel most frustrated about?

(e.g. Lack of social support, language barriers or lack of information)

11) What about the actions of family services agencies or special education systems

has been especially helpful to you and your family?

12) How could family services agencies or special education systems serve your

family's needs better?

13) Is there anything else you would like to say about you, your family or your child

with disability?