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MASTER'S THESIS FOR HUMAN ECOLOGY

A Case Study of
Three Mothers of Children
with Autism Undergoing Early
Intensive Behavior Intervention

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ABSTRACT

Although the stigma and discrimination against individuals with disabilities are still ongoing concerns in South Korea, the demand for special education services has continued to increase. Early Intensive Behavioral Intervention, known as EIBI, is often referred to as the most scientific and effective approach to significantly establish and develop socially significant skills of children with ASD. To gain optimal results from the EIBI services, the role of parents is especially important in expanding children's behaviors and skills that are learned in structured one-on-one therapy sessions. Without parent involvement in intervention, children with ASD may not be able to generalize these learned behaviors into larger or different settings. Although numerous studies examined the effect of the intervention on the individuals, only a few focused on how culture shapes the understanding and management of autism and EIBI within Korea context.

The overarching aim of this study is to look into the lives of families of children with ASD and how they experience the child's disability. As this study explores the lives of families undergoing EIBI, I examined their lives within EIBI context.

The research questions for the study are as follows.

1. How do parents perceive the child's disability and the intervention process?
2. How do their perceptions on the disability and the intervention process impacted intervention outcomes?

To conduct this study, three 3 years-old children with moderate to severe ASD, their mothers and EIBI therapists were recruited and

selected by using purposeful sampling. Each family was visited three times when all family members were present, with the time of stay averaging 2.5 hours. Then main caregivers, who were all mothers, and therapists were all interviewed.

A thematic analysis followed through the collected interview data, observational data, assessment evaluation, center's evaluation of the child's performance and the mother's personal notes on the child. The result demonstrated that mother's acceptance of child's disability depended on the severity of child's symptoms. Mothers perceived that EIBI is a treatment approach to improve specific social and cognitive skills rather than a treatment to improve the overall development of the child. Moreover, since it was difficult for all the family members to participate in the intervention process, mothers implemented the behavior techniques alone in the house. As a result, all children with ASD in this study demonstrated generalization issues.

The findings can be used as a reference to professionals in South Korea who can support parents with their parenting knowledge, attitude and practice and EIBI professionals who can collaborate with families to implement early behavioral intervention.

Keywords : Autism Spectrum Disorder, Disability Acceptance, Early Intensive Behavioral Intervention, Korea

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I. INTRODUCTION

1. Background of the Study

Autism Spectrum Disorder (hereafter, ASD) is a condition related to brain development that impacts one's perception and socialization, therefore causing impairments in social interaction and communication and limited and repetitive patterns of behavior.

There has been an extensive research on the cause of ASD around the world, yet the exact cause has still not been determined. Scientists believe that a combination of genetic, environmental and some other unknown factors contributes to the 'spectrum' of symptoms and its severity. Such spectrum causes children with ASD to suffer from deficits in all areas of development including communicative, social, cognitive, play, motor and adaptive skills, and display a range of problems related to sleep patterns, eating habits, temper tantrums and aggression (Spreckley & Boyd, 2009). ASD is thus pervasive and chronic, and it affects the overall cognition and behaviors.

Because ASD does not affect the physical appearances of children, it can be seen as an invisible disability. Its diverse symptoms and invisibility give parents difficulties in understanding and accepting ASD, especially in countries where the disability creates multiple barriers against the individuals with disability and their families. Moreover, because ASD is mostly not diagnosed and identified until the age of four (Christensen et al., 2016), it is even harder for the parents to accept their children's diagnosis of ASD.

Parents in denial about their child's disability also have difficulties selecting the best intervention for their children. Numerous research has found that an appropriate intervention makes significant

differences to cognitive, social and daily living skills of children with ASD, emphasizing the importance of identifying the disability and providing services as early as possible (Boyd et al., 2010; Magiati, Tay, & Howlin, 2014). However, Grinker and Cho (2013) found that Korean mothers only participated in private social skill therapies that were conducted in the form of play, believing that such therapies would improve their children's deficits. These mothers chose to use the word "at the border" rather than ASD to imply that the disability would soon disappear and that it only affected the social area of development. They denied that ASD is a spectrum, pervasive and permanent disorder. As a result, their lack of knowledge and denial of the disability resulted in the failure of providing the appropriate intervention based on children's needs.

There is no treatment effective for all children and the outcomes vary depending on each child's symptoms and their severity. However, among many treatment options, Early Intensive Behavioral Intervention, known as EIBI, is often referred to as the most scientific, evidence-based approach to produce significant and lasting behavior change in children with ASD regardless of the severity of symptoms (Larsson, 2005). The treatment involving the learning theory increases or decreases target behaviors using reinforcements. However, it should also be noted that the treatment requires more than 20 hours of participation per week, which requires both parents and professionals to be heavily involved in the process.

EIBI has gained attention from Korean parents of children with ASD as well, but the mothers' understanding of the disorder in different cultures may affect their perception on the treatment and its effect. As shown in the study of Grinker and Cho (2013), Korean mothers may expect EIBI as one of the approaches to

improve their children's social skills.

Therefore, diverse understandings of ASD raise the question of how differing perceptions of ASD can impact the treatment outcomes. Although EIBI is recognized as one of the best treatments for ASD, parents and family members who participate in EIBI without deeply understanding the disorder or the intervention process might not be able to provide an effective intervention.

In this study, I wanted to explore how Korean parents of ASD perceive the disability and the intervention process. Then, I wanted to explain how their perceptions differed by each family's characteristics and child's symptoms. I expanded on previous qualitative studies by conducting both home-observations and in-depth interviews.

2. Research Questions

The purpose of the study was to look into the experiences of mothers raising children with ASD. As this study explores the lives of families undergoing EIBI, I wanted to examine their lives within EIBI context.

My research questions is as follows: 1) how do mothers perceive child's ASD and the intervention process? and 2) how does mothers' perception of child's ASD and the intervention impact the intervention outcomes?

II. Literature Review

1. Autism Spectrum Disorder: Definition and Diagnosis

ASD is a neurological and developmental disorder characterized by lack of social interaction and communication, and restricted and repetitive patterns of behaviors. Since ASD is a spectrum disorder, the core deficits can range from one end to the other end of the spectrum by varying degrees of symptoms.

The severity of individuals' symptoms would make every individual look different from one another. For instance, a person who is non-verbal, lacks social reciprocity and has a restricted patterns of behaviors would look different from a person who is verbal, socially appropriate, but shows repetitive patterns of behaviors.

History of Autism Spectrum Disorder

Interestingly, due to ASD's heterogenic characteristics, its definition and diagnosis have dramatically changed throughout the history since 1900. The word "autism" was first coined by the psychiatrist Eugen Bleuler in 1908 to describe a schizophrenic patients who were especially withdrawn and self-absorbed. However, it was American child psychiatrist Leo Kanner who first published a paper in 1943 to describe 11 children with "early infantile autism" who were highly intelligent yet desired to be alone and displayed "obsessive insistence on the preservation of sameness." A year later, a German scientist named Hans Asperger found a group of children with "milder" form of autism later described as Asperger Syndrome (Happé, 1995).

American Psychiatric Association (APA) initially specified autism as

one of the symptoms of “childhood schizophrenia” in the first and second edition of the Diagnostic and Statistical Manual of Mental Disorders, the DSM (1952) and the DSM-II (1968) (Grinker, 2008). Additionally, due to the unknown cause of the disorder, the idea of ‘refrigerator mom’ continued to emerge throughout this period. During this period, mothers were blamed for being emotionally distant, thereby causing the disorder. Such ideas were debunked in the 1970s when the research findings revealed that the condition occurred as a result of genetic predisposition. In the 1980s, DSM-III clearly separated autism from childhood schizophrenia and made it into its own diagnostic criteria (Shorter, 2013).

DSM-IV (1994) expanded the criteria by defining autism as one of the several Pervasive Developmental Disorders (PDDs), including PDD-NOS (Not Otherwise Specified) and a new diagnosis, Asperger’s Disorder. The changes in DSM-5 (2013), which currently removed the subtypes and collapsed all the PDDs into ASD, broadened the definition of autism even more and included both high and low functioning autism into the same ‘ASD’ category (Shorter, 2013)

Clinical Assessment of Autism Spectrum Disorder

The term “Spectrum Disorder” connotes the wide range of symptom severities of every child with ASD. Although many existing clinical assessments measure child’s language delay, cognitive functioning and behavioral issues to diagnose ASD, it is also important to measure the severity of impairment.

The psychiatric diagnosis is significantly important in helping children receive therapeutic, financial, and educational benefits. In South Korea, clinicians rely on the DSM for diagnostic criteria and also administer the diagnostic instruments which observe the conditions consistent with

the DSM such as the Autism Diagnostic Observation Schedule (ADOS) (Grinker & Cho, 2013).

It is known that most genetic, neuroscience and intervention research have been using the ADOS (Lord, Rutter, DiLavore, & Risi, 2000) to estimate the severity of core autism features. It is an observation tool which directly observes the social and communication behaviors of individuals of 12 month old and older.

It is difficult to classify Autism or ASD by ADOS alone because it only examines the social and communicative part of autism features. Thus, experts recommend other tests as well in order to supplement a diagnostic test. For instance, Autism Diagnostic Interview–Revised (ADI–R; Rutter, LeCouteur, & Lord, 2003) is used to obtain information on children’s other behavioral characteristics and a caregiver history (Lord, Rutter, DiLavore, & Risi, 2000).

There is also the Psychoeducational Profile–Revised (PEP–R; Schopler, Reichler, Bashford, Lansing, & Marcus, 1990) used to assess the developmental level of young children who are not used to a formal testing situations. For those children with ASD from 6 months to 7 years of age who have uneven learning abilities, the observational PEP–R tool provides information on developmental skill levels and measures the severity of symptoms.

Moreover, experts use the Vineland Social Maturity Scale (Doll, 1965) to measure the differential social capacities of an individual. It is designed to measure social maturation in eight social areas such as self–help general, self–help eating, self–help dressing, self direction, occupation, communication, locomotion, and socialization.

As described, there are various diagnostic tests to assess child’s intellectual, developmental and social capacities in Korea and the increasing number of hospitals and certified clinicians exist to help

children get appropriate diagnosis for better therapeutic and educational benefits. However, the research demonstrate that Korean children are still seldom diagnosed as ASD due to high disability stigma (Kang–Yi, Grinker, & Mandell, 2013). Before providing appropriate clinical, financial, and educational services to children with ASD, it is important to examine how the disability is understood and managed within the cultural context.

2. Perceptions of Disability in Korean Culture

Although the perception of disability has been largely studied, it is only recently that studies have shed light on the perspectives of parents in non–Western cultural background. Even these studies mostly focused on experiences of non–Western families raising their children with disabilities in the United States (Cho, Singer & Brenner, 2000; Park & Turnbull, 2001), but not on experiences of families who actually lived in non–Western countries such as South Korea. To comprehend experiences of families living in Korea, it is first necessary to develop cultural awareness of Korean parent’s unique characteristics as the main caregivers and their perception of disability.

Confucianism and Perception of Disability

In Korea, Confucianism emphasizes women's duty to follow and fulfill the wishes of three men, father, husband and her eldest son, over the course of her life (Lee, 2005). Thus, it is common for women to stay at home to support their husband and raise children. You and McGraw (2011) further explained that a mother’s success is considered equal to a child’s success, which can be usually determined by the child’s academic success, admission into a prestigious university and entering

into having a high paying job.

Due to these mothers' beliefs, Korean mothers place a strong emphasis on, or even show obsession with their children's education, which is often described as *kyoyukyul* (education fever) (Kwon, Suh, Bang, Jung, & Moon, 2010). In this process, most mothers do not question their mothering responsibilities of sacrificing their life to support their children's success while fathers engage very little in taking care of for their children. Based on Confucian thought, both mothers and fathers believe that the mother must take the full responsibility of child rearing, while the father only provides financial support for the family (You & McGraw, 2011).

Confucianism also affects how Korean parents perceive and react to their child's disability. Many research has found that high levels of stigma in South Korea are caused by the Buddhist belief that an individual's disability is the result of one's negative karma from the previous lives (Chen, Jo, & Donnell, 2004), or by the Confucian belief that one's disability brings dissonance to the structured relationship within family members and even with the larger society (You & McGraw, 2011).

Additionally, disability restricts individuals from success and following the customary norms of the society (Kim & Kang, 2003). In Korean society where a mother's success is closely related to a child's success, it is especially more difficult for the mothers to accept their children's disability because they understand the extent to which their children would be limited from success because of disability.

Perception of Autism Spectrum Disorder in Korea

Accordingly, the overall cultural factors of Korea lead to the unawareness and denial of children's disability. Parents of children with

ASD have particularly difficult times recognizing and understanding the disability due to its unique mixture of symptoms in each child.

The first and the only epidemiological study conducted in Goyang City, near Seoul South Korea, with 55,000 children from 7–12 years old estimated that the ASD prevalence rate was almost 2.6% (Kim et al., 2011), which far exceeded the ASD prevalence rate of 0.12% estimated by South Korea Ministry of Education, Science, and Technology (2015). Two-thirds of 2.6% children in the study were undiagnosed and untreated but still attended mainstream schools, which again demonstrated a low level of public awareness of ASD.

Grinker, the author of *Unstrange Minds* (2007) and the father of a child who's also diagnosed as ASD, claimed that the presence of individuals with ASD in Korean community has been often viewed as a tragedy from which the family might never recover. All members of the family were less eligible for marriage, more likely to encounter discrimination, and be excluded from important social circles.

Such harsh stigma made parents rather prefer to acquire a diagnosis of Reactive Attachment Disorder, a disorder often caused by significant abuse or neglect from caregivers, both because it is not permanent and the mother could take the blame for it (Grinker, 2007).

Korean mothers also chose to call their children “border children” rather than ASD or autistic. They refused to receive an official diagnosis of ASD, which was needed for children's public clinical and special education services. Mothers from this study considered their children to be “at the border (*kyungyesung*)” which implied that their temporary impairment did not require a clinic label. Although “border children” are not “normal (*chungsang*)” like the other typically developing children, this label provided glimpse of hope for normalcy (Grinker & Cho, 2013).

Not surprisingly, mothers of children with mild ASD had a harder time giving up the hope of the children's change towards normalcy. If children had mild disability conditions, their mothers believed that their children would one day excel in school like their typically developing peers and tried even harder to improve child's conditions. These mothers chose not to use free government special education services and searched for private treatments and therapies which they perceived to be a more intense level of private care for their children (Park & Chung, 2015; You & McGraw, 2011). Interestingly, mothers did not have any professional consultation and support during this process. Mother's perception of ASD solely influenced their decision making for children's therapeutic services.

3. Early Intervention for Autism Spectrum Disorder

A series of legislations and mandates have been enacted to expand inclusive education and to increase the number of social services for families of young children with disabilities. In addition to the recent increase in the number of inclusive preschools and daycare facilities that parents can use at free cost, Korea Ministry of Health and Welfare implemented the electronic voucher system to financially support families of individuals with disability (Yoo, Yun, Seo, & Choi, 2015). Korean families has gained much more access to the government funded financial and educational resources as well as professional support in caring for children with ASD.

However, Korean parents who are still reluctant to register for their child's disability seek various private therapeutic services that are not funded by the government. These parents of children with ASD have to personally navigate through a broad range of services because their

children suffer from pervasive impairment in several areas of development. According to the research findings, Korean parents of children with disability receive four private therapies on average up to seven therapies (Kim et al., 2014), hoping that their children would reach normal levels of overall functioning before entering the formal education system (Park et al., 2006). There is also the finding that parents of children with ASD only take their children to private social skills programs, which are designed in a form of play rather than clinical therapies to treat social deficits (Grinker & Cho, 2013). Conclusively, parent's perception of disability rather than a clinical assessment of children's developmental conditions was significantly associated with mothers' treatment choices for their children.

The Application of Early Intensive Behavioral Intervention

Among these services, Early Intensive Behavioral Intervention (EIBI) has gained attention from parents for being the most effective, empirically supported treatment for ASD regardless of the severity of symptoms. EIBI is already known as the powerful evidence based behavioral treatment model for young children with ASD in the United States (National Autism, 2015), and many private agencies and state insurance programs provide insurance coverage for behavioral treatments for ASD (Dawson & Bernier, 2013).

EIBI is based on the principles and technologies of applied behavior analysis (ABA) which is derived from the learning theory. Data collected from ABA is used to make decisions on the next steps of behavioral changes. While ABA treatments vary in intensity and structure, EIBI refers to more specific type of therapy for young children on the moderate to severe end of the autism spectrum (Chasson, Harris & Neely, 2007).

The EIBI is usually conducted in a highly structured one-to-one instructional setting with few distractions to help child to focus on a task. In the famous study of Lovaas (1987), almost half of the children who received 40 hours of EIBI program per week for two years eventually attended classes with their typically developing peers with increased level of cognitive, language, adaptive and compliance skills. Many researchers additionally supported his study by proving that these programs established long-term improvements in intellectual, social, emotional, and challenging behaviors as well as adaptive functioning within the context of the individual's social environment (Eikeseth, Smith, Jahr, & Eldevik, 2002; McPhilemy & Dillenburger, 2013).

The most popular and commonly used strategy is called the Discrete Trial Training. It breaks down complicated tasks into simple steps of desired behaviors or responses and positively reinforces every simple steps with rewards. EIBI session lasts less than an hour with two to five minutes trial and one to two minute break in between, but the length of each session depends on the ability and characteristics of each child (Smith, 2001). The Discrete Trial Training is recognized for its effectiveness in teaching color recognition, verbal requests or social situations, but is known to be ineffective in teaching sequential behaviors such as brushing teeth and doing laundry (Steege, Mace, Perry, & Longenecker, 2007).

The Role of Family Members and Professionals

One of EIBI program's greatest strengths is to break down complex tasks into simple steps by individualizing them for each child through numerous training trials. This allows children with ASD to easily identify the target response and learn them through repetition. However, there are also some disadvantages such as generalization issues (Steege

et al., 2007).

As children with ASD learn these specific socially significant skills in highly structured settings, they encounter difficulties generalizing them in other environments. For example, they might succeed in making eye contact in a structured desk setting, but fail to do so at home. Such failure occurs because the behavior is not professional-directed and the children might not receive the same powerful reinforcers at home (Steege et al., 2007).

Therefore, even if EIBI enhances overall behaviors and skills of children with ASD in structured setting, professionals and parents should additionally ensure mastery and maintenance of those skills in different environments as well. In order to successfully implement behavior strategies across settings, professionals and parents need to cooperate to design the support plan that best meets the child's situations. It is recommended for families to consider EIBI as a life pattern and provide consistent and intense feedback to child's behaviors, at least 20–40 hours per week depending on the needs of each child (Matson, Tureck, Turygin, Beighley, & Rieske, 2012).

It is often quite demanding for all the family members to consistently manage child's behaviors and skills across settings and implement behavioral strategies at home. Especially when programs require mothers to act as co-therapists themselves to generalize the gains in naturalistic environment, it can be overwhelming and stressful (Love, Carr, Almason, & Petursdottir, 2009; Smith, Buch, & Gamby, 2000). Thus, it is not surprising that not only the child but also mothers are in great need of professional support in the intervention. Professional's role is significant in helping both child with ASD and family throughout the intervention process to provide optimal outcomes for the children with ASD.

Early Intensive Behavioral Intervention in Korea

Since Korean government and private agencies do not provide any insurance coverage for the behavioral treatments, parents are responsible for the full treatment payment. Despite the cost ranging from 700,000 Korean won (approximately 7,00 US dollars) to 2,000,000 Korean won (approximately 2,000 US dollars) every month ("Therapy? It Cost a Fortune, 2011), many Korean parents still participate in the EIBI program hoping to "cure" their child's ASD.

Additionally, this evidence-based intervention program is relatively new compared to other therapies available in Korea and only a few private centers offer the programs in Korea. Existing research conducted in Korea settings emphasize the effects of EIBI and parent participation on individual children but have not considered the role of cultural influences on the treatment programs..

Thus, it is significant to investigate Korean mothers' experiences with the intervention program and how they cope with their child's disability throughout the intervention process.

III. METHODS

1. Overview

The purpose of this study was to examine how Korean mothers of children with ASD undergoing Early Intensive Behavioral Intervention (EIBI) perceive their children's disability and intervention process in Korea and how their perceptions affect the intervention outcomes.

All participating families were observed at home to see how each family interacted with the child with ASD. Then mothers and EIBI therapists of children with ASD were all interviewed to share their perceptions on the intervention process of the target children. This chapter described in more details about the participants, methodology and the data analysis for the study.

2. Researcher's Perspective

I would first like to provide my background information to share my interest and knowledge on the subject. Throughout graduate school, I have been working part-time assisting certified therapists at the EIBI center at least 6 to 12 hours a week for two years since January 2016. I am not a Board Certified Behavior Analyst, yet I am currently taking online ABA courses to be certified in the year of 2018.

I have been participating in an intensive early intervention program with young children from 18 to 36 months, a program with young children aged 3 to 5 years-old and one-to-one individualized program sessions, which helped me to meet numerous children with varying symptoms and their parents.

During all the programs which last for 40 minutes to 3 hours, usually mothers stay at the parent waiting room and/or stand in the hallway to look through the one-way mirror and to see child's performances. After each session, all the therapists have one-to-one consulting sessions with mothers or fathers for 10 to 30 minutes.

I also participated in the consulting sessions with or without the head manager. These experiences helped me to learn the characteristics of each child with ASD and the family, parent's concerns and expectations towards the intervention process. Sometimes professionals' concerns and expectations towards each child with ASD conflicted with those of parents. Such experiences at the center enriched my overall understanding of the spectrum of the disorder and the dynamics within the EIBI center.

As an intern therapist and a graduate student, I wanted to explore parent's understanding of the disability and provide an insight into distinct lives of parents raising a child with ASD undergoing EIBI intervention. As a graduate student majoring in Child and Family Studies, I have more strength-based perspectives on the participant children and families which would further help me to shed more light on mother's efforts to understand ASD and the intervention process.

3. Participants

A case study often looks into small size population and selects cases meeting the criteria used to identify the right subjects. As most case studies conducted an in-depth analysis with three to five cases (Creswell, 2002), this study recruited three families undergoing EIBI and their therapists.

Samples of Children with ASD, Mothers, and Therapists

Participants were chosen according to three criteria: (a) children should be diagnosed as Autism Spectrum Disorder by a certified clinician. According to the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5), children have to demonstrate social communication and interaction deficits across multiple contexts and show restricted and repetitive patterns of behaviors or interests; (b) children with ASD need to be in their preschool years ranging from aged 3 to 5 years-old and should be undergoing EIBI program. (c) A child's family member and a therapist who contact with the child most often in and out of the center should be included.

Considering that Korea Annual Report for Special Education 2016 (Ministry of Education, Science & Technology, 2016) identified that most therapy and welfare centers for children with special needs were concentrated in Seoul, the capitol city of South Korea, I thought it would be best to first to meet with the director of the EIBI center, also located in Seoul, that I have been working as a part-time assistant. I presented the official recruitment document to the director which explained the purpose of the study and the list of things that I could ask for during the study such as participating child's performance evaluations or behavior reports. After the director consented to participate in the study, I posted the official recruitment flyer on the center's board placed on the parent's waiting room. The recruitment flyer listed all the required criteria for the study.

Three mothers contacted me through the flyer and agreed to participate in the study. Their children diagnosed with ASD were 42-55 months and were all engaged in EIBI program and one-to-one private sessions. The length of EIBI program participation ranged from 18 months to 20 months, with 15 to 20 hours input per week. All three

children were not currently attending preschool.

When mothers were asked to sign the consent form after listening to the details about the purpose and procedure of the study, they all willingly agreed to sign the form. Mothers and I have already established rapport for past years, and they perceived me as one of the credible therapists at the center. It was much easier for me obtain their permission to observe their families for two to three hours every visit.

After obtaining mother's consent, I then contacted children's therapists at the center to ask whether they were willing to participate in the study. They all agreed to sign the consent form. They were all certified behavior analysts who worked 40 hours per week. Two of them had two years of experience and one of them had four years. These participating therapists were responsible for developing the participant child's year long plan and for consulting with parents every day after the session.

Before I began home observations, I collected the survey questionnaires on basic demographic information filled out by both mothers and therapists who contacted with the target children most often. Between August to October 2016, each family was visited three times at home when all family members were present, with time of stay averaged 2.5 hours.

I asked for the copy of child's assessment reports and collected mother's notes or journals on child's behaviors, if any, as artifacts. One week after all the observations were completed, each mother was interviewed, each lasting approximately from 30 minutes to an hour. Then each therapist was interviewed one week later, each lasting approximately from 50 minutes to 90 minutes. The interviews were semi-structured based on home observations and behavior notes collected at home. The interviews were conducted in person, recorded

and fully transcribed in an average of 10 pages.

4. Procedures

In order to investigate the target children and their families from multiple perspectives, observations, field notes, interviews, and artifacts were all used to triangulate the data. The triangulation method was used to ensure the validity and reliability of the results and help the readers to view the phenomenon in the same way as the researcher (Chenail & Malone, 1997).

The research process was as follows: first, both mothers and therapists filled out the survey which collected basic demographic information, the time the parents and therapists spent with their children during the weekdays and the weekend, and the developmental characteristics of the child. Each family was scheduled for three 2-hour home observations within a maximum period of two weeks, and field notes were taken during the observation sessions. During the observations, both fathers and mothers were asked to engage in routine activities. I took field notes on child and family's characteristics, where activity took place, how family members were interacting with the child with ASD, and reflective information which were mainly my thoughts and questions about the situation. To check for accuracy, I also voice recorded all the observations.

After home observations, the interaction patterns of the child and each family member were analyzed. The data was later used to compare children's performances and behaviors between home and center settings. All the conversations that I made with the family members during the observations were all audio recorded for the analysis.

One week after the observations, the one-to-one semi-structured interviews were conducted with the mothers. Interview topics included sets of questions regarding their experiences of parenting a child with ASD and undergoing EIBI. They all consented to share all of their information gained from home-observations to the therapists, as they wanted to know therapists' opinions on how they were doing at home.

One week after the interviews with the mothers, the interviews were conducted with the therapists who were mainly responsible for the subject children in the center. All the interviews were audio recorded to secure the collected data's reliability and I also took memos of the general impressions and observations of the participants to include while transcribing the interviews. To maintain and confidentiality of the data, every participating child with ASD was renamed.

After all the observations and interviews, each family received a brief 3-page report on the observations. The observation report explained how well the family members were implementing behavioral techniques and how the therapists perceived the family members' behaviors at home.

5. Data Analysis

A thematic analysis was followed through the collected in-depth interview data, observational data, center's child performance evaluations and mother's notes on the child. The interviews and observations recorded in Korean were transcribed using the laptop, but the interpretation and coding process was done by hand. After all the codes were classified into themes and categories, all the Korean transcripts were translated into English.

The coding proceeded using the triangulated data, by identifying the

codes that emerged in both mother and therapist interviews and in observation notes. Emic approaches was initially used to capture the participant's views and statements and all the recurring codes were grouped into themes (Creswell, 2002). Among all the emerged themes, I searched for themes that were related to my research topic, parental perception on their child with ASD and intervention process, and additionally etically coded the texts to add any emergent themes.

Specifically, the themes related to mother's experience as a main caregiver, lack of knowledge about the disability and intervention, and their feelings of uncertainty for the future were maintained throughout the study. I have repeatedly read all the materials to validate my analysis.

[Table 1. Themes for Interview]

Categories	Interview Themes
Mother's caregiving experience	Spending the whole day with their children without any breaks, getting no professional and family support
Home situations	Letting child relax, letting them 'be kids' at home, recognizing child's new problem behaviors and generalization issues at home
Attitude towards ASD	Not accepting children's disability, not accepting that ASD is pervasive and permanent
Attitude towards therapies	Perceiving it as studying sessions, ways to improve child's cognition and studying attitude
Attitude towards child's future	Being certain about child's future, having a lot of questions before they make decisions, still uncertain about their choices and want the assurance

[Table 2. Participant Child's General Information]

	Hani	Shin	Jay
Autism Diagnostic Observation Schedule (ADOS)	Severe Autism	Severe Autism	Mild–Moderate ASD
Age at Diagnosis (Current Age)	36 months (48 months)	31 months (55 months)	33 months (42 months)
Psycho Educational Profile–Revised (PEP–R)	Developmental level less than 12 months old	Developmental level less than 12 months old	Developmental level less than 18 months old
Social Maturity Scale (SMS)	Social Age: 15 months Social Quotient: 35 (moderate mental retardation)	Social Age: 18 months Social Quotient: 57 (mild mental retardation)	Social Age: 22 months Social Quotient: 66 (mild mental retardation)
Short Description	Has identical twins; non-verbal; impaired in all areas of development	Sticks rules and routines; can speak using one to three words	Loves singing; very talkative and sometimes speaks using songs
The Length of EIBI Participation	20 months	20 months	18 months

IV. Results

1. Hani and Hana's Family: mother's demand for social development

1) Characteristics of Hani and Hana's Family

Short description of the family

Hani: is 4 years old. She was reported to have severe, non-verbal autism with the developmental level of 12 months at 36 months.

Hana: is an identical twin of Hani. She is also 4 years old and has a severe, non-verbal autism like her sister.

Mother: is a full-time mother. Her intervention is focused on the twin's communication skills and social interaction. She usually spends her whole day waiting for the twins to finish during EIBI and physical therapy sessions and running a household at home.

Father: is a medical doctor. He always gets home late from work but attempts to spend as much time as possible with his daughters when he gets home.

* They used to live in the city few hours away from Seoul, but they moved to Seoul to get closer to therapy centers.

Hani and Hana are identical twins who are at the severe end of the spectrum, low-functioning autism, which can cause extensive impairments in all areas of development. Some of the impairments include lack of language skills, awareness of other people, fine motor skills, and self-help skills.

Both Hani and Hana received the same result of the ADOS and PEP-R when they were 36 months. As shown in Table 3.1, they completely lacked communication or social interaction skills when they first visited EIBI center. They expressed sounds that were meaningless and did not make any verbal or non-verbal gestures with other people.

The only time the twins interacted with the mother was the time they wanted food. They 'knew how to drag their mother's hands in front of the refrigerator when they could not reach the food.' Hani's ADOS score exceeded twice the Autism cutoff scores in every category, which implied that her symptoms were severe.

As shown in Table 3.2, the twin's developmental level was less than one year old when they were 36 months old. They almost had no imitation and fine motor skills, and had low cognitive abilities to solve even the simplest puzzle. They had, however, moderate level of gross motor skills and could climb up and down and stairs. Even at the house, they often jumped on the trampoline. Moreover, the twin's SMS scores in Table 3.3 demonstrated that the twins had low self-help skills such as eating and dressing, communication, locomotion and socialization by the time of diagnosis.

The mother explained that other than these deficits, the twin also showed severe sleeping problems and other challenging behaviors. Due to mother's 'lack of understanding of [her] daughters' behaviors led to frequent temper tantrums during the day and night.'

Unsurprisingly, the twins underwent difficult times adjusting to the rigid, structured EIBI classroom settings and were considered as the difficult and aggressive twins by the therapists. The older sister, Hani, has attended an early intervention program with four other children, while Hana only received one-on-one private lessons because of her extreme temper tantrums.

According to the therapists, they were both slow learners who needed continual repetition of practices to modify and acquire the desired behaviors and skills. When they first began the program, they started with small tasks like sitting, looking, and understanding the meaning of pointing.

[Table 3.1 Hani’s Assessment Evaluation – 36 months]

Autism Diagnostic Observation Schedule (ADOS ¹⁾): Severe			
Category	Child’s score	Autism cut off score ²⁾	Further Details
Communication	10	4	Expressed words were meaningless. There were no verbal nor non-verbal gestures observed.
Reciprocal Social Interaction (RSI)	14	7	She did not look/turn when called upon and had no interaction with others
Communication and RSI Total	24	12	She did not make sounds or make an interaction with other people with intention. She dragged her hand when in need of something
Imagination / Creativity	4	N/A	She showed no play activity with toys
Stereotyped Behaviors and Restricted Interests	6	N/A	She demonstrated self-stimulatory and stereotyped behaviors

1) ADOS's first and second module is used for non-verbal children and children with less than 4-year old level of language. Each activity is scored from 0 (showing typical behaviors) to 4 (showing disruptive and untypical behaviors) (Lord, Rutter, DiLavore, & Risi, 2009).

2) The tool distinguishes Autism from ASD, which includes PDD-NOS and Asperger’s Disorder identified as a milder form of autism in DSM-IV. To receive an ADOS diagnosis of Autism or ASD, an individual’s scores must meet the cut-offs in the Communication domain, a Social domain, and the summation of the two.

[Table 3.2 Hani's Assessment Evaluation – 36 months]

Psycho Educational Profile–Revised (PEP–R): Developmental Level is less than 1–year old		
Category ³⁾	Child's score ⁴⁾	Further Details
Imitation	11 months	Joint attention was not observed. she was not able to imitate simple actions neither.
Perception	1 year	she looked at the bubbles but could not blow the bubbles. She could not solve simple puzzle.
Fine motor skills	11 months	She could not remove the stick from the brick. She could not hold the pencil and scribble.
Gross motor skills	2 years 6 months	She was able to climb up and down the stairs. She could push the ball, yet could not throw and catch the ball.
Eye–hand integration	11 months	She could not point to the body parts named by the inspector.
Cognitive non–verbal behavior	11 months	She had no word expressions
Cognitive verbal behavior	11 months	She could not differentiate and point to the objects. She could not imitate any words or sounds

3) The tool consists of the developmental scales. The developmental scale, consisting of 131 items, assesses the overall functioning of the child with 7–subscales.

4) Every item is graded as pass (2), fail (1) or emerge (0), which represents children's lack of ability to fully complete the task by themselves or their ability of complete with the observer's help. The summation of raw scores in developmental scales is then calculated to determine child's developmental level (Schopler et al., 1990).

[Table 3.3 Hani's Assessment Evaluation – 36 months]

Social Maturity Scale ⁵⁾		
Social Age ⁶⁾	Social Quotient	Range
15 months	35	Moderate Mental Retardation

5) The scale consists of 89 items grouped into year levels, and is shown to be highly correlated with intelligence. It is designed to measure social maturation in eight social areas: self-help general, self-help eating, self-help dressing, self-direction, occupation, communication, locomotion and socialization.

6) The summation of the passed scores is compared with the social age (SA) from the VSMS manual and this SA is divided by the chronological age and multiplied by 100 to compute the social quotient (SQ), which shows the severity of the individual's mental retardation.

Several therapists insisted that ‘the twins’ adjustment to the structured environment was even more challenging because of their parents’ permissive training methods.’ The strict training procedures at the structured center setting and the lenient environment at home created significant inconsistencies that hindered the learning process. Luckily, differences in the settings, the twins still showed noticeable progress in attitudes and behaviors throughout training sessions.

After two years of intervention, both children learned to imitate some simple gestures, use pointing to request for food, express their desire for food by making sounds such as ‘Ah’ or ‘Bah,’ and look up when someone called their names. Hani even learned to urinate in the toilet after nearly 7 months of training.

As I stepped into the house, I saw foods scattered on the floor. The mother placed several plates of food on the kitchen table and the sisters threw the foods all over the floor. With only shirts and diapers on, both twins were sitting on the sofa and running all around the house as if they were exploring for the freedom.

The mother mostly spent her time listening to her children’s requests for food and swiping the floor with a broom. She wanted to do everything for her ‘unfortunate kids’, which made her respond to all of their requests. Each child requested for something in approximately every 20 minutes, which made it almost impossible for the mother to have her own time.

While I was observing the children’s energetic faces, the mother said excitedly with her sparkling eyes, “Don’t you think my children are calmer and more stable at home?” She claimed that her children seemed to understand the house rules and they acted ‘like a typical one year old.’

This peace... We did not have it before. Their needs, their

frustrations... There was only screaming. (Mother)

Interestingly, the children seemed to understand how to avoid conflicts with one another. For instance, when both of them approached the mother to make a request, Hani waited for her turn while Hana asked her request first. Similarly, as one of them spent time on the trampoline with the mother, the other one enjoyed her own time in the play room.

Perhaps they were intentionally giving each other time to spend with the mother because when the father came home, they did not compromise at all to take the father's hand first. This gave me an understanding of what the mother said – both children implicitly made rules in the house to avoid fights.

The father was an 'optimistic and lenient man just like' the mother and was highly satisfied with the his daughters' changes. He was mostly happy that 'his daughters are finally sleeping well at night.' He was a surgeon who usually came back home from work after 9 pm from Monday to Saturday, but he never 'forgot to play with his children' and 'always attempted to take them out for picnic on Sundays so that the children could explore new environments around the city.'

The mother thought that his main role was to provide financial support for the twin's expensive EIBI therapies and highly appreciated his effort to spend time with the children whenever he was available. She never asked him to implement the EIBI techniques at home because she did not want to give him the pressure that could cause a negative influence in their relationship.

He's an exhausted man who needs to spend time alone eating and doing other things...He has never had his meals comfortably without the twins. And asking him to do EIBI techniques...it would've made him even more exhausted. And it shouldn't make our relationship fall apart. I mean he sometimes ask, *what do kids learn*

*at hagwon*⁷⁾? but he doesn't really give instructions to kids at home.
(Mother)

It was interesting to note that she did not make any comments about herself spending the whole day with twins and doing all the households by herself without ever taking a break.

2) Mother's experiences with ASD and EIBI

The mother of Hani and Hana learned about EIBI from the hospital where the children were diagnosed. If she registered her twin's disability, she would have been able to receive economic, educational and therapeutic services, but she chose instead to participate in intensive private therapeutic services regardless of the high cost. As a result, she personally had to decide on how long her children would have to receive the EIBI treatments without getting any consultations from professionals other than the therapists.

Contrary to her firm belief that her twins needed continuous ABA services, 'currently the most effective treatment for ASD,' the children were undergoing several difficulties implementing the skills they learned from the EIBI center. For example, target behaviors of Hani, such as following an instruction of an adult, ceased when the intervention did not continue at home. Two assumptions for such generalization issues were: 1) the mother's personal judgement on what was best for the children's development and 2) the environmental conditions that prevented the mother from implementing behavioral techniques at home.

It was apparent that ever since the mother chose to engage in private therapeutic services, she was used to making decisions for her children on her own. During the first year of the EIBI program, she believed

7) private tutoring institutions which majority of Korean students participate in to improve academic performances

that an intensive ABA program would eventually ‘cure and improve’ her children’s social skills, which made her sign up for the program that involved six hours of training per day. She did not mind the high cost of 7,000,000 Korean won per month (approximately about 7,000 U.S. dollars) for both twins and only wished that the treatment would ‘improve them into the normal functioning level after 6 months.’ Unfortunately, after realizing that her children were still non-verbal and did not show much improvements after the first year, she reduced the intervention hours to three hours.

Even if my daughters are like this (severely impaired), I might be able to make their life easier. This year I also learned to accept that they are learning even more slowly than I initially expected. Ah okay. Then I’ll slow down with them. Only if they learn how to learn to speak and interact with us (the mother and father), it does not matter how long it takes. Until last year, I thought the intensive programs would make them speak, but it only gave them a hard time. I mean, think about it. They never even had experiences of studying before and suddenly they were studying like 6 hours a day! (Mother)

As she accepted that her children were developing at a slow pace, she started to focus solely on improving child’s self-help and communication skills. She even asserted that ‘increasing cognition is useless for [her] children’ and she only wanted her children to be healthy and socially interactive. Her goal, similar to the goals of the mothers presented in the study of Grinker and Cho (2013), focused on improving only one of the core deficits of ASD, the social competence. Thus, her wish of twin’s healthiness and social activeness created such a lenient training environment at home and made her responding to all of the twins’ requests.

Moreover, although the mother was determined to continue with EIBI services, ‘even if it was 4 hours per week’, she still thought that her children should ‘rest at home from a long day of studying at the

center.’

I want Hani and Hana to get involved in the [EIBI] program because I think they need to steadily be in the environment of studying. I want them to understand what ‘studying’ is in this EIBI structured setting. (Mother)

This demonstrated that she perceived the intervention center as a form of learning institute and she also lacked understanding of the importance of receiving 20–40 hours of consistent treatments across settings to improve the overall functioning of children with ASD (Lovaas, 1987).

Expectedly, the mother of Hani and Hana confronted with the EIBI therapists at the center for being inconsistent. Hani’s therapist described that she had been making a list of activities that the family could do together at home, since Hani’s intervention progress was much slower than other classmates. The therapists at the EIBI center knew that the consistency of training, which could significantly impact the overall outcome of the twins’ treatments, was not successfully being achieved.

I’ve been making the list of things Hani’s mother can do with Hani at home with the guidelines of how she should specifically provide instructions. But... this is very rare — telling mothers what she should do at home. I’ve only been in this field for two years, but I know this case is very rare. We are doing this for Hani’s mother so that she can have deeper understanding of her child...I think we are already much more involved than usual. (Therapist)

The mother admitted that she had not been proactively engaged in the intervention process, but on the other hand, she apparently did not have the time to implement such behavioral strategies at home.

The mother previously hired a nanny to take care of one of the sisters during the day, but it did not work out because of the twin's denial of an unfamiliar person. Doing all the households and taking care of the twins alone gave her an overwhelming life already, and it

was physically impossible for her to create the desired learning environment at home. For instance, although Hani's therapist asked the mother to take Hani to bathroom every hour for toilet training, the mother could only take Hani to bathroom once or twice every day. Both the therapists and the mother were frustrated for understandable reasons.

Well, she says she does all the things on the list, but I wonder if she is actually doing all these things. Sometimes I want to ask can you video tape what you've done? (Therapist)

Teacher (therapist was called 'teacher') was telling me [my kids were making slow progress because] I let my kids do whatever they want to do at home, but that's not the case. One is crying, and the other one is at the bathtub going Ek Ek Ek (imitating child's noise). And there goes another one pooping. You see, it's different in reality. (Mother)

When the mother had some time to engage in home training with the children, she only did it with the older sister, Hani. During the 10 hours of observation, she did not engage in any kind of training with the younger sister, Hana, except for responding to her requests for food. In addition to the problem of not having enough time for home training, the mother also did not understand the correct method. She did not have anyone to observe her actions at home to provide her guidelines on how to deal with her children at home. It was apparent that the mother needed more professional and family support in the home setting.

3) Challenges of the child and the mother

One of the reasons that the therapists' desperately demanded to utilize behavior techniques at home was that it was the last year for Hani and Hana at the center. At this point, Hani still had generalization issues with her mother, the main caregiver. Children with

ASD do not have generalization problems with the mother because the main caregiver serves as the primary or secondary reinforcer who provides cookies or toys.

Hani had problems following the instructions of her parents. Her therapist had been teaching the concept of 'let's go,' which involved holding her hand and walking around the center. It took her four months to successfully understand the concept of walking together and changing directions.

Her therapists believed that she completely mastered the 'let's go' program, but in reality she failed to repeat it at home. Even when the mother attempted to drag her arm to move to the other room, she did not move a step and simply burst into tears. This came as a shock to both her therapist and the family.

She doesn't move with her mother? At all? Wow, it's really shocking....I mean, I always wondered why she would only take her sister around the building after the sessions... I just assumed that, you know, her sister is more compliant and all, and maybe that's why. But in reality, maybe she couldn't take Hani around because Hani doesn't follow her instructions. (Therapist)

Even worse, because of the continuous conflicts with the therapists, the mother avoided consultations at the end of the therapy sessions. She was worried that her actions might offend them, which could also negatively influence the intervention program of the twins. At the same time, she did not have the solution to her complex situation and was doing what she thought was best for her children.

Recently, she learned that Hani and Hana would no longer have a space at the center from next year, so she began to actively search for other therapy centers and preschools that would accept both twins. She had been seeking help from the therapists and other mothers to collect information.

In the process of observing all the options, she reached out to me for help. She asked if I could find any other EIBI therapists who would be willing to participate in home-intervention with her children. As long as [her husband] could afford the therapy, she would be willing to continue the intervention program. None of the parents deeply understood the process of the program or the importance of the intervention techniques, but they still wanted to give therapies to their children just like a drowning man would catch at a straw.

She then described about her plans of joining the occupational therapy sessions beginning next March, which I gladly recommended. When she said, "Thank you, teacher. I just needed the assurance that I was making the right decision," I could feel her ambivalence of whether or not she was making the right choice to best meet her children's needs, although there was no doubt that she was doing everything possible. There was no given solution for her situation, but it was also unfortunate that she did not have access to all of her available options.

2. Shin's Family: mother's demand for school readiness

1) Characteristics of Shin's Family

Short description of the family

Shin: is 4 years old. He has severe, non-verbal autism with the developmental level of 18 months at 31 months.

Shin's mother: is a full-time mother who is very organized. Her intervention goal is to improve Shin's studying attitude. She also spends her day waiting at the EIBI center during Shin's therapy sessions and running a household.

Shin's father: works late hours and is usually very quiet.

Shin's sister: is energetic like her mother. She is 6 years old. She has never talked about her brother's disability with the mother.

Shin is a 4 year-old boy and has been participating in EIBI for 2 years. According to his assessment evaluations, Shin has severe, non-verbal autism with the developmental level of 18 months as shown in Table 4.1. By the time he was 31 months, he only could use two to three noun words and had problems with pace and tone of voice. He interacted with his mother only when he requested for food. The observer's comment in Table 4.1. demonstrated that Shin displayed self-stimulatory and stereotyped behaviors which limited his daily living behaviors. The mother's journal also revealed that his self-stimulatory behaviors recurred frequently throughout the day.

Table 4.2 also demonstrated that he was at developmental level of one year old when he was 31 months. He had lack of imitation skills and fine motor skills but could react an adult's visual and auditory cues. He could perform simple gestures like poking with the stick and holding the stick, but could not participate in more complex tasks such as placing the puzzle in the right place.

Although Shin was reported to have the same developmental level as the developmental level of Hani and Hana, Shin could perform much more skills than the twins. As shown in Table 4.3., Shin had severe autism, yet had mild mental retardation.

This little boy, who somehow reminded me of Winnie-the-Pooh, went through depression last year and used to be lethargic for a long time. Gladly, he seemed delighted and energetic when I saw him during the observation.

I walked into the spacious and luxurious apartment of Shin's family, which was located in a city that was an hour away from Seoul. Shin's mother had been travelling 2 hours back and forth to Seoul every morning for the past 2 years to let her child participate in EIBI.

[Table 4.1 Shin's Assessment Evaluation – 31 months]

Autism Diagnostic Observation Schedule (ADOS): Severe			
Category	Child's score	Autism cut-off score	Further Details
Communication	6	4	He only used 2–3 words appropriately
Reciprocal Social Interaction (RSI)	14	7	He showed deficits in understanding and use of gestures and problems with pace and tone of voice; it is recommended to assist him to imitate other's gestures through repetitive training
Communication and RSI Total	20	12	He requested for food once, but did not request for any other toys. He only responded to those who are close to him. He showed inappropriate laughing at times.
Imagination / Creativity	4	N/A	–
Stereotyped Behaviors and Restricted Interests	4	N/A	He demonstrated self-stimulatory and stereotyped behaviors, which can further limit daily living. Thus, intervention is recommended.

[Table 4.2 Shin's Assessment Evaluation – 31 months]

Psycho Educational Profile-Revised (PEP-R): Developmental Level is less than 1-year old		
Category	Child's score	Further Details
Imitation	1 year	He did not imitate the inspector's gestures
Perception	1 year	He responded to the visual and auditory cues and could react to the other's gestures. He was unable to place the puzzles in the right place.
Fine motor skills	1 year	He could poke the clay and hold the stick with his hands, but he did not participate in the activities such as removing the stick from the brick.
Gross motor skills	2 years	He could throw, kick and carry around the balls, but did not participate in the activities such as clapping hands and placing the puzzle.
Eye-hand integration	1 year	He did not scribble when he was given a crayon and a paper. His eye-hand integration can be improved through placing the puzzles
Cognitive non-verbal behavior	1 year	He could pick the right puzzle when the inspector said 'circle.' He could not point to the right body parts named by the inspector.
Cognitive verbal behavior	1 year 8 months	He could ask for help, but could not use any words.

[Table 4.3 Shin's Assessment Evaluation – 31 months]

Social Maturity Scale		
Social Age	Social Quotient	Range
18 months	57	Mild Mental Retardation

The house was attractively furnished with white ruffled curtains at the window, and the living room was neat and tidy. The walls were beautifully decorated with albums, and there were some math posters and magnet board attached.

Shin seemed very calm and relaxed in contrast to the therapist's description of a boy who could be 'aggressive and extremely stubborn when things don't go his way.' He was quiet as if he did not know how to say a single word. He silently sat on the sofa playing with his toys. As I sat on a chair to write notes and audio record the observations, Shin's mother went into her room and took out two different plastic folders. The folders contained all different kinds of graphs and documents related to Shin.

I carefully explored his diagnostic assessments, performance graphs, 24-HR Analysis/Summary scatter plot, time schedule for toilet training, Behavior Modification check sheet, and data sheet for practicing vocabularies. As I was amazed by how neatly all the documents were organized, I first went through his developmental files and his monthly developmental reports written by a EIBI therapist.

Through intervention, he learned toilet training, eye contacts, and the concept of studying. As Shin became familiar with more words and started using them during intervention, he expressed his needs using nouns and verbs. His mother was sincerely grateful for the therapists who helped him to acquire the basic, yet significant, social skills.

Shin's mother described that it was initially difficult to understand his personality because his tantrums seemed unpredictable. However, as she comprehended that Shin set his own, particular routines to the order of his life, it became much easier to react. For instance, he liked to use a certain toilet, eat his food in a certain order, and place puzzles in certain patterns that others could not recognize. Thus, when his mother

broke these patterns, he used to throw tantrums. As time went on, however, he seemed to give up his patterns to some extent and follow the instructions of his therapist or mother.

As she recalled the intervention process, she emphasized the importance of raising emotionally stable children. Her 6 year-old vivacious daughter, June, still did not know his disability (or pretended as if she did not know about it). This curious young girl asked numerous questions about my research while I stayed for observation, but her mother informed me that June had never asked a single question about her brother. She did not know when to openly communicate with her daughter about Shin's disability.

The children's father did not take much part in their upbringing. I only had chance to meet the father once throughout my visits because he usually came back from work after 10pm or even later.

He claimed to have spent time with June and helped the house chores but only interacted with his son in special occasions. Even when I was around, he spent time with June for a short period and helped the mother with the dishes until I left the house. The father said, "I don't force [Shin] to talk to me. I just let him be comfortable around the house. If he talks, he talks. If he doesn't, he doesn't."

It was the mother who mainly educated and nurtured the two children at home and the father's role was limited to interacting with the children during the weekends or helping the mother with house chores.

2) Mother's experiences with ASD and EIBI

The mother first sought private therapeutic centers when Shin was two. As Shin's challenging behaviors gradually spilled into the family, she found out about EIBI, the center known to be the best at shaping

these behaviors. As the therapists recalled, Shin ‘was still non-verbal, had difficulties sitting at the table, and threw recurrent tantrums’ when he first began his therapy sessions.

Yet the mother continued to doubt her son’s disability during the first few months of the intervention process until she witnessed other children’s similar patterns of behaviors. After 6 months, she brought Shin to the hospital where he was diagnosed as ASD at the age of three.

Even after the diagnosis, she held on to the hope that Shin would be capable of adjusting into new environment with typically developing peers. She reluctantly shared her experience of covertly sending Shin to preschool without telling the therapists at the EIBI center. Since she was convinced that her son’s disability would eventually fade away once he spent time with the typically developing peers, she hoped that the preschool teachers would successfully help his transition to new surroundings. Unsurprisingly, her plan failed miserably.

I thought his behavioral disposition....would gradually fade away as he grow old. But it became even worse. Shin might have a lower cognitive level, but he still felt the same way as his friends. It seemed like he knew that he couldn’t do what everyone else could do. He was sad... and he experienced a lot of failures. My selfishness caused his pain and depression...So I stopped everything. I am still sorry for what I have done to him. He might have just had bad impressions on participating in group activities. But...since he’s more grown, I don’t know, the situations might be different now...?
(Mother)

Attending both preschool and the EIBI center simultaneously caused Shin tremendous amount of stress, which led to his depression and lethargy. One year after the mother and therapists both noticed Shin’s insufficient progress, the mother finally felt the need to change her attitudes. In the second year of the EIBI program, she started to

exchange journals with the therapists, participate in parent training and actively implement behavioral techniques at home.

Since March [of 2017], I started reading books on ABA and ASD... and asked for a lot of help from the therapists. My desperation drove me to do all of this work. What if Shin speaks in staccato when he grows up? This fear was getting bigger. Drawing graphs and scatter plots helped me to see his training improvements and such...Well, I have always liked to keep things organized. (Mother)

Shin's therapist could appropriately involve the mother in the intervention process and the mother knew exactly what activities to engage in with her son. As her main concern was to reduce his challenging behaviors and improve his communication skills, all of her daily journals revealed her efforts to manage his tantrums and improve his speaking abilities. She always recorded her journals in two sections, 'General Message' and 'Language Studying' as shown below.

[Taken from Shin's Mother's Journals]

<i>Date</i>	<i>April 14, 2017 Friday</i>
<i>Shin's Condition</i>	<i>Well</i>
<i>General Message</i>	<i>Just like when Shin struggled with his friend to get the toy car at the center, he threw tantrums when he fought with his sister to get the tablet at home. He hit me hard, but I sternly told him to 'do not hit' and waited until he stopped crying. It took awhile, but he stopped eventually. I hope he studies well today. Have a great weekend!</i>
<i>Language studying</i>	<i>When Shin says 'chug-chug, puff-puff' and I usually repeat after him. Today, I was occupied with something else and forgot to repeat after him, and he loudly shouted 'Chug-Chug, Puff-Puff!!' I never knew he could speak so loudly! hahaha</i>

[Taken from Shin's Mother's Journals]

Date May 24, 2017 Wednesday
Condition Well
 <Observation note on Shin's spitting behavior>
 In his room, he was playing with his
AM 6:00: *saliva after spitting -> ignored his*
behavior
 On the way to the center, he put his
AM 9:30: *fingers in his mouth and tried to spit ->*
ignored his behavior
General
Message *PM 1:30:* *He spitted while he was watching TV ->*
ignored his behavior and directed his
attention to other toys at home
 He got annoyed in the car and tried to
PM 4:30: *spit. Then he immediately took a nap*
-> ignored his behavior and directed his
attention by singing to him
 PM 9:10: *In his room, he was playing with his*
saliva -> ignored his behavior
Language
studying *These are the words that I practiced with Shin today:*
"food" "no" "go" "hi". He said "see-saw"
independently when we went to the playground
together.

'Shin improved immensely since the mother started to fully implement behavioral techniques at home,' said Shin's therapist. The journals clearly showed a gradual decrease in the tendency of his challenging behaviors, and finally, Shin's mother only had to record notes on their speaking practice in the month of August.

[Taken from Shin's Mother's Journals]

Date August 14, 2017 Monday
Shin's Condition Well
General Message *It seems like Shin is curious about many*
things nowadays. Today, he brought the towel
and stared at me in the eyes as if he wanted
to know how to pronounce it. When I slowly

said 'tow-el,' he smiled and repeated 'tow-el.' These days I am a bit worried that his motivations to learn is low, but he has not been showing that much challenging behaviors or tantrums. I feel a lot more peaceful these days :)

The mother was noticeably in control of her son's behaviors. She accounted that the EIBI therapy assisted her to comprehend Shin's personality and the underlying meaning of his disruptive behaviors. Although she 'did not believe that EIBI was the ultimate method to improve Shin's functioning, it was still the best choice for him to learn from numerous repetitive practices.'

Even Shin's mother, however, believed that she had to let her child take a break at home. Such belief was unexpected because she properly implemented the appropriate behavioral techniques at home, unlike Hani's mother. Recalling from Hani's mother's interview, she considered EIBI therapy center as one of *hagwons* and intentionally avoided practicing skills at home to let the children rest. Similarly, Shin's mother perceived the therapy center as a place 'to study.'

During the observation, the mother practiced cognitive and language tasks such as reading cards out loud and/or completing puzzles in less than 30 minutes, and she followed the behavior management procedures for tantrum behaviors. She minimized the 'study time' to reduce Shin's stress at the home setting.

Shin now knows the concept of studying. He understands that the center is the place to study and the house is the place to get rest. That's why he does so much better at the center. (Mother)

Despite Shin's overall improvements, the treatment was not fully expanded in the home setting. Additionally, the family members were not involved in intervention process. Her six-year old daughter and the

father did not interact with Shin throughout the entire observations. They did not understand how to appropriately interact with Shin because he did not show any social initiations to his family members and/or reciprocate their social interactions.

3) Challenges of the child and the mother

I witnessed that the generalization issues prevailed. Shin's mastered target behaviors did not generalize into natural, unstructured settings and did not occur with his family members. For instance, he was perfectly capable of reading cards or counting numbers in a structured table setting, but he did not respond to the cards without the therapist and his reinforcements such as compliments or cookies. Moreover, in an unstructured house setting without the therapist, he did not attempt to voluntarily verbalize any words. The mother always had to start with the first sound in a word, such as 'wa-' to make him say 'water' on his own.

His therapists were unaware of such situation and seemed to be surprised when I discussed these issues during the interview. The therapists were reported to be sensitive and responsive to the mother's concerns, yet they could not provide sufficient support at home.

During the observation, there was one time when Shin had a temper tantrum for 50 minutes because he could not tolerate the concept of waiting for dinner. He only had to wait for 5-10 seconds to get his rewards at the center, and therefore he could not understand the reason for not receiving his food at home, even after 10-long-seconds of waiting.

Shin's mother did not know how to make him wait longer; however, she blamed no one for these problems.

the therapists at the center fully recognize the issues, and I know they

are doing all they can to fix it. I have no complaints with them. It's all up to Shin to overcome the issues...(Mother)

Despite of Shin's generalization issues, she was not distressed about the situation and believed that he would one day overcome the hardship. Even worse, she did not know any professionals to consult with in order to make future decisions for her son. It was not the EIBI therapists' specialty, and the mothers of other children with ASD all had different situations due to their varying symptoms. Her husband was supportive of her decisions, but was not involved in the process of decision making. She was all alone in raising Shin.

Shin's mother also had numerous questions for me as she thought that I was also working as an 'expert.' Most of her concerns were concentrated on the relationship of June and Shin, and how she should reveal Shin's disability to her daughter.

In addition, she had various questions about Shin's school readiness. She was planning to send Shin to an inclusive preschool in the year of 2018, since Shin's condition has improved significantly. However, at the same time, she feared that she might be making the same mistake again. She also had more questions about sending Shin to elementary school in the future: whether she should send both of their children to the same school or intentionally separate them into different schools for June's sake. I could sense her fear that her daughter might become the target of discrimination from her friends. She also added that "I wish she does not have to feel the pressure or burden of having to take the responsibility of taking care of Shin."

As she accepted and comprehended the complex nature of Shin's disability and gained more confidence in guiding her child through the intervention process, she continued to encounter different issues. Feeling of uncertainty continued to exist throughout her journey with her son.

3. Jay's Family: mother's demand for cognitive development

1) Characteristics of Jay's family

Short description of the family

Jay: is 4 years old. He exceeded the ADOS ASD cut-off scores and was reported to have mild-moderate symptoms.

Yoon: is 2 year old. He occasionally attempts to interact with his older brother, but always gets pushed away. He is raised by his grandmother most of the time.

Jay's mother: is a enthusiastic mother who used to study ABA by herself to teach Jay. She spends most of her time waiting for Jay during different therapy sessions such as EIBI, sensory-motor, language, art, music, and physical therapies. She plans to start working after she sends Jay to an inclusive preschool.

Jay's father: works shifts. He may work 12 hours a day for 3 days with the next 3 days off. He wants to know more about Jay, but has little knowledge on his disability.

Jay's grandmother: lives in the same house. She still does not accept that Jay has a disability. She takes care of Jay's younger brother when the mother is not around.

Jay's symptoms are less severe compared to those of Shin, Hani and Hana. He has been diagnosed to have mild-moderate symptoms with developmental level of 18 months at 33 months. Given that three participant children aged from 42 to 55 months, Jay could use much more vocabularies and performed complicated tasks utilizing cognitive, play, and social skills than other two participant children.

The mother explained that he already memorized more than 100 melodies and sang the songs that explained the situations when he was 2 years old. For instance, if he wanted to play with a robot, he sang a song about a robot. He understood and spoke of the world through

the melodies.

When he was 33 months, he could only say four words and his pronunciation was unclear as shown in Table 5.1. As Jay's therapist recalled, no one could understand what he said. He only made eye-contacts when he needed something. He had an understanding that making eye contact is necessary to express his needs. The ADOS report also explained that he repeated the same words throughout the observations. From my observations, I found out that this problem still existed.

He could perform most of the simple tasks such as playing along with clay and peekaboo, matching shapes and colors, stacking blocks and follow simple verbal instructions, but he had difficult times reacting to the questions. Thus, as shown in Table 5.2. and Table 5.3., he had high levels of cognitive abilities and had mild mental retardation, yet still needed to improve his social and communicative abilities.

Moreover, he did not have any self-help skills other than dressing up at the time. Surprisingly, compared to Shin who already learned how to independently go to a toilet and eat by himself, Jay still did not have any of these autonomy skills at the time of observation.

The mother said he has been participating in the EIBI program for a year and a half. Jay's house was almost an hour and a half away from the center. Among three participant families, Jay's family lived in the smallest house with five family members. The house shook to the sound of vivacious boys — the sound of their romping feet and squeals as they played with their mother and the balloon. Jay pulled the balloon string while watching it fluttering around the house. His younger brother, Yoon, happily followed him behind and tried to pull the string as well. However, such excitement did not last for a long time.

[Table 5.1 Jay's Assessment Evaluation – 33 months]

Autism Diagnostic Observation Schedule (ADOS): mild-moderate			
Category	Child's score	ASD cut off score	Further Details
Communication	4	2	He had 4 words that he knows and uses but the pronunciation was hard to understand (ex: etaki/ah-yo).
Reciprocal Social Interaction (RSI)	11	7	he reacted to his name but had difficulty following instructions; He dragged the inspector's hand when he needed something.
Communication and RSI Total	10	7	He made eye-contacts only when he needed something. He reacted to his name and only to familiar instructions
Imagination / Creativity	2	N/A	Obsession on trains or vehicles was observed
Stereotyped Behaviors and Restricted Interests	4	N/A	He repeatedly said the same words. He imitated the motion of car moving and the action persisted for awhile.

[Table 5.2 Jay Assessment Evaluation – 33 months]

Psycho Educational Profile–Revised (PEP–R): Developmental Level is less than 18 months		
Category	Child’s score	Further Details
Imitation	17 months	He played along with clay and peekaboo. He could imitate the action one by one but not sequentially. He imitated sounds with inaccurate pronunciation.
Perception	3 years 6 months	He could match figures, shapes, sizes, and colors.
Fine motor skills	2 years 5 months	He picked up things with his thumb and index finger. He could put strings into beads.
Gross motor skills	2 years 8 months	He could walk alone, clap hands, climb up a stair, and drink water with a cup.
Eye–hand integration	2 years	He could stack 3 blocks, solve puzzles, and color with color pencils
Cognitive non–verbal behavior	2 years	He could follow simple verbal instructions and could distinguish body parts. He could not point to the objects that the inspector was telling him about.
Cognitive verbal behavior	1 year 5 month	He asked for help by pulling the inspector's hands and was not able to react to the questions.

[Table 5.3 Jay’s Assessment Evaluation – 33 months]

Social Maturity Scale		
Social Age	Social Quotient	Range
18 months	57	Mild Mental Retardation

Having difficulties interacting with his peer, Jay occasionally pushed Yoon out of the way to be alone with the toys. Yoon would then burst into tears and start hitting his mother to show his anger. The mother had to play with her younger son alone to separate him from Jay.

Jay showed his obsession for a long string and enjoyed playing with the string tied to the end of the balloon, playing with a tape ruler, and unrolling the scotch tape. When the mother stopped him from playing with these objects, he would uncontrollably collapsed into his mother's arms and burst into tears for 10–20 minutes. Even if I observed him crying several times, in her interview, she did not perceive him as a difficult child. On the other hand, the EIBI therapist perceived Jay as a difficult child whose tantrum behaviors should be managed across settings.

He was always very stubborn with a long string, and I knew that the mother had difficulties taking it away from him. I mean, Jay would have meltdowns constantly. But when I asked her if she was okay, she just said 'my child is easy to handle. I want him to study more.'
(Mother)

It was interesting that during the interview, she revealed her difficulties by commenting that '[she] stopped her friend from getting married because [she did] not think having a child is a good thing.' She even asked me, the researcher, to not get married by saying, 'how do I look? Do you really want to live like this?'

Fortunately, her mother-in-law was living in the same house and helped her with running a household and taking care of Yoon during the day. During the observations, Jay's grandmother spent time in her room with Jay's father watching TV, prepared for dinner and/or did laundry. Jay's mother whispered to me that the grandmother still has not accepted Jay's disability and wanted me to reassure her that he was

normal (chungsang).

When both Jay's grandmother and mother were in the kitchen preparing for dinner, Jay's father came out to the living room and sat on the sofa. As the mother asserted, 'just like any other men, he [did] not know how to play with his children.' Even if he was in the living room, he just stared at his phone on the sofa, waiting for dinner. When Yoon was doing a puzzle, he sat next to him and tried to help him only when the mother asked the father to do so. He sometimes spoke to Jay, but Jay never looked or responded to his father.

Unlike Shin and Hani's fathers, Jay's father worked two to three 24-hour shifts, followed by two to three consecutive days off duty. He sometimes drove Jay to therapy centers and consulted with the therapists when he was off duty, but was very unfamiliar with the situations and could not bring up questions that he had in mind.

Jay's language therapists was like, Jay needs to interact more and make more eye contacts. Please practice them at home. So I was like okay...yes, he needs to practice...(laugh) But I could not really ask any more questions at the time. What do I have to do? I say 'look at me' all the time but he never looks at me! What do I have to do?
(Father)

The father still encountered difficulties properly interacting with his son with ASD even if he had more time with his sons than other fathers in this study. However, I could sense that he was willing to learn more about how to communicate with Jay.

2) Mother's experiences with ASD and EIBI

Jay's mother has been sending Jay to several therapies such as sensory-motor, language, art, music, and physical therapies since Jay was 15 months old. She said when she first realized that her son had problems making eye contacts, she began play and music therapies.

Jay was diagnosed as ASD at 20 months at the hospital and was recommended to receive more language therapies. It was when she began to send Jay to language therapies and participated in Mother-Child Attachment therapies sessions with him for a year. In line with previous findings of Grinker (2007), the mother's participation in Mother-Child Attachment therapies showed that she preferred her son to have Reactive Attachment Disorder instead of ASD.

She learned about Applied Behavior Analysis in one of her parent training sessions at the hospital. Jay's mother first studied behavioral techniques on her own and made an effort to teach Jay at home. However, her attempts failed miserably as her son did not even sit properly for 30 seconds. Finally, the mother decided to participate in EIBI programs when Jay was 33 months, and again visited hospital to get a diagnosis of ASD.

When I used to implement behavioral techniques at home by myself, it was even difficult to make [Jay] sit. Like, even if I say 'raise your hands,' he would totally ignore me...It was hard. Maybe I didn't have the right techniques...And wow, he was sitting on the chair doing things that I never expected him to do when he started to participate in the EIBI program. There were so many things he could do. And yeah.. I think I didn't have the ability to figure that out on my own. Hahaha. it is the expert's specialty to bring out abilities of the child and nurture their talents. (Mother)

Jay's mother was especially content with his cognitive improvements and focused on assisting him to practice those skills at home. Although Jay was diagnosed as ASD twice, the EIBI therapist insisted that Jay's mother still perceived Jay to be just 'developmentally delayed.' The therapist believed it was the reason why she only focused on improving his cognitive abilities. The therapist shared her experience of the first meeting with Jay's mother on March, 2017.

I remember the first time meeting with Jay's mother on March.

All the other mothers mostly talk about their difficulties handling child's tantrum behaviors or making them speak. But Jay's mother only mentioned that her son is very tractable and she only wants him to focus on studying. (Therapist)

As Park and Chung (2015) discussed that mothers of children with mild disabilities have harder times letting go of their hope for change and normalcy, Jay's mothers also tried harder to improve Jay's conditions.

She engaged in various cognitive activities with Jay such as playing with the puzzles, counting numbers, and identifying objects in books at home. Everything seemed well until around the dinner time when I noticed something distinctive about the mother's reaction to Jay's wetting.

After I observed Jay's wetting several times during the day and asked about his toilet training, the mother responded casually. "He can use the toilet at the center. I heard he never makes mistakes there." She did not seem to be particularly working on toilet training with her son at home. Moreover, the mother spoon-fed him for the whole time while he was walking around the house.

It came to me as a surprise because even Shin, who was younger and had more severe symptoms, voluntarily used fork and spoon during the meal time. Jay's self-help skills were not supported, yet the mother was paying little attention to these autonomy skills and the therapist was unaware of the situation.

He's been done with his toilet training for awhile...It's too bad he still wets himself at home....You see, Jay's mother...well, she usually talks about how well Jay did with his studying at the center, and she worries a lot about it too. When we first did number matching, she was worried that he might have learning disabilities such as dyslexia. He definitely needs to enhance his self-help skills and behaviors, but she only thinks he's just a bit late. Her focus is on cognitive skills. (Therapist)

It was apparent that the mother perceived the EIBI center to be the place to study cognitive skills and to prepare him for preschool. Besides, Jay's grandmother's denial of disability might have also pressured her to send her son to school with typically developing peers, and thus made her solely focus on enhancing cognitive performance.

Furthermore, just like the other participant mothers, Jay's mother believed that she just had to let her child 'play with water and let him do whatever he wants to do' at home. It was in contrast with the earlier findings that mothers undergoing EIBI program experienced high levels stress when using behavior strategies at home (Smith, Buch, & Gamby, 2000).

In fact...I don't have that much difficulties. Hahahaha.I just let him do whatever he wants to do and let him play with water...I might not be paying that much attention? Um...When I let him play on his own, there aren't many parenting challenges. (Mother)

Overall, it could be concluded that even if the mother participated in the EIBI program for 18 months, she partly wished that she only had to reduce cognitive impairment. As a result, the mother did not feel the need to improve other skills and did not ask the other family members to participate in the intervention process.

3) Challenges of the child and the mother

Expectedly, Jay also suffered from generalization issues with his family members. He was able to follow mother's instructions but had difficulties responding to his father. Jay's father used sentences that Jay would never respond to. For instance, not knowing that his son only responds to "Jay, close the door", he said, "That's not right Jay. You have to close the door. Hey, you need to close the door." Jay could not react to such complicated sentences.

Not knowing what to do, the father just patted him on the head for a short time or just stared at Jay playing with toys. Because both therapists and mothers perceived that it was realistically difficult for other family members to learn how to systematically interact with the child using the behavioral techniques, they both held back in telling the family members what to do.

As you see, there are things that Jay would do only with his mother, but not with his father and grandmother. Well, I know it's hard to talk his father or grandmother about it, but I do ask his mother to practice these behaviors at home. (Therapist)

Even though Jay displayed deficits in self-help skills and generalization issues with his father, Jay's mother's beliefs that there were no issues at home prevented her from honestly communicating with the therapists.

[Asked about whether Jay's therapist helps her in anyways to support Jay at home] Well, I don't really talk to her about what's going on at home. For example, if I ask Jay did this and this and this, what should I do? She answers to my questions and help me through the process, but other than that, I don't ask her about other things...Well, I mostly just ask her about what he learned at the session. (Mother)

In the year of 2018, Jay will be attending preschool which has classes for children with special needs. Jay's mother also expects to quit EIBI center once preschool begins due to the distance of traveling back and forth.

Although the therapists still had 'concerns with Jay's tantrum behaviors which occasionally occurred when Jay had to share his toys with the other people', the mother showed no sign of fear or worries at least during the interview and the observations. Although she commented that it was difficult to raise a child with ASD because

every child has different symptoms and there was no guidelines to follow, she had no doubt that her son would adjust well in the new preschool environment.

Throughout the interview, she completely trusted that therapists would manage her son's overall behaviors and skills and further bring out the best intervention outcome. This faith might have contributed to her confidence that she had everything in control, even though in actuality, she still was facing various issues across settings. She did not consult with anyone throughout decision making process, when she planned for her child's future course. Whether she realized it or not, she separated herself from the world and decided what would be the best for her child by herself.

V. Discussion

In this study, I hoped to gain a deeper insight into three unique families of children with ASD and how Korean mothers perceived their children's disability during the EIBI process. The goal of this study was to understand the mothers' experiences with the disability and the intervention process within the Korean culture.

Overall, the study confirmed the results of the previous studies that showed how Korean mothers were still unaware and/or in denial of their children's disabilities. Similar to the study of Park and Chung (2015), the conditions of a child's disability affected the mothers' perceptions. For instance, Hani and Hana's mother accepted her children's disabilities after recognizing severe symptoms and developmental delays, while Jay's mother had more difficulty of accepting her child's mild disability probably because the conditions were not so severe.

As Grinker (2007) described, Jay's mother initially participated in Mother-Child Attachment therapy sessions to cure her child's Reactive Attachment Disorder for few months before realizing that Jay's conditions did not get better. Moreover, she tried harder to increase Jay's cognitive and linguistic abilities by attending more therapies than Hani and Shin's mother. She believed that he would eventually be able to excel in school and get along with other typical children.

Regardless of the severity of her child's symptoms, Shin's mother still could not fully accept and understand the child's disability. Because of the mother's lack of knowledge and false belief that the disability would someday just disappear, Shin had to face the challenge of attending preschool with typically developing peers without any monitoring from professionals. Moreover, because Shin continued to

attend the EIBI sessions in the afternoon, he was physically and emotionally exhausted from battling tremendous amount of stress and anxiety.

There were also cultural influences that led to the mothers' misconception. Although the purpose of the EIBI program was to increase the overall functioning level of children with ASD to that of a typical child, the mothers used EIBI as a tool to promote a specific area of development.

Hani and Hana's mother thought that increasing cognitive skills was useless and wanted to focus instead on developing the twin's social competence. Similarly, Jay's mother insisted that her only goal was to increase Jay's cognitive abilities, despite of the therapists' suggestion to include programs that would help Jay's self-help skills. The two mothers made personal judgments on which training techniques to implement at home, believing that those techniques would be most beneficial for their children. Such result validated the finding of Grinker and Cho (2013), which demonstrated that Korean mothers were denying the fact that ASD was a pervasive disorder and thus only desired to improve specific skill deficits.

Another problem was that the Korean mothers perceived EIBI as a *studying* program to learn skills rather than as intervention sessions. Mothers have repetitively described that their children were *studying* at the center, not mentioning that they were actually getting therapies. Shin's mother even asserted that her main goal of the intervention was to develop his *studying attitude* through the EIBI's structured studying environment. Because of *kyoyukyul*, the excessive passion towards education, and the mothers' denial of disability, the mothers seemed to perceive the intensive intervention program as private tutoring services for children with ASD. They believed that children should fully rest at

home and sometimes intentionally avoided implementing behavioral techniques.

Moreover, due to the Confucian belief that mothers are fully responsible for child rearing, none of the family members other than the mothers participated in implementing the behavioral techniques (You & McGraw, 2011). Three full-time mothers spent unbelievable amount of time for their children and doing households. They had little support from their families throughout intervention process

The families' perceptions of the disability and the intervention also influenced the children's generalization problems. The children were unable to use social skills with family members other than the mothers and could not transfer their skills to different settings. It has been well understood that intervention within a specialized setting is not sufficient to produce a generalized change of behavior and that all family members should be involved in transferring the attained skills to other environments (Egel & Powers, 1989; O'Donnell, Tharp, & Wilson, 1993). When family members failed to properly implement the techniques at home, all of the gains that had been achieved through training might be lost in environments other than the therapy center (Witt, Martens, & Elliot, 1984). To prevent such generalization problems, the EIBI professionals have to make sure that all family members know the importance of continuing the EIBI process at home.

During my observations and interviews, I also had witnessed cultural influences on the mothers' decision making process for their children's future plans. Because the mothers refused the free special education services offered by the government, they had very little or no information on how to appropriately support their children in the future. All three mothers took full responsibilities of raising their children without any support from the families or professionals, so they

were completely alone in the decision making process of their children's therapeutic and educational needs. They asked me whether to send their children to other therapies and/or inclusive schools next year or to hire agents for personal assistance. Hani and Shin's mother continuously demonstrated her fear of failing to make the best decisions for the children, and Jay's mother talked about the difficulties associated with not having any specific guidelines for children with ASD.

All mothers had difficulties during and even after the intervention process due to the absence of the government and professional support even when there were a wide range of social services available for them. This cultural phenomenon of not accepting children's disabilities resulted in the need for further research on how to effectively implement EIBI and other early intervention strategies within the Korean context.

Limitations

The first limitation of this study was the presence of the researcher. Given that the researcher had been working at the center for more than a year, the mothers might have viewed the researcher as a therapist and avoided negative comments about therapists during the interview. Additionally, the participants might have acted differently in the presence of a new person during the home observation and attempted to hide any negative behaviors. The second limitation was the sampling process. Since all the participants were chosen from the same center and self-selected, the process could not be considered as random sampling. It is hard to generalize the findings as other mothers and therapists might have different experiences and opinions. Understanding the limitations, future studies should include more participants from different backgrounds in order to achieve further results.

Implications

Despite some limitations noted above, there are several implications for the process of collaboration between professionals and parents of children with ASD in Korean context. This study suggested that professionals need to be fully aware of family's adaptation process to disability and especially the behavior analysts need to consider family's circumstances when implementing behavioral strategies across settings.

In addition, the need for parent education is evident. Professionals in the related special education field should recognize that there needs to be more professional guidance since the early stage of child's diagnosis of ASD. By providing practical information on child rearing and education, professionals should help parents understand the unique characteristics of ASD and how to cope with the disability.

It is also important for both EIBI therapists and parents to acknowledge that the key to successful intervention is full participation of all the family members in process of behavior support. To design the optimal interventions and support for children, the support plan should not only involve the center-based program to promote children's overall socially significant skills but also reflect the realities of the physical and social environments out of the center (Dunlap & Fox, 2007). Although EIBI is scientifically proven to be the most effective in developing child's overall skills, if these skills are not appropriately implemented in different settings, we cannot say such intervention outcome has been gained and maintained.

Lastly, there needs to be more evidence-based research conducted across different settings in Korean context. By establishing more research outcomes, the increase in awareness of EIBI will lead to increasing acceptance of ABA in public special education programs, which would lessen financial burden of parents of children with ASD

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Appendix

Basic Survey Questions

(A) Questions specific to Mothers

- Basic personal questions
 - Child's Age
 - Period of Diagnosis
 - Hours of stay at the center every week
 - Other attending centers
 - Monthly income of the family
- Developmental Characteristics
 - How would you describe the child?
 - What are some of the developmental characteristics?

(B) Questions specific to therapists

- Basic personal questions
 - Age
 - Length of Career
 - How long do you see the target child every week?
 - How long have you known the target child?
 - Type of certification
- Developmental Characteristics
 - How would you describe the child?
 - What are some of the developmental characteristics?

Interview Questions

(A) Questions specific to Child with ASD (therapists/Mothers)

- Basic personal questions
 - Period of Diagnosis
 - Where they were diagnosed
 - Length of time receiving ABA intervention
- Overall intervention goals for the target child
 - What were the goals of the intervention? Why?
 - What were some of the child's intervention gains?
- Difficulties
 - Have you experienced any difficulties with the child?
 - Why was it particularly difficult?
 - Why do you think it happened?
 - Did you get any help to handle such difficulties?

(B) Questions specific to therapists

- Opinions on the observed scenes at each family's house
 - How is the child acting differently from the center?
 - Were you already aware of these situations?
 - What do you think the family should do?
 - What would you have done differently if the same thing happened at the center?
- Opinions on working with mothers
 - How do you support the child and family in and out of the center?
 - Is the family cooperative in supporting the child throughout the intervention?
 - What do you think is the most important thing to do for the family to support child's behaviors and skills across

settings?

(C) Questions specific to Mothers

- Opinions on using ABA techniques out of the center
 - Do you try to implement behavior strategies at home?
 - Why do you think it is / it is not necessary?
 - What difficulties do you have when implementing ABA at home?
- Opinions on child's behaviors across settings
 - Has the child shown any improvements at home as well?
 - What do you do if you have any troubles with child's behaviors outside the center?
- Opinions on working with therapists
 - Do you think therapists also support you and the child outside the center setting? If they do, how?
 - Is it easy to communicate with therapists at the center? Are they responsive to your opinions and thoughts?
 - If there is anything you would like to change about the intervention program, what would it be?
 - Do you have any difficulties working with therapists at the center?

초록

한국에서의 장애에 대한 부정적인 인식이 한국의 자폐아 부모들의 장애 자녀 양육에 부정적인 영향을 끼치고 있다. 하지만 최근 자폐에 대한 인식이 높아지면서 자폐 자녀의 치료나 교육에 대한 수요도 많아지고 있으며, 그 중 서구에서 이미 지난 60년간 과학적 효과가 증명된 조기집중행동중재 (Early Intensive Behavior Intervention, EIBI)에 대한 수요도 늘어가고 있다. EIBI는 학습과 동기 부여에 대한 과학적 원리를 사용해 행동변화를 이끌어내는 중재 방법으로 자폐성 아동의 전반적 발달에 주요한 모델로 부각되고 있다.

EIBI가 개별 자폐아동의 발달에 미치는 연구들이 한국에서도 많이 이루어지고 있지만, 아직 장애 수용도가 낮고 부정적인 인식이 있는 한국 사회 맥락에서 가족들이 자녀의 장애와 EIBI를 어떻게 경험하고 있는지에 대한 연구는 부족하다.

이 연구는 자폐아 가족의 삶을 들여다보면서 가족들이 자녀의 장애에 어떻게 대처하는지를 알고자 한다. 그리고 EIBI를 받고 있는 가족들의 삶을 살펴보면, 장애에 대한 가족의 대처과정을 중재 과정 속에서 살펴볼 예정이다.

연구문제는 다음과 같다.

1. 부모는 자녀의 장애와 중재 과정을 어떻게 인식하고 있는가?
2. 부모의 자녀의 장애와 중재 과정에 대한 인식이 중재효과에 어떠한 영향을 미치고 있는가?

본 연구에서는 3살짜리 자폐아 3명(경도장애 1명, 중증장애 2명)과 아동의 어머니, 그리고 응용행동치료사들을 수집하였다. 각 가족의 집에는 평균 2.5시간씩 3번 방문하여 관찰하였고, 관찰이 끝난 이후에는 어머니와 치료사들을 인터뷰하였다. 주제범주화 분석을 통해 인터뷰, 관찰기록, 치료센터의 행동리포트 등을 수집하고 어머니가 개인적으로 자녀에 대해 작성한 일

지도 수집하였다.

연구결과로는 어머니가 장애의 수준에 따라서 장애를 수용하는 정도도 다른 것으로 나타났으며, EI/BI를 아동의 전반적 발달을 돕는 중재라고 생각하기 보다는 특정 분야에서의 발달을 돕는 장치라고 생각하는 경향이 있는 것으로 나타났다. 또한 가족 모두가 가정에서 행동중재에 참여하는 것은 어렵다고 생각하여 어머니가 혼자 중재에 참여하는 경우가 많았기 때문에 아동이 어머니 외의 가족과는 상호작용 하는 것을 어려워하였다. 결과적으로, 본 연구는 한국사회에서 장애부모를 지원하는 전문가들이 앞으로 부모들의 장애수용과 조기중재에 있어서 어떻게 도울 수 있는 지에 대해 도움을 줄 수 있을 것이다.

주요어 : 자폐스펙트럼장애, 조기집중행동중재, 장애수용

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