

Families' Perceptions of Community Inclusion for Their Young Children with Disabilities: A Comparison of Korean and American Families

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《요 약》

This article reports the outcomes of a qualitative investigation of the differences and similarities in Korean and American parents' perception regarding the opportunities their preschool child with disabilities has for inclusion in community activities and the factors that influence their child and family's access and participation. The present study represents an extension of a previous study (Kim & Horn, 2008) in which the perceptions of Korean families was investigated. Utilizing essentially the same procedures including the same interview protocol, seven American families living in the Midwest region of the US were interviewed and their responses were then compared and contrasted to those of Korean families from the previous study. The findings noted that overall reports on participation in community activities were very similar between the Korean and American families, while reports on perceived benefits, barriers experienced, and needs for supports and services were differed between the two groups. Such differences may be explained by the different cultural and societal values and beliefs as expressed by the families. Furthermore, the differences in the longevity and role of special education policy and law appear to influence the outcomes.

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I . Introduction

A core principle of inclusion is to maximize children with disabilities and their families' participation opportunities in their natural settings including home,

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community, and educational settings (Beckman & Hanson, 2002; Dunst, 2001; Guralnick, 2001; Guralnick, 2005; Schwartz, Sandall, Odom, Horn, & Beckman, 2002). Participation in everyday community contexts provides children with a variety of learning opportunities including the opportunity to interact with many different people and materials and to learn the social and cultural expectations in terms of the rules, roles, and routines of successful participation (Beckman et al., 1998; Dunst, Harmby, Trivette, Raab, & Bruder, 2000; Dunst; Guralnick; Kim & Horn, 2008). Furthermore, it has been suggested that children with disabilities may improve their developmental and life skills from such everyday, typically occurring diverse learning opportunities (Bruder, 2001).

Despite confirmation of the considerable importance of community inclusion, several challenges limit community participation of children with disabilities and their families. Specifically, previous studies (i.e., Beckman et al., 1998; Beckman, Hanson, & Horn, 2002; Guralnick, 2005; Kim & Horn, 2008; Odom, Brown, Schwartz, Zercher, & Sandall, 2002; Stoneman, 2001) have identified three primary challenges. First, the negative attitudes of the general population toward people with disabilities can limit children with disabilities and their families' ability to fully access and participate in community activities (Kim & Horn; Odom, et al., 2002; Stoneman, 2001). Second, parents often report a lack of time and energy for themselves because they are so tied to their child's schedule (Guralnick; Kim & Horn). Third, parents of children with disabilities may lack sufficient financial or informational resources and supports to easily access community activities (Beckman et al., 1998; Dunst, 2001).

The experiences and perceptions of the families from individual countries and cultures regarding the community integration of their children with disabilities may be best understood through the filter of their common as well as unique cultural and societal backgrounds. People with disabilities and their families regardless of their cultural and societal backgrounds have historically experienced difficulty in participating fully in their community (Beckman & Hanson, 2002). However, the kinds and the degree of difficulties encountered in participating in community activities may be different due to their different cultural contexts. Hanson and Zercher (2001) define the culture context as, "Culture typically refers to the tendencies or shared perspectives of a group of individuals and includes all facets of life, such as values, beliefs, behavior, and ideas (p. 414)". Furthermore, they noted that members in a culture and society may have a common framework for their lifestyles based on the cultural orientation. Finally, Hanson and her colleagues (1998)

reported that cultural and societal backgrounds and experiences influence a family's knowledge and view about community integration.

Thus following the premise noted above, (i.e., that the influence of cultural and country may best be understood through the filter of common as well as unique cultural and societal backgrounds), the purpose of this study is to understand the differences and similarities in the perspectives and experiences of American and Korean children with disabilities and their families regarding their community inclusion opportunities and the factors that influence access and participation in these activities. Three specific research questions related to community participation of Korean and American families will be addressed: (a) what are the types of community activities American and Korean children with disabilities and their families participate in and how are they similar or different for the two groups? (b) what factors do American and Korean families identify that influence (either positively or negatively) their child's access to and participation in community activities and how are they similar or different for the two groups? and (c) what are the supports American and Korean families identify as needing in order to increase their child's participation in community activities and how are they similar or different for the two groups?

II. Method

To best address the set of research questions posed, the decision was made to utilize qualitative research methodology. Qualitative methodology is appropriate for investigating participants' perspectives of a phenomenon of interest (Merriam, 1998; Rossman & Rallis, 2003; Rubin & Rubin, 2005). In this study, qualitative methods were employed to generate depth of understanding of the nature of the differences and similarities between the American and Korean families' perception of the importance and ease with which their young children with disabilities participate in inclusive community activities. A semi structured interview approach was determined to be the best technique for gaining in depth stories from the parents (Merriam). The same interview protocol that was used for an initial study with the Korean parents was used with the American families. The following sections describe the participants and the process for data collection and analysis.

1. Participants

In addition to the ten Korean parents from the initial study (Kim & Horn, 2008), the researcher recruited participants in the Midwest region of the US by contacting school districts and local parent association. The target population was parents of preschool aged children with disabilities who were currently attending an inclusive preschool educational program. Through this process a total of seven American families including seven mothers, four fathers, and one grandmother consented to participate.

Table 1 presents a brief summary of the demographic characteristics of the Korean and American families including age, race and ethnicity, marital status, family income, and educational level. The five of the seven American families were native born American citizens. Of the remaining two families one family's cultural heritage was Indian. That is, while the mother was a first generation Indian American, the father was born and raised in India and had been living in the US for more than 10 years. For the seventh family, the mother originally came from England, married an American and had been living in the US since coming for her college education. All the seven American families spoke English as their first language except the father who was born and raised in India. All the ten Korean families were native Koreans and spoke Korean as their first language living in big cities of South Korea. Specifically, five of the ten families lived in the northwest region of Korea and the remaining five lived in the southeast region of Korea.

All participants had at least a high school diploma but their educational level ranged from a high school diploma to a doctoral degree. The socioeconomic status of all of the participants would be considered middle class but they did range within this from lower middle to upper middle. All participants were married except one American mother who was a single parent at the time of interview. This single mother lived in her parents' home with her two children. All other families' household, both the Korean and American included a husband and a wife living together with their child(ren) without any extended families in the same household at the time of the interview.

Table 1 Parent Demographic Information

	Korean (%)	U.S. (%)
Relationship with the child	Mothers (<i>n</i> =10, 100%)	Mothers (<i>n</i> =7, 100%); fathers (<i>n</i> =4, 57%); grandmother (<i>n</i> =1, 14%)
Age	20's (<i>n</i> =1, 10%); 30's (<i>n</i> =7, 70%); over 40 (<i>n</i> =2, 20%)	Mother and grandmother: 20's (<i>n</i> =1, 14%); 30's (<i>n</i> =5, 72%); over 40 (<i>n</i> =1, 14%)
Race/ethnicity	All Korean (<i>n</i> =10, 100%)	Father: 30's (<i>n</i> =3, 75%); over 40 (<i>n</i> =1, 25%) Asian (Indian) (<i>n</i> =2, 16%); white (<i>n</i> =10, 84%)
Marital status	All married (<i>n</i> =10, 100%)	Married (<i>n</i> =11, 92%); single mother (<i>n</i> =1, 8%)
Family members	All Parents & their child(ren) (<i>n</i> =10, 100%)	Parents & their child(ren) (<i>n</i> =6, 86%); grandparents, a mother and her children (<i>n</i> =1, 14%)
Status of employment	All full-time homemaker (<i>n</i> =10, 100%)	Fathers: all full-time job (<i>n</i> =4, 100%) Mother and others: full-time job (<i>n</i> =2, 25%); full-time homemaker (<i>n</i> =3, 38%); part-time job (<i>n</i> =3, 38%)
Socioeconomic status	All middle class (<i>n</i> =10, 100%)	All middle class (<i>n</i> =7, 100%)
Highest degree in education	High school graduate (<i>n</i> =2, 20%); some college (<i>n</i> =3, 30%); bachelor (<i>n</i> =4, 40%); master (<i>n</i> =1, 10%)	High school graduate (<i>n</i> =1, 9%); some college (<i>n</i> =1, 9%); bachelor (<i>n</i> =5, 42%); master (<i>n</i> =2, 16%); doctoral (<i>n</i> =3, 25%)

Table 2 summarizes information about the children with disabilities and their siblings including their ages, diagnoses, and gender. The four of the seven American children and the eight of the ten Korean children had a diagnosis of developmental delay. Of the three remaining American children one had a diagnosis of Down syndrome, one a diagnosis of pervasive developmental delay and the third autism spectrum disorder. Of the two remaining Korean children one had a diagnosis of mental retardation and the second had not been diagnosed but was considered at significant risk for subsequent diagnosis of developmental delay. The five of the American children were boys while two were girls with the eight of the Korean children boys and two girls. Of the seven American children, three had at least one typically developing sibling, two of the children did not have a sibling, one was expecting to have a younger sibling, and the seventh child had a first grade aged sibling with autistic spectrum disorder. For the ten Korean children, only one did not

have at least one typically developing sibling, while none had a sibling with a disability.

Table 2 Child Information

	Korean (%)	U.S. (%)
Diagnosis	Developmental delay ($n=8$, 80%); mental retardation ($n=1$, 10%); not diagnosed yet ($n=1$, 10%)	Developmental delay ($n=4$, 57%); Down syndrome ($n=1$, 14%); autistic spectrum disorder ($n=1$, 14%); pervasive developmental delay ($n=1$, 14%)
Gender	Boys ($n=8$, 80%); girls ($n=2$, 20%)	Boys ($n=5$, 71%); girls ($n=2$, 29%)
Age	3 years old ($n=2$, 20%); 4 years old ($n=5$, 50%); 5 years old ($n=3$, 30%)	3 and a half years old ($n=1$, 14%); 4 years old ($n=4$, 57%); 5 years old ($n=2$, 29%)
Number of sibling(s)	None ($n=1$, 10%); one sibling ($n=8$, 80%); two siblings ($n=1$, 10%)	None ($n=2$, 29%); one sibling ($n=3$, 43%); two siblings ($n=1$, 14%); other (one expecting) ($n=1$, 14%)
Gender of sibling(s)	Girl(s) ($n=6$, 60%); boy(s) ($n=4$, 40%)	Girl(s) ($n=2$, 29%); boy(s) ($n=3$, 43%); unknown yet ($n=1$, 14%)
Age of sibling(s)	Less than 2 ($n=1$, 10%); 3 years old ($n=1$, 10%); 4 years old ($n=1$, 10%); 6 years old ($n=2$, 20%); more than 7 years old ($n=5$, 50%)	Unborn ($n=1$, 14%); less than 1 year old ($n=1$, 14%); 1 year old ($n=1$, 14%); four years old ($n=1$, 14%); five years old ($n=1$, 14%); six years old ($n=1$, 14%)

2. Data Collection

As in the initial study (Kim & Horn, 2008), a semi structured interview was used to gather family thoughts and perceptions. An interview guide was developed in the initial study based on the study purpose, a review of literature on inclusive community activities, and discussion and review by knowledgeable colleagues. For the current study, the initial study interview served as the base for developing the interview guide for the American families. The purpose of the guide was to keep the interview format consistent. Guiding questions helped ensure that all the Korean and American parents had similar opportunities to share information. This type of interviewing was used to gain certain types of information, yet the particular phrasing and order of questions varied in response to the direction and flow of the interview.

