The Quality of Mainstreaming in Preschool: The Views of Parents of Children with Down Syndrome

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Abstract

Down syndrome (DS), one of the developmental (cognitive) deficits, is the most common syndrome that arises from genetic disorders. The mothers of children with DS who encounter the most intense emotional situations since the tendency to take responsibility the children’s care and development usually belongs them. Among these intensive feelings, mothers are also responsible for providing needs, such as special education support, searching for a suitable preschool institution to accept their children, and access to specialists who can understand their medical needs. This case study aims to investigate the opinions of the mothers whