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Korean Parents' Perceptions of their Child with a Disability's Opportunities for Community Participation

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《요 약》

When young children with disabilities participate in community activities they are provided with increased opportunities to learn, practice, and generalize important skills. Not all families, however, may know how to access activities and even when they do they may experience some barriers to achieving full access. This article reports on a qualitative investigation of the perception of ten Korean parents of preschool children with disabilities regarding the opportunities their child has for inclusion in community activities and the factors that influence their child and family's access and participation. Through a semi structure interview format families expressed a strong commitment and positive attitude for supporting their child's participation. They also noted that their child's actual community participation is limited by a number of barriers. Key among the barriers they reported was the bias they experienced towards their children by those in the community and a lack of individuals in the community that had the necessary knowledge to support their child's participation. The findings suggest that families may need more supports and services in order to effectively broaden the types of community activities accessed and to ensure full participation by their child and family.

주제어 : Preschool children, Community participation, Families, Inclusion

Ⅰ. Introduction

The concept of inclusion of persons with disabilities is increasingly viewed by those in the field of disabilities as more than simply inclusion in educational context but rather includes a broad array of contexts within children's family and community

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life (Beckman & Hanson, 2002). Supporting families to broaden their community and family experiences to include opportunities for play, learning, and engagement in multiple everyday community contexts provides children with disabilities increased opportunities for learning and to build social linkages (Beckman et al., 1998; Dunst, Harmby, Trivette, Raab, & Bruder, 2000). Specifically, this increased opportunity for interaction and engagement with a variety of people, materials and contexts also increases the opportunities for child knowledge acquisition, enhancement of child developmental skills, and child learning of social and cultural expectations, rules, roles, and routines (Dunst, 2001).

Even with the recognition of the importance of community integration, there are several problems that may limit the community inclusion opportunities for children with disabilities. First, although parents of children with disabilities often make great efforts to include their children in diverse community activities, they may view many of the activities as frustrating or difficult (Beckman et al., 1998; Dunst et al., 2000). A primary source of this frustration for families is that their child's delays in specific developmental skills impedes their appropriate social interaction with typically developing peers (Guralnick, 2001; Odom, Brown, Schwartz, Zercher, & Sandall, 2002). Secondly, children with disabilities often have a full schedule of speech therapy, occupational therapy, music therapy, and other activities related to individual or group therapies thus limiting the time available. Thus, although meaningful social relationships may be gained by participating in common activities (Guarlnick, 2001), children with disabilities often have fewer meaningful opportunities for social interactions with typically developing children due to the fact that they need to spend much of their time for meeting their special needs. Thirdly, parents of children with disabilities may lack the necessary financial, social, emotional, or informational resources (Dunst, 2001). This may be particularly the case for parents of a young child who has been recently diagnosed with a disability in that they have limited information and lack experiences accessing information about disabilities and strategies for addressing barriers that may arise (Beckman et al., 1998; Dunst).

To date there have been relatively few studies addressing inclusion outside of the school or educational context and little information about factors that influence participation of children with disabilities in the larger community in the United States (Beckman & Hanson, 2002). Furthermore, studies that address community inclusion in Korea are even more limited. Although several studies have reported on recreation and leisure opportunities for children with disabilities in Korea, they did not specifically focus on inclusive activities (Choi, 2005; Choi & Kwon, 2005; Kim & Park, 2002; Lee, Choi, & Cho, 2003). Inclusive activities for the present study are defined as everyday, typically occurring learning experiences in community life just like those for typically developing preschool children (Bruder, 2001). In addition, all of the Korean studies cited above focused on school age children with disabilities rather than preschoolers. Thus, no study to date has been found which specifically addresses preschool children with disabilities and their families.

While limited the work completed by researchers in the United States reporting on families' experiences could serve as a foundation for understanding the issues faced by families in Korea. Thus, the purpose of this study is to understand Korean families' perceptions regarding the opportunities their child with a disability has for community inclusion and the factors that influence both positively and negatively access and participation in these community activities. Specifically, three research questions related to participation in community activities will be addressed: (a) What are the types of community activities that children with disabilities and their families currently are active participants? (b) What factors do families identify that influence (either positively or negatively) their child's access to and participation in community activities? and (c)What supports do families identify as needing in order to increase their child's participation in community activities?

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 how Korean parents perceive community activity participation for their child with a disability and what factors influence their access to and participation in community activities. A semi structured interview approach was determined to be the best technique for gaining in depth stories from the parents (Merriam, 1998). The following sections describe the participants involved and the process for data collection and analysis.

Participants

The researcher who is a native speaker of Korean visited Korea to recruit potential participants. Specifically, Korean parents of preschool aged children with disabilities who were currently attending an inclusive preschool educational program were the target population. The participants of this study were recruited through contacts with school district directors (typically the principal) of early childhood special education programs. Through this process a total of ten mothers consented to participate.

Table 1 presents a brief summary of each participant's demographic information including age, marital status, income level, and educational level. All ten of the mothers lived in Korea at the time of the interview, spoke Korean as their first language and were the biological mothers of the children with disabilities. The average age of the mothers was 37 (Range 26 to 45 years). All participants had at least a high school diploma but their educational level ranged from a high school diploma to a master 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. They all were married, living with their spouse and child(ren) but without any extended families in the same household, and were full time homemakers at the time of the interview.

Table 2 summarizes information about the children with disabilities and other members of the families of the participants including age, diagnosis, and gender. Five of the ten children attended Kyrin Preschool, a full day inclusive preschool located in the northwest region of South Korea. The remaining five children attended Dongle Preschool, which is located in the southeast region of Korea which also provides a full day of inclusive preschool activities. Eight of the children had a diagnosis of developmental delay, one had a diagnosis of mental retardation, and the final child had not been diagnosed but was considered at significant risk for subsequent diagnosis of developmental disability. Eight of the children were boys and two were girls. Only one of the children did not have at least one typically developing sibling, while none had a sibling with a disability.

Table 1. Parent Demographic Information

Interviewee	Marital Status	Age	Family members	Status of Employment	Income Level	Highest Degree in Education
Youngho's mother	Married	36-40	Parents & their children	Full-time homemaker	More than 2,000,000 won	Some college
Daeho's mother	Married	36-40	Parents & their children	Full-time homemaker	More than 2,000,000 won	High school Graduate
Jihee's Mother	Married	36-40	Parents & their children	Full-time homemaker	More than 2,000,000 won	Bachelor
Taegyun's mother	Married	41-45	Parents & their children	Full-time homemaker	More than 2,000,000 won	Master
Sangyoon's mother	Married	41-45	Parents & their child	Full-time homemaker	Other	Bachelor
Sunyoung's mother	Married	26-30	Parents & their children	Full-time homemaker	1,000,000~ 1,500,000 won	High school Graduate
Gwangsue's mothe	Married	36-40	Parents & their children	Full-time homemaker	More than 2,000,000 won	Some college
Mansue's mother	Married	36-40	Parents & their children	Full-time homemaker	No fixed income	Bachelor
Hodol's mother	Married	31-35	Parents & their children	Full-time homemaker	1,000,000 ~1,500,000 won	Some college
Juho's mother	Married	31-35	Parents & their children	Full-time homemaker	More than 2,000,000 won	Bachelor

Table 2. Child Information

Child with Disability	Disability	Sex	Age	Number of Siblings	Sex of Siblings	Age of Siblings
Youngho	Developmental Delay	Boy	3	1	Boy	10
Daeho	Developmental Delay	Boy	4	2	Girls	Elementary ages
Jihee	Developmental Delay	Girl	4	1	Boy	7
Taegyun	Developmental Delay	Boy	5	1	Girl	15

Child with Disability	Disability	Sex	Age	Number of Siblings	Sex of Siblings	Age of Siblings
Sangyoon	Not yet	Boy	4	·	·	·
Sunyoung	Developmental Delay	Boy	5	1	Boy	3
Gwangsue	Developmental Delay	Boy	3	1	Girl	4
Mansue	Developmental Delay	Girl	5	1	Boy	17mos.
Hodol	Mental Retardation	Boy	4	1	Girl	6
Junho	Developmental Delay	Boy	4	1	Girl	6