Minor changes were made in guiding questions for the American families as

necessary to accommodate for linguistic, cultural, and societal differences. As with the initial study, the modified version of the guide was piloted to identify weaknesses in the interview guide, to recognize possible sources of confusion that needed rewording and to receive feedback from individuals who had an “insiders’ perspective” (Arksey & Knight, 1999). The final interview guide contained 7 questions that can be viewed in Table 3. The interview guide served to facilitate the interview rather than control the interview process. Additional follow up questions or probes were asked if further information was needed for a specific question or response. The researcher tried to be respectful, non judgmental, and non threatening during the interview sessions (Merriam, 1998).

Table 3 Interview Protocol

1.	Tell me about some of the community activities that your family participates in with (child’s name).
2.	With whom does (child’s name) usually participate in these activities (e.g., siblings, neighbor children, preschool classmates)?
3.	How did you find out about these activities? [Who is the key informant? What is the key information source? (e.g., through your teacher, friends or acquaintance, or through books, magazines, newspapers, or internet)]
4.	Once you found the activity, how did you go about getting (child’s name) ‘enrolled’ or participating? Were there any challenges or barriers to getting (child’s name) enrolled? If yes, please describe them. Describe some of the procedures or things programs did that were helpful in getting (child’s name) enrolled or participating.
5.	What are some of the factors that have made you decide to have (child’s name) continue with these community activities? (a) What are some of the challenges or barriers you experienced for on going participation? (b) What has been helpful in supporting on going participation?

6. What benefits do you believe your child and family gain through participation in community activities?

7. (a) What supports have you and your child received as a result of participating in community activities?

(b) What additional supports do you think would be helpful for your child and family as you participate in community activities?

The interviewer is a native Korean and a doctoral student in the area of early childhood special education. The interviews with the Korean families were conducted by telephone due to the distance while the interviews with the American families were conducted by face to face meetings. All interviews were conducted at times noted by the interviewee as convenient. Interviews with the American families were conducted at location that they designated, mostly in their homes. The interviews were audio taped with simultaneous written notes and then transcribed verbatim. No interview session required more than an hour and forty minutes to complete (i.e., range 35 to 100 minutes) and averaged just over one hour (i.e., M=71 minutes). The interviews with the Korean families were completed in a similar time frame (i.e., range 45 to 90 minutes, M=80 minutes). Follow up interviews were conducted only when it was found that additional information or clarification was needed.

3. Data Analysis

As noted earlier all interviews were audio taped. Audio taping interviews allow data to be preserved in its original state for analysis (Merriam, 1998) and increase the accuracy and accessibility of the information collected during interviews (Seidman, 1991). Verbatim transcription was completed for all audio taped interviews by the interviewer immediately following the completion of each interview. The researcher transcribed the interviews sentence by sentence listening to the audio tape and using the written notes to aid in understanding. An independent listener, a doctoral student who is a native speaker of English reviewed each transcript for accuracy. Any discrepancy between the independent listener and the researcher were discussed until consensus was reached.

The data collection, coding, and analysis were done concurrently. An inductive

process was the primary data analysis method as it was in the initial study (Patton, 1990). However, in this case the four primary themes identified in the initial study served as the starting point of data analysis. That is, using a matrix approach as suggested by Maxwell (2005) the themes from the first study were placed on the matrix with exemplars, expansions, sub themes, and in some cases additional themes emerging as the research reviewed each interview in turn. In this way the patterns including similarities and differences across individual interviewees and across the two groups were allowed to emerge directly from the data (Maxwell; Rossman & Rallis, 2003). The researcher made notes regarding her thoughts and impressions of each interview specifically within the context of the primary research question regarding the similarities and differences of the two groups of the families. The researcher completed the analysis process by summarizing the similarities and differences that emerged between the American and Korean families' responses.

To ensure analysis credibility and validity, the second author reviewed each transcript and confirmed the appropriateness of the coding matrices. The two reviewers then discussed the comparative analysis summary. All discrepancies in interpretation were discussed until consensus was reached.

III. Findings

The four key themes that emerged from the initial study continued as the key themes for the present study. These four themes are families': (a) identification of the types of and ways in which they participate in community activities, (b) perceived benefits of participation in community activities, (c) reports of barriers experienced that influenced access and participation in community activities, and (d) expressed needs for supports and services to improve their access and participation. Each theme is discussed in the following sections, highlighting the similarities and differences across the two groups.

1. Participation in Community Activities

To fully understand the ways in which families accessed and participated in community activities, this section has been divided into the following section: (a)

types of community activities, (b) the child with a disability's participation partner(s), and (c) strategies for accessing the community activities.

Types of community activities. As in the initial study, the interviewer provided the families with a listing of types of community activities with examples of activities that might fall in that category in order to assist the families as they reported on their current engagement in the community (Kim & Horn, 2008). The list was adapted from one developed by Dunst and his colleagues (2000). The five types of community activities with examples are (a) socialization activities (e.g., child's friends over to play, visiting neighbors, family gatherings), (b) play activities (e.g., art activities, playgroup), (c) community events (e.g., festivals, zoo, park, shopping center, library), (d) recreational activities (e.g., hiking, swimming, fishing, dancing, bowling) and (e) religious activities (e.g., going to worship, preschool activities sponsored by church or temple).

Table 4 displays the types of community activities reported by each of the family groups. Both groups of families reported that they participated in socialization activities. Three of the ten Korean mothers and six of the seven American families reported participation in play activities. Participation levels in art activities and playgroups were similar across the two groups. However, 71% of the American families also reported participating in an "open gym time" which none of the Korean families reported. "Open gym time" appears to be a relatively new play activity option available in Korea. All families reported participating in a range of community events.

Almost 90% of the families reported participation in recreational activities yet there were clear differences between the two groups on the subcategories reported. For example, the Korean families participated in hiking and riding a kickboard or bicycle while the American families participated in bowling, T ball, or dancing. Attendance in religious activities was also reported with similar frequencies by both groups. However, while both Korean and American families reported that their children with disabilities participated in preschool activities sponsored by their church, it was only the American churches that provided these activities in an inclusive format (i.e., for both typically developing children and children with disabilities). The Korean families reported that their churches provided the activities specifically for children with disabilities.

Table 4 Types of Community Activities

Types of community activities	Subcategories of each type of community activity	
	Korean (%)	U.S. (%)
Socialization activities	Having friends over to play (60%); visiting neighbors (50%); visiting extended families (90%); family wedding (10%); social gathering (40%)	Having friends over to play (29%); visiting neighbors (43%); family gathering (86%); social gathering (57%)
Play activities	Art activity (10%); playgroup (30%)	Art activity (14%); open gym (71%); playgroup (43%)
Community events	Festivals (30%); indoor/outdoor playgrounds (100%); zoo (30%); going to park (100%) for taking a walk (100%) and having a picnic (20%); going to shopping including grocery shopping (70%); going to library (10%)	Festivals (29%); indoor/outdoor playgrounds (57%); zoo (29%); going to park (86%) for specific activities or program in park; going to shopping including grocery shopping (71%); going to library (29%)
Recreational activities	Hiking (40%); swimming (30%); fishing (10%); Taekwando (10%); riding a kickboard or bicycle (40%)	Swimming (43%); bowling (14%); T-ball (14%); dancing (14%); going to movie theater (14%)
Religious activities	Religious based day camp (10%); Going to church (40%); -preschool activities sponsored by church	Going to church (29%); - preschool activities sponsored by church

Child participation partner(s). Both groups of families reported that their child with a disability's primary community activity participation partners were family members, specifically mothers and siblings. One of the Korean parents said, "She spends lots of time with family. She goes to playground or mart with me. She rarely does something with her peers." These families reported that cousins who are the same age as their child were also good participation partners. One American grandmother talked about the important role of her grandchild's cousin as a role model as well as a play partner. She said, "They semi grew up together ...they interact...that's the person he probably plays with the most as a child... we have him do things and have Grant follow him and do what he's doing."

Strategies for access. Both Korean and American families reported that their primary strategy for gathering information about accessible and available community

activities for their child was through the sharing of information with other parents of children with disabilities. Three of the American families reported that their neighbors who had children of a similar age were also good resources for information. In addition, both groups reported that they typically found useful information through internet websites, advertisements from district television channels, or fliers related to community activities. One American mother reported that she had no difficulty in finding out about and accessing a variety of community activities. She said, "I am the kind of person that if I want to know about it, I go and seek information. I am satisfied as far as knowing what's going on."

Some of the American families (i.e., three of the seven) also noted that professionals, including their child's teachers or therapists were useful informants. Gary's mother, for example said, "Amy, his special education teacher, is my go to person. I ask her everything. ...and therapists, even his (Gary's) teacher, she has two boys who have done a lot of different activities growing up and she has been a good resource." However, the Korean parents reported that professionals were typically not helpful in providing information on community activities.

In general, many aspects of participation in the community appear to be similar for the American and Korean families. However, the American families are more likely to have a greater variety of individuals that they access for information including other parents in their neighborhoods and professionals that work with their child.

2. Perceived Benefits

The two groups of families appear to hold different beliefs about the value of their participation in community activities. The seven American families reported that the primary benefits of participation were (a) having diverse learning experiences for their child, and (b) increasing the socialization of their child with a disability. On the other hand, the ten Korean parents reported that the primary benefits were (a) a greater sense of family connection, and (b) increased interaction with and support from extended families. In other words, it appears that the Korean families tended to focus on family related benefits while the American families focused on child related benefits. These two focuses are explored further in the following section.

Child-related benefits. One of the American families explained the benefits of her daughter's participation in community activities in terms of learning new skills.

They said, "It's new challenges, Angela's learning new tasks, learning how to interact with different people in different environments. It's taking her out of her comfort zone..." Another of the American families talked about how the diverse experiences offered by the community activities helped their son improve his social skills and thereby leading to an improvement in overall quality of life for the whole family. They said, "They (both children have special needs) are learning social skills by watching normal children ... It's not an immediate benefit but you know that the more your children socialize, the more they can succeed in society." Angela's mother also noted how her child's improvements in socialization contributed positively to their family's quality of life. She said, "The more we do it (make her play with children) the better she gets ..., the better it is for our family because it makes it easier for us to do things as a family."

Family-related benefits. Although several Korean parents mentioned some child focused benefits, in general they tended to emphasize the positive benefits for the family as a whole. One Korean mother explained that participation in community activities increased the number of opportunities for the entire family members to be together. She said, "We spend time all together so we are doing everything together ... we became more active, we became more stick together." Another of the mothers said, "It is finally good for every family member. My children remember everything we did. ... Everything we do seems helpful. It is helpful for the development of children in all areas."

Increasing the support provided by the extended family members due to more frequent interactions was another benefit identified by the Korean parents. One mother explaining how her extended family provided support to her and her child said, "I intentionally try to visit them as often as possible because of Sangyoon. ... they follow what I ask or they observe and imitate what I do. They really take care of him."

3. Barriers Experienced

Both groups of families were asked to provide information on the barriers they may have encountered in accessing and participating in the community. Both American and Korean families identified the attitudes or more specifically a negative bias towards individuals with disabilities by those in the general population as a significant barrier. Each group also identified some unique barriers. The American

families as a group identified two key barriers (a) a lack of information and accessibility to information, and (b) their child's individual challenges. The Korean parents, on the other hand, identified barriers such as (a) the negative attitudes of typically developing children's parents, and (b) limitations on parents' personal time as a result of arranging for community activities. Each of these barriers is discussed in more detail in the following sections.

General populations' attitudes. The general population's lack of understanding or acceptance of individuals with disabilities was identified as a significant barrier by both groups. The families reported that individuals in the general populations typically had very limited knowledge or understanding about people with disabilities and thus frequently displayed a negative reaction to their child with a disability and/or them as parents. One American family relayed a particularly unpleasant episode,

We have several situations where either the store complained or someone reported me to the child protective services...the good thing is I got a helper as a result and our quality of life got much better, but the bad news is I had to go through interrogation and had to be treated as child abuser.

Another parent offered the following example,

Some people are just, it's not that they are against kids with special needs but they don't understand, they just don't, it's something foreign to them. I think even with friends or family, they don't really understand Chuck so they typically don't interact with him.

The second parent, from above, went on to explain how she attempted to address this challenge. She wrote an article in a newsletter at her child's school. She explained,

What I wanted to make sure their understanding, ...because some family said, 'don't interact with Chuck at school' cause just they don't think it's really know about him or know what to do. And what I meant clearly in the article was, I talked about Chuck's interests.

Because if they knew you know what he might like animals things like that, that will be giving them something to interact with him. ...That's about educating people.

The Korean parents also provided negative bias examples. One mother said, "People's prejudice is the biggest barrier. They pity. Do not play with him. He is a different person from us." Another mother described a negative experience, saying "I was concerned by people's dirty looks because (he) behaves differently from other children."

In addition to such similarly identified barrier, each group of families identified unique barriers. American families noted that they lacked information and their child's individual challenges while Korean families identified limited personal time for the parents as barriers which limited their access to and participation in community activities.

Lack of information. Four of the seven American families reported that a lack of information about and for accessing community activities limited their child and family's participation in community activities. One mother talked about her difficulties in finding out about appropriate activities for their child saying, "How to access available activities for Gary. Even if you learn about some program but don't know whether it is right or not." Another family explaining their lack of information about accessible community activities in their small town said, "We are kind of limited because it is a small town...It just takes awhile. It would be nice if everything was set up and they could just hand you a pamphlet with all of these names that you need to get a hold of."

Yet another American mother pointed out the difficulty in understanding special education policy or law. She said, "One of the hardest things parents find is understanding their rights... I think the disability law can be quite complicated. I think sometimes parents are not entirely sure what it is that they're entitled to...it's quite complicated." The same mother also emphasized the importance of serving as an advocate for one's child, saying, "...you realize you are gonna have to advocate really hard. You're gonna have to get really kinda strong if you're gonna do it for your kid."

Child's individual challenges. Five of the seven American families talked about their child's individual challenges such as medical/health issues and lack of age appropriate developmental skills. One family said, "Because of his seizure activity,

we've been pretty limited as far as what we allow him to do, just because of safety issue." Another family said, "All the kids they did a bunch of different activities but Chuck was there but he can't sleep away at night because of his sleep and medical issues."

Limited personal time. The Korean parents complained that they needed time for themselves because they were typically tied to their child's schedule. One mother said, "Personally, I want to have my own time. It is my desire. ... it is me that usually spends time with Daeho but I need one or two hours every day to spend for myself." Another mother said, "I want to work. But I should take care of Hodol, so I don't have my own time. I want to get a job and have things I want to do." Given that all of the Korean mothers were full time homemakers and some of them gave up their jobs after their child was found to have special needs, it is not surprising that they spent most of their time with their child and thus were frustrated by the lack of time for themselves.

In summary, both groups identified the general populations' lack of understanding of people with disabilities as the biggest barrier towards participation in community activities. However, even given this commonly held concern there was a subtle but important distinction between the two groups (i.e., lack of information about and accessible community activities and child's individual challenges for the American families; and limited parents' personal time for the Korean parents).

4. Need for Supports and Services

Both groups of families reported a need for supports and services for increasing their child's participation in community activities that were directly related to the identified barriers. Not surprisingly, both groups presented societal acceptance of people with disabilities, more specifically, a change in the general populations' negative attitudes and attainment of a better understanding of people with disabilities as a primary need. Each group also presented some additional needs for supports and services. The needs for supports and services commonly reported by the American families were community supports and information about and accessibility of community activities. On the other hand, the Korean families reported a need for increased proximity of programs or services in their community. Each of these four areas of support need identified by the families is discussed in more detail in the following sections.

Societal acceptance. Both family groups emphasized the importance of societal acceptance on the part of the general population as a needed support for facilitating their child and families participation. One American family said, "I guess an understanding from the community about kids with special needs. ... if the child doesn't behave in ways that people think of as normal, they are not typically accepting of that child. Just being more aware,..." Even the family who did not report the general populations' lack of understanding as a barrier said that they hope other parents treat her daughter just as they would a typically developing child. They said, "For the most part, we treat her as a child who is typically developing and try not to treat her any differently... And we expect, we hope that other parents treat her that way."

The Korean parents also expressed their wish for a change in the general populations' negative attitudes and thus as a result experiencing more acceptance of their children with disabilities. One Korean mother said, "I want them (general populations) to change their attitudes towards children with disabilities and their families. I want that they accept our children without some prejudice or bias..." Some of the Korean parents specifically emphasized the importance of the community activities staff's acceptance of their child with a disability. One Korean mother said,

Taegyun's coach did not have information about children with disabilities but he was willing to say 'yes.' ... Taegyun has excellent motor skills but he does not know the rules so that he cannot keep to the rules. I explained that Taegyun was simply going to play. So, the coach plays with him.

Community supports. The American families reported that they needed and wanted to have community supports such as modified environments and the employment of staff by the programs who are knowledgeable of how and are available to support their child's participation in activities. One American mother explained how environmental modification helped her child and family participate in a variety of community activities,

They (Larryville Autism Society) are working to get the community to support kids with autism. Like they have a couple of times had a movie theater, on Saturdays, ...it's an anybody can attend

but that people have to know that there's gonna be a lot of kids with autism or special needs there. So they are going to turn down the volume so it's not so loud and not get so dark...he won't be expected to sit in his seat the whole time. And he can still experience being at the movie theaters.

Another one of the American families talked about having adults who can support their child's participation in activities. They said,

I think if the department of parks and recreation employed young people to be paras and if they could say your child can join any class in the schedule and we are giving you a para...that would really make all the difference because then you can assign your child to any activity you wanted. ...If we wanted him to be in dance class or something like, he wouldn't have to do by himself right now.

Information and accessibility. One of the American mothers explained the difficulty in looking for other families who can share information due to the rarity of her child's special needs. Yet another of the American families, a grandmother, pointed general issues with accessing information in her community,

I think a lot of the communities need, they need to do more with getting fliers or something out letting people know. Especially, if there's a mother that ...when you have a lot of kids you don't get out much. So they just need to network better.

Proximity of programs. Some of the Korean mothers reported the need for programs in close proximity to reduce transportation and travel time, and other related accessibility issues. One Korean mother said, "I really want Mansue to do everything in our community. It is inconvenient when this can't happen because mothers then must look for an appropriate place and it takes a lot of time ... transportation problems..." Another Korean mother also said, "I hope services or programs are in our accessible proximity. We should spend too much time and expense to travel in order to have appropriate services and programs in different communities."

In summary, both groups of families reported societal acceptance of people with disabilities as the most frequently addressed need for supports and services. More specifically, the Korean families noted that the attitudes of community staff are a critical decision factor for their child's participation in an activity. Each group of the families also presented some unique needs for supports and services. The American families presented community supports such as modified environments and adults who support their child's engagement and information about and accessibility of community activities for their needs for supports and services. The Korean families, however, reported close proximity of services or programs as their need for supports and services.

IV. Discussion

The purpose of the present study is to understand the nature of the differences and similarities between American and Korean families' perception of their child with a disability's inclusive community activities and the factors that influence access and participation in these activities. As previously noted, children with disabilities and their families across both countries generally experience similar challenges and difficulties participating in community inclusion opportunities (Beckman & Hanson, 2002). However, the specific nature of the challenges particularly in terms of the kinds and degree of difficulties that they have encountered as they participate in community activities may differ as a result of country, societal and cultural specific contexts. Hanson and her colleagues (1998) provide support for this perspective as they noted that families' views and perceptions of community inclusion are strongly influenced by their cultural and societal values, beliefs, or ideas. Therefore, it is important to examine how country, societal and cultural contexts may uniquely impact families' participation in community activities, perceptions of the value of participation, and barriers experienced in accessing and participating in order to understand how to appropriately support families and gain a broad understanding of community inclusion.

1. Participation in Community Activities

Participation in the five categories of community activities was very similar for both groups of families although the specific types of activities engaged in differed. These differences may well simply reflect differences that people in these two countries have in terms of the activities they enjoy. Both groups of families reported that the typical participation partners for their child with a disability were family members. Both groups most frequently obtained information about available and accessible community activities from parent associations or on their own. A difference was noted, however, in terms of their perception of professionals' role. The American families reported that professionals were helpful informants about community activities whereas Korean professionals do not seem to view providing information about activities and services outside of those provided by the school as one of their roles and thus families do not expect it from them.

2. Perceived Benefits

When discussing the benefits of participating in community activities, the two groups differed substantially in their focus. The American families identified primarily child focused benefits such as the child experiencing diverse learning experiences and increased social competence. The Korean families, however, identified family focused benefits such as family connectedness and improvements in extended family interactions and support. This difference may reflect a fundamental difference in their cultural and societal values. The American perspective is predominantly based on individualism (Chan, 2004). Koreans, however, are strongly rooted in a collectivist perspective, as do most Asian countries. A collectivist perspective values a family centered orientation and interdependence while an individualistic perspective values autonomy, independence, or self reliance. Thus, it is not surprising that when asked to articulate their beliefs about the value of community activities for their child the Koreans discuss the benefits in terms of the impacts on the whole family and the child as a member of their family.

3. Barriers Experienced

Children with disabilities and their families' participation in community activities were impeded by several barriers in spite of their having noted benefits. The most frequently identified barrier for both groups was the general populations' lack of understanding of people with disabilities. Nonetheless, each group's reactions to negative experiences from the general populations were subtly different. For example, the American families seem to be more understanding about the negative attitudes they experienced by attributing it to a general lack of knowledge. They reported that they attempted to "educate" people they encountered about children with disabilities. However, the Korean families tend to get upset when they encounter a negative bias but did not report any attempts to change another's perspective.

This phenomenon may be best understood through two explanations. First, Koreans may have greater difficulties in understanding differences since generally Korean society is very homogeneous. Korean people have had less exposure and thus are less likely to be sensitive to diversity in general and in particular to people with disabilities. Second, South Korea as a country has a relatively short history of promoting special education policies particularly in comparison to the United States. Therefore, the general population as well as the parents of children with disabilities may be relatively unaware of the rights to services and protections found in special education policy and law.

4. Limitations

Several limitations are noted although this study provides important information for understanding the similarities and differences of Korean and American families of preschool children with disabilities regarding their participation in inclusive community activities. First, the use of telephone interviews for Korean families is a limitation. Although telephone interview was inevitable due to the long distance, telephone interviews did not allow the interviewer to interpret important nonverbal behaviors of the parents. Second, the lack of participation in the interviews by the Korean fathers may have limited the outcomes of the study. Although American fathers' perspectives did not vary greatly from the American mothers', Korean fathers may have provided different information particularly since fathers are typically the primary decision makers in the Korean family structure (Chan, 2004).

Third, the findings of this study are limited in terms of generalizations to other populations due to the small sample size. The participant total was only 17 families (i.e., ten Korean mothers and seven American families). Furthermore, the participants were relatively homogeneous in that the participants of both groups were all considered middle class; the majority was two parent families, and all were relatively well educated. Although the goal of this study was to generate a depth of understanding rather than breath (Rubin & Rubin, 2005), homogeneity and the small sample size limit generalization of the findings to other populations of families.

5. Implications for Practice

The lack of understanding and negative attitudes found towards people with disabilities was a big challenge for both groups. Therefore, increasing public awareness regarding people with disabilities is an important implication for policy makers, service providers, and advocates in both societies. Public awareness through such avenues as books including children's books, films, and public awareness activities should be systematically implemented by educational policy makers and other professionals in the disability field. In addition, collaboration between service providers, community staff, and families is greatly needed for both societies. Particularly, in Korea, collaborative activities across and between disciplines, professionals, and lay people need to be encouraged.

Lastly, systematic development of special education policy and law is urgently needed in Korea. Recently, Korean professionals in the disability field began to drastically revise the special education policy and law. Korean special education policy and law specifically for young children with disabilities or at risk, which has been the weakest and the most undeveloped area, has begun to experience systematic development. As a result, Korean families of children with disabilities may be able to experience the opportunity to advocate for their child and family's rights in much the same way as noted by one of the American mother interviewed. She said, "You just have to, you know, you realize you are gonna have to advocate really hard. You're gonna have to get really kinda strong if you're gonna do it for your kid."

References

- Arksey, H., & Knight, P. (1999). *Interviewing for social scientists*. London: Sage Publications.
- Beckman, P. J. & Hanson, M. J. (2002). Community participation of children with disabilities. In S. L. Odom, *Widening the circle: Including children with disabilities in preschool programs* (pp. 109-119). New York: Teachers College Press.
- Beckman, P. J., Hanson, M. J., Horn, E. (2002). Family perception of inclusion. In S. L. Odom, *Widening the circle: Including children with disabilities in preschool programs* (pp. 98-108). New York: Teachers College Press.
- Beckman, P. J., Barnwell, D., Horn, E., Hanson, M. J., Gutierrez, S., & Lieber, J. (1998). Communities, families, and inclusion. *Early Childhood Research Quarterly*, 1, 125-150.
- Bruder, M. B. (2001). Inclusion of infants and toddlers: Outcomes and ecology. In M. J. Guarlnick, *Early childhood inclusion: Focus on change* (pp. 203-228). Baltimore, MD: Paul. H. Brookes.
- Chan, S. (2004). Families with Asian roots. In E. W. Lynch & M. J. Hanson (Eds.), *Developing cross cultural competence: A guide for working with young children and their families* (3rd ed., pp. 251-354). Baltimore, MD: Paul. H. Brookes.
- Creswell, J. W. (2003). *Research design: Qualitative, quantitative, and mixed methods approaches*. Thousand Oaks, CA: Sage Publications.
- Dunst C. J. (2001). Participation of young children with disabilities in community learning activities. In M. J. Guralnick, *Early childhood inclusion: Focus on change*. (p. 307-336). Baltimore, MD: Paul. H. Brookes.
- Dunst, C. J., Hamby, D., Trivette, C. M., Raab, M., & Bruder, M. B. (2000). Everyday family and community life and children's naturally occurring learning opportunities. *Journal of Early Intervention*, 3, 151-164.
- Hanson, M. J., Wolfberg, P., Zercher, C., Morgan, M., Gutierrez, S., Barnwell, D., & Beckman, P. J. (1998). The culture of inclusion: Recognizing diversity at multiple levels. *Early Childhood Research Quarterly*, 13, 185-209.
- Guralnick, M. J. (2001). Introduction and overview. In M. J. Guarlnick, *Early childhood inclusion: Focus on change* (pp. 3-38). Baltimore, MD: Paul. H. Brookes.
- Guralnick, M. J. (2005). Inclusion as a core principle in the early intervention system. In M. J. Guarlnick, *The developmental systems approach to early intervention* (pp. 59-72). Baltimore, MD: Paul. H. Brookes.
- Kim, T. & Horn, E. (2008). Korean parents' perceptions of their child with a disability's opportunities for community participation. *The Journal of Special Education: Theory and Practice*, 9, 423-444.
- Maxwell, J. A. (2005). *Qualitative research design: An interactive approach*. Thousand Oaks, CA: Sage Publications.
- Merriam, S. B. (1998). *Qualitative research and case study applications in education: Revised and expanded from case study research in education*. San Francisco, CA: Jossey Bass.
- Odom, S. L., Brown, W. H., Schwartz, I. S., Zercher, C., & Sandall, S. R. (2002). *Classroom ecology and child participation*. In S. L. Odom, *Widening the circle: Including children with disabilities in preschool programs* (pp. 25-45). New York: Teachers College Press.
- Patton, M. Q. (1990). *Qualitative evaluation and research methods* (2nd ed.). Newbury Park, CA: Sage Publications.
- Rossman, G. B. & Rallis, S. F. (2003). *Learning in the field: An introduction to qualitative*