Data Collection

An interview guide was developed by the researcher based on the study purpose, a review of literature on inclusive community activities, and discussion and review by knowledgeable colleagues. The purpose of the protocol was to keep the interview format consistent. Guiding questions helped ensure that all 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 according to the direction and flow of the interview. A pilot interview was conducted 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 (Arksey & Knight, 1999). Additional follow up questions or probes were asked if further information was needed for a specific question or as a response for the purpose of following up more closely on something a respondent had said. The interview guide was provided in written format to the participants prior to the telephone interview. The researcher tried to be respectful, non judgmental, and non threatening during the interviews (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?
   (a) Were there any challenges or barriers to getting (child's name) enrolled? If yes, please describe them.
   (b) 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 researcher who is a doctoral student in the area of early childhood special education served as the interviewer. All interviews were conducted by telephone because of the geographical distance. A mutually convenient time were scheduled for the interview with each parent. The interviews were conducted in Korean, audio taped with simultaneous written notes, and at a later point transcribed verbatim. Each interview was completed in a 45 to 90 minutes time frame (M=80 minutes).

Follow up interviews were conducted as needed when it was found that additional information or clarification was needed or if the interview ended prematurely due to an unexpected interruption.

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 in Korean immediately following the completion of each interview. The Hangul 97 software (Haansoft, 1997) was used for transcribing the interviews. 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 also a native speaker of Korean reviewed each transcript for accuracy. The discrepancies between the independent listener and the researcher were discussed until consensus was reached. All data analysis was conducted using the Korean transcripts for later use in developing the English manuscript.

The data collection, coding, and analysis were done concurrently. This process took an inductive form (Patton, 1990) in which emergent themes, patterns, and questions emerged from the data (Maxwell, 2005; Rossman & Rallis, 2003). As Maxwell suggested for data analysis, the researcher used matrices for comparison across the interviews, and interview summaries to retain the context of the data. In this process, unanticipated ideas were allowed to appear and influence the emphasis in interviews according to the interpretation of the researcher (Rossman & Rallis, 2003). The researcher wrote thoughts, impressions, and analytic memos and then re read them from time to time (Maxwell, 2005; Rossman & Rallis, 2003). Then, the researcher shared the ideas with professional peers in the area of early childhood special education. Throughout these procedures, the researcher sorted the data into several sub categories. The sorted sub categories were repeatedly checked for accuracy and consistency and then were modified if the researcher thought the initial interpretations were not correct (Rubin & Rubin, 2005). Therefore, the sub categories were gradually refined and reduced to a defined set of categories (Rubin & Rubin, 2005).

For the credibility and validity of the analysis, a colleague with previous experience in qualitative research reviewed each transcript and confirmed the appropriateness of the categories. The researcher, the first reader of transcripts and developer of the codes, discussed the analysis of the data with the second reviewer. The discrepancies between the interviewer and the second reviewer were discussed until consensus was reached. Finally, the discrepancies were reviewed by another professional in the field of disabilities and one who was also experienced in qualitative research methodology.

Ⅲ. Findings

The findings are presented according to the four primary themes that emerged from the content analysis of the parent responses to the interview. These four themes are: (a) participation in community activities outside of those provided by the preschool, (b) perceived benefits of participation in community activities for the child and family, (c) barriers experienced that influenced access and participation in community activities, and (d) expressed needs for supports and services to improve access and participation.

Participation in Community Activities

Community activities included any of the organized activities in which the families reported participating but were outside of those provided as a part of the preschool day. These activities typically occurred in the afternoon or evening during weekdays, weekends, or on school holidays. The three sub themes that emerged were (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. The interviewer provided families with a list of categories of community activities with some examples in each category in order to assist families as they thought about and responded to the first interview question - "Tell me about some of the community activities that your family participates in with your (child's name)." The list was adapted from one developed by Dunst and his colleagues (2000). These same categories or types of community activities were then used to organize the families' responses such that a summary of the types of activities in which these Korean families participated could be produced. The five types or categories with examples from the interviews are (a) socialization activities (e.g., having friends over to play, visiting neighbors, visiting extended families, social gathering, family wedding), (b) play activities (e.g., art activities, playgroup), (c) community events (e.g., festivals, indoor/outdoor playgrounds, zoo, park, shopping center, library), (d) recreational activities (e.g., hiking, swimming, fishing, Taekwando, riding a kickboard, riding a bicycle) and (e) religious activities (e.g., day camping, going to church or temple, preschool activities sponsored by church or temple).

All of the mothers reported participation in socialization activities such as: having friends over to play (n=6), visiting neighbors (n=5), visiting extended families (n=9), social gathering (n=4), and family wedding (n=1). Three of the ten mothers reported participation in play activities such as: art activities (n=1) and playgroup (n=3). Two of the three children attended playgroups run by a public agency in their community while another child attended playgroup run by a private agency. All of the mothers reported participation in community events including: festivals (n=3), indoor/outdoor playgrounds (n=10), zoo (n=3), taking a walk (n=10) or having a picnic in the park (n=2), going shopping including grocery shopping (n=7), and the library (n=1). Nine of the ten mothers reported participation in recreational activities including: hiking (n=4), swimming (n=3), fishing (n=1), Taekwando (n=1), and riding a kickboard or bicycle (n=4). Four of the ten mothers reported attending religious activities such as: religious based day camp (n=1), going to church (n=4), and preschool activities sponsored by church (n=3). Interestingly, church sponsored preschool activities provided only to children with disabilities and not available for children without disabilities. Three of these four mothers reported that their family chose to attend this church because it had such program.

Child participation partner(s). The families reported that their children with disabilities primary community activity participation partners were family members. Specifically, mothers and siblings were the most frequently reported participation partners. For example, Jihee's mother reported that Jihee's older brother was a particularly good model for the Jihee's participation in community activities. Her mother said, "Jihee rides a kickboard very well on the road. So, when we go to the park in our community, she rides a kickboard and her brother rides a bicycle. … She has a brother, so she observes what her brother does, either a kickboard or bicycle. She imitates her brother a lot."

All of the parents, however, reported some regret that their children had few chances to have interactions with their preschool friends outside of the preschool because lived in different communities. Sometimes, however, when time allowed the parents had their child play with their preschool peers on the preschool's playground after school.

Strategies for access. All of the mothers reported that the primary strategies that they used for gathering information about what and how to access community activities was through the sharing of information with other parents of children with disabilities. Parents of children in the Kyrin Preschool had a parents' association to share ideas as well as other useful information. One mother said, "I find information throughout the internet and get lots of information from the Kyrin Parents' Association. So, I don't feel I need more." In addition, the parents of a young child who had been recently diagnosed reported that the veteran parents were one of their most helpful and reliable sources of information. Moreover, all of the mothers said that they could easily get information by accessing internet. None of the mothers reported having any difficulty in finding out about and accessing a variety of community activities.

Perceived Benefits

The primary benefits that the families reported regarding participation in community activities for their child with a disability and their families were the opportunities to have pleasant family interaction and high quality time with their family. Two sub themes were identified: (a) a greater sense of family connectedness and (b) increased interaction with and support from extended families. However, before discussing these two themes it needs to be noted that a few of the mothers reported that they did not feel their child's participation in community activities had any special meaning. That is, for their family, participation in community activities is a part of the natural routine of the family whether or not the child has a disability.

Family connectedness. Seven of the ten mothers noted that they were very pleased that participation in community activities resulted in increased opportunities for all family members to be together. They also believed that providing diverse learning opportunities for their child was one of their primary responsibilities as a parent. One mother said, “My husband and I thought that we needed intentionally to provide a variety of learning opportunities for Daeho. However, it is good for every family member. My children remembered everything we did together. Although he cannot express, his sisters express, you know. …It is helpful for promoting children’s developments in every area.”

A number of the mothers said that once having realized this benefit of greater connectedness, they made efforts to participate in community activities on a more frequent and regular basis than in the past. However, one mother noted that always feeling the need to be actively participating in the community actually at times served as a stressor because she and her husband felt that they could not take a break and just relax at home. The mother said, “We spend time all together and we are doing everything together, you know… Because of Sunyoung, we became more active, we stick together more. The bad part, however, is that even if we want to take a break, we do not do so because we feel the pressure to provide her something or to take her somewhere. We do not feel comfortable taking a rest.” Thus we see that while parents indicated they believe that participation in community activities is important and provides benefits for their child and family, it may at times also contribute to feelings of stress when they sense that they cannot take a respite from all of the activities.

Increased support from extended families. Nine of the ten mothers said that they attempted to visit extended families as often as possible if distance was not a barrier. They reported that having interactions with extended family members, particularly cousins of a similar age as their child’s, provided good socialization opportunities. One mother said that her family had frequent interactions with her sister’s family who lived nearby and they also shared child care since her sister had two similar aged children. She noted, “They (her sister’s family) are my family, you know, that’s why they play with him Daeho. …frequent interaction with my sister was a big help. If not, I would have had a very hard time and felt down.” The mothers’ responses in this sub theme illustrate that interactions with extended families serve as an important emotional and social supports for the parents as well as providing social benefits for the child with a disability.

These same nine mothers reported that their child with a disability had positive relationships with their extended family members (i.e., grandparents, uncles and aunts) due to the fact that they frequently visited one another. This was true even though the children lacked the necessary skills to easily initiate and engage in social and communication exchanges with others. One mother explained how her extended family provided support, “I intentionally try to visit them as much as possible because of Sangyoon. … I ask to them (grandparents or uncles) in advance, like ‘you should do this way when Sangyoon is behaving in this way.’ And as they play with Sangyoon, they consider my advice. … they follow what I ask for my child or they observe and imitate what I do with Sangyoon.” Five of these nine mothers noted that especially the grandparents showed great affection toward their child, which significantly contributed to the strong, positive relationship that the grandparents had with their grandchild.

Barriers Experienced

The mothers interviewed identified barriers that influenced the ease with which their child and family accessed and participated in community activities. The following two sub themes were commonly identified: (a) bias toward persons with disabilities, (b) attitudes of typically developing children's parents, and (c) lack of parents' personal time.

Bias. Five of the ten mothers agreed that the most challenging barrier that they faced was the bias toward persons with disabilities found in the general population. These mothers reported that the general population often reacted negatively, for example, looking at their child with a scowl when their child had a serious tantrum or laid down on the floor in public. One mother confessed, “Definitely, other people's bias. …I cannot ignore other people's perception when Sunyoung behaves strangely or differently from typically developing children. I don't feel comfortable. I am always in a state of tension. …So, quickly we go back home or leave the place?” These five mothers also noted that they felt guilty about their child's inappropriate behaviors because people might consider a child's misbehavior as the parent's fault. According to the mothers, it might be partly because in general people do not have any knowledge or understanding regarding the characteristics of a child with a disability and partly because their child did not have any difference in appearance from typically developing children and thus others could not recognize that their child had special needs.

One mother shared her experience of living in China. Interestingly, she compared the different perceptions on people with disabilities between China and Korea. She said, “Keeping aloof from children with disabilities for no reason… although it (disability) is not the infection, people dislike and avoid them (children with disabilities) as if disability is contagious. …I had an experience of living in other countries such as China and people in other countries did not see us like Koreans do. … the general population’s bias is the biggest barrier.” Another mother also shared her experience with another country. She shared that when she visited her sister’s family in Singapore, she reported that she felt much more comfortable with her child with a disability because Singaporean did not show any distinctive response to her child. It was an interesting finding because China and Singapore share many cultural values and beliefs with Korea yet according to these mothers’ experiences the bias of the general population against persons with disabilities seems more serious in Korea. It is possible that the Korean value of and belief in the importance of a unitary race may influence this difference.