- research*. Thousand Oaks, CA: Sage Publications.
- Rubin, H. J. & Rubin, I. S. (2005). *Qualitative interviewing: The art of hearing data*. Thousand Oaks, CA: Sage Publications.
- Schwartz, I. S., Sandall, S. R., Odom, S. L., Horn, E., & Beckman, P. J. (2002). "I know it when I see it": In search of a common definition of inclusion. In S. L. Odom, *Widening the circle: Including children with disabilities in preschool programs* (pp. 10-24). New York: Teachers College Press.
- Seidman, I. E. (1991). *Interviewing as qualitative research: A guide for researchers in education and the social sciences*. New York: Teachers College Press.
- Stoneman, Z. (2001). Attitudes and beliefs of parents of typically developing children: Effects on early childhood inclusion. In M. J. Guarlnick, *Early childhood inclusion: Focus on change* (pp. 101-126). Baltimore, MD: Paul. H. Brookes.

한국과 미국 가족들의 장애유아의 지역사회 활동참여에 대한 인식 비교

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<초록>

통합의 개념은 일반적으로 교육현장 내에서의 통합으로 국한되어 연구되고 논의 되어왔다. 하지만, 통합의 핵심적 개념은 교육현장에서 나아가 장애 아동들이 일상적으로 생활하는 가정이나 지역사회 등 보다 더 넓은 범위 내에서 이해되어야 한다. 특히, 장애를 가진 어린 유아들은 그들의 가정이나 지역사회에서 가족, 친지, 혹은 또래친구들과 함께 경험하는 모든 일상들이 그들의 발달 및 학습 증진에 큰 영향을 미치기 때문에 지역사회 활동참여 여부는 매우 중요한 의미를 지니고 있다. 하지만, 장애 유아가 그의 가족들은 일반 유아들과는 달리 지역사회 활동참여에 여러가지 어려움에 직면하게 된다. 이러한 어려움은 문화, 사회, 국가적 배경과 상관없이 장애유아와 그의 가족들이 겪는 현실일 것이다. 이에 본 연구는 지난 논문 (Kim & Horn, 2008) 주제를 좀 더 넓혀 문화와 사회적 배경이 다른 환경에서의 장애유아 부모님과 가족들의 인식의 차이를 알아보고자 한다. 본 논문은 한국과 미국 장애유아 부모님과 가족들의 지역사회 참여 및 통합에 대한 인식은 어떠한가, 또한 양국의 다른 문화 및 사회적 특성에 따른 지역사회 통합에 대한 인식의 차이점은 무엇인가를 질적연구를 통해 알아 보았다. 이에 본 연구는 한국 부모님들께 사용했던 인터뷰 내용을 토대로하여 미국 중서부에 거주하는 일곱 가정을 대상으로 그들의 지역사회 참여경험을 인터뷰 하였다. 인터뷰 결과, 한국과 미국 부모 및 가족들의 지역사회 참여활동 범위 및 종류, 그리고 활동을 알아보는 방법 면에서는 공통점을 많이 찾아볼 수 있었지만, 이들의 활동참여에 영향을 미치는 긍정적, 부정적 요인에 대한 인식은 양국간에 차이가 있음을 알 수 있었다. 즉, 한국 부모님들은 긍정적 요인으로써 가족 전체에 대한 잇점을 강조한 반면 미국 부모님들 및 가족들은 장애유아와 직접적으로 관련된 잇점에 초점을 두었다. 또한 지역사회 활동참여에 미치는 부정적 요인으로써 양국의 부모님들 모두가 일반인들의 장애인에 대한 이해부족 혹은 부정적 시각을 가장 많이 언급했으나, 이에 대한 양국 부모님들의 견해적 차이가 현저했다. 이에 본 저자는 양국의 다른 문화적 혹은 사회적 가치, 신념, 및 특수교육의 역

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사 및 배경적 차이를 분석하여 이러한 양국 부모 및 가족들의 인식의 차이를 논의해 보았다.

주제어: 장애 유아, 지역사회, 통합, 가족, 비교

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