Interestingly, four of the five mothers whose children attended Dongle Preschool did not report bias as a barrier. These mothers believed that the general population tends to have a special regard for their child’s special needs. One mother said, “I talk to other mothers that Hodol has a disability. Then, they try to help my child. They take care of my child in several ways… And I don’t try to keep my child’s disability a secret. So, I have more comfortable relationships with them…” Another mother said, “I overcame people’s bias. I do not care about them because they do not raise my child. I am his parent, not them. I do not feel ashamed due to my child’s disability…”

This difference between the two groups of mothers may be explained by the differences in socioeconomic status, parental ages, and community characteristics. That is, mothers of the Dongle Preschool were of a lower socioeconomic status and on average younger than those of the Kyrin Preschool. In addition, the Dongle community is located at a greater distance from Seoul than the Kyrin community which translates to an important difference in terms of perceived status. Thus it is likely that the mothers whose children attended the Kyrin preschool had more negative experiences than the mothers of the Dongle preschoolers due to one or a mix of the above factors.

Parents' attitude. Many of the mothers were concerned that their child had few chances to interact and play with typically developing children outside preschool days. These mothers explained that their child's lack of social and communicative skills limited an interactive play with other children. Moreover, the attitude of typically developing children's parents affected their child with a disability's social interaction with peers. Sangyoon's mother said, "Our children are lack of social skills and have limited expressive and acceptive language skills. So, actually some mothers say, even in front of me, 'My child goes to the preschool not for competing with these children (children with disabilities), I chose here because of the good program.' Mothers talk like this. Even in the Kyrin Preschool… So, we cannot say with an open mind, 'let's children play together!'" She continued, "I tried everything I can do, you know. I tried to teach mothers sewing and they came to my home with their child in curiosity at first but they do not continue coming. …Therefore, I gave up inviting people now…" Sangyoon's mother additionally commented that she changed a strategy from attempting her child with a disability to interact with typically developing peers into attempting her child to interact with typically developing siblings of other children with disabilities. She regretted that her child did not have a typically developing sibling. She mentioned that typically developing siblings of a child with a disability might have better understanding about a child with a disability and thus be good social partners of her child. Her comments highlight again that typically developing siblings or other family members such as cousins are key persons for a child with a disability to have socialized opportunities.

A mother expressed a concern about having relationships with new parents or neighbors in the future. The mother said, "Now, neighbors know about my child's special needs so it is not difficult for Junho to make friends here. However, we cannot stay here forever. Probably, Junho needs to go to school in a different district as he ages. As a matter of fact, it is hard for me to move to a new district because I am afraid if I can have good relationships with new neighbors or he can make friends in a new environment."

Lack of parents' personal time. Most mothers complained that they needed time to spend for themselves. Mothers were typically tied to their child's schedule so that they had no time and energy for themselves. The only free time was when their child was in the preschool. One mother said, “You can guess I don’t have my own life. …As a matter of fact, I want to work. …However, I am tied to his schedule.”

A couple of mothers reported that they were estranged from their friends because they don’t have the time and energy for socializing. In addition, they said that they worried about whether their friends understood when their child displayed inappropriate behaviors in public. Seven of the ten mothers reported that they missed many things that they did before, such as family weddings, and having a dinner with friends. Gwangsue’s mother told of several recent social events, a wedding and dinner with friends in which she and her child participated. She indicated that only because her child’s behavior had improved was she willing to try this.

Need for Supports and Services

The need for supports and services for increasing their child’s participation in community activities in the future was closely related to the barrier that influenced the child’s access and participation in community activities. The issue of supports and services is presented across three sub themes: (a) change of general populations’ bias toward persons with disabilities, (b) attitudes of community staff working with a child with a disability, and (c) proximity of programs or services in community.

Change of bias. As noted above, the general population’s bias toward people with disabilities was a critical issue. Mothers said that the general population, by and large, viewed people with disabilities either sympathetically or negatively. Youngho’s mother said, “People with disabilities are, honestly, members of our society as well, you know? They are not abnormal but normal and natural people. … Korean people still regard children with disabilities as incapable and pitiful people who need some help or others.” However, Youngho’s mother added later that changing such perception was not easy because the general population did not have many opportunities for interacting with people with disabilities. She said, “We had such a hard time and great agony in the process of accepting our child’s disability. So, will it be possible for the general population to accept and understand disability? They do not have any experience.” In addition, some of the mothers reported that they thought that not everyone had negative attitudes to their child with a disability. The problem was that there were a few people who were not respectful of persons with disabilities in Korean society.

Attitudes of community staff. Mothers reported that the attitude of community activities staff was a crucial factor in their deciding whether their child was able to participate in an activity. A mother made a decision for her child to learn TaeKwonDo because the director had a child with a developmental delay who was at that time a high school student. The mother explained, "Junho is learning TaeKwonDo. A director's attitude is very important. The director knows and understands children with disabilities like my child very well cause' his son also has a developmental disability. He takes care of my child well because he knows that Junho is the child who lacks social skills."

Another mother emphasized the significance of the staff's attitudes. She made a great effort to search for an appropriate swimming coach for her child. She said, "Taegyun's coach did not have information about children with disabilities but he was willing to say 'yes'. He is not a person who studies special physical exercise for children with disabilities. 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. I am so satisfied. My child loves swimming." The mothers confirmed that a positive attitude was the most important characteristic for staff members followed by their knowledge or experiences with children with disabilities.

Proximity of programs. Mothers reported that there were few community activities conveniently located in their own communities. Thus, these mothers had to seek out activities outside of their community, which resulted in additional difficulties such as the need for transportation. One 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 and time…I wish that Mansue could go everywhere without me. And I wish every service would be provided in one place, or one building."

Ⅳ. Discussion

In this paper we have described the findings of a study focusing on Korean parents of children with disabilities' perceptions regarding their child's community inclusion opportunities and the factors that influenced their community access and participation. The families reported that their Korean children with disabilities most frequently occurring type of community activities included socialization activities [e.g., visiting extended families (n=9), having friends over to play (n=6)] and community events [e.g., taking a walk in the park (n=10), indoor/outdoor playgrounds (n=10)] from the total of five categories of community activities. Parents reported that typically their child with a disability participated in these activities with family members. Specifically, siblings and cousins were the key socialization and play partners. Parents learned about available community activities from parents' association, other parent, or on their own. Previous studies in the U.S. (i.e., Beckman et al., 1998; Dunst, 2001) reported that the parents of a young child who has been recently diagnosed with a disability may lack the necessary informational resources. However, less experienced parents in this study did not report a lack of informational resources because they were able to easily connect with and obtain useful information from veteran parents.

The Korean parents of this study reported that family connectedness and increasing positive interaction with extended families were the most valuable benefits of participating in community activities for their child and family. These parents believed that providing frequent learning experiences for their child is one of their primary responsibilities as parents. This finding supports those reported in previous U.S. studies in that diverse opportunities for interaction and engagement with a variety of people in everyday community contexts has been reported as providing children with disabilities increased learning opportunities, improvement of developmental skills, and opportunities for building social linkages (Beckman et al., 1998; Dunst et al., 2000; Dunst, 2001).

These parents' commitment and positive attitude towards their child's participation in community activities, however, were impeded by several barriers such as was the case in the U. S. studies (Beckman et al., 1998; Dunst et al., 2000; Guralnick, 2001; Odom et al., 2002; Stoneman, 2001). The most frequently identified barriers were the general populations' bias towards persons with disabilities including typically developing children's parents and the drain on parents' time and thus feelings of dissatisfaction with and need for some personal or respite time for themselves. Thus, when ask to identify needs for supports and services, the parents identified a need for a change in the general populations' view and understanding of people with disabilities. Furthermore, the parents noted that if the proximity of the activities and other support services to their homes could be decreased the barriers of transportation and drain on parents' time could be decreased. Finally, the parents' highlighted the importance of community staff have a "can do" or positive attitude as a critical factor for enhancing their comfort with and their child's satisfactory engagement in community activities.

Limitations

Although this study provides important initial information for understanding the perspectives of Korean parents of preschool children with disabilities in terms of their experiences in providing for their child's participation in community activities, several limitations are noted. First, the use of telephone interviews is a limitation. Although telephone interview was inevitable due to the long distance, it limits data collection. Telephone interviews do not allow the interviewer to interpret important nonverbal behaviors of the parents. Using international phone cards which lead to less than optimal sound quality and occasionally the parent having difficulty in hearing the interviewer's voice clearly was also a potential limitation. Second, the lack of fathers' participations may have limited the outcomes of the study. Although mothers were the primary caregivers of the families in this study, interviewing with fathers may have provided different perspectives on their child's participation in community activity specifically considering the fact that fathers are the primary decision makers in the Korean family structure (Chan, 1998). Finally, the participants of this study were homogeneous so that the generalization for the study was decreased. That is, all of the participants were full time homemakers (i.e., non working mothers), and in financially considered middle class. Although the goal of this study was to generate depth of understanding rather than breath (Rubin & Rubin, 2005), homogeneous participants limits the ability to generalize the findings of this study to other groups of Korean families.

Implications for Research

More research that includes perceptions of professionals who are working at educational settings or at community programs or services is needed to better understand the whole picture of community integration of young children with disabilities. Although the findings from the present study provide useful information on community integration of children with disabilities from the parents' perspectives, a research including other people who are working with children with disabilities may provide different perspectives and information on community integration.

Implications for Practice

An important implication for policy makers and advocates for persons with disabilities in Korea of this study is to address increasing public awareness of people with disabilities. The general populations' lack of understanding and negative bias towards people with disabilities makes it difficult for children and their families to more fully engage in community activities. Therefore, public awareness through such avenues as educational and story books, films, and public activities should be systematically implemented by policy makers and those in the disability field. In addition, disability service providers and community staff should collaborate in order to share useful information and resources about community activities for each other and provide them to families of children with disabilities. Moreover, policy makers and service providers need to work collaboratively for providing beneficial programs and services for young children with and without disabilities in a manner that is convenient for families.

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장애 영유아의 지역사회 활동참여에 대한 부모들의 인식

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<요약>

일반적으로 통합의 개념은 교육현장 (유치원이나 학교) 내에서 국한하여 주로 연구되고 논의 되어왔다. 하지만, 통합의 핵심적 개념은 보다 광범위한 범주, 즉 장애 아동들이 일상적으로 생활하는 가정, 지역사회, 그리고 교육현장 등에서 이해되어야 한다. 특히, 장애 영유아들이 지역사회에서 가족, 친지, 혹은 또래친구들과 함께 경험하는 모든 일상은 이들의 발달 및 학습 증진에 큰 영향을 미치기 때문에 매우 중요한 의미를 지니고 있다. 하지만, 장애 영유아나 그의 가족들은 지역사회 활동참여에 일반 아동들이 경험하지 못하는 여러가지 난점을 겪을 수도 있다. 이에 본 연구는 현재 한국에서 통합유치원을 다니는 장애 영유아들의 부모님들 10인과의 개별 심층 인터뷰를 통해 이들이 지역사회 내에서 참여하는 활동들 그리고 그런 참여활동에 미치는 부정적 혹은 긍정적 영향들을 질적연구를 통하여 알아 보았다. 인터뷰 결과, 장애 영유아들의 지역사회 통합에 따르는 가장 큰 난점은 일반 사람들의 장애아동에 대한 인식 부족 및 이에 따른 사회적 지지 혹은 지원부족이라는 것을 알 수 있었다. 따라서 본 연구는 장애 영유아 및 그들 가족이 보다 활발하게 지역사회 활동에 참여할 수 있도록 보다 실질적이고 효율적인 지원과 방안을 제시했다. 즉, 행정가, 학교장 및 기관장, 그리고 교사들이 중심이 되어 대중매체를 통한 장애인에 대한 대중적 인식 향상과 지역사회 내에 있는 각 전문가들 간의 원활한 정보교환 및 의사소통을 통해 보다 적극적인 장애 영유아 가족 지원이 절실하다고 본다.

주제어: 장애 영유아, 지역사회 참여, 가족, 통합

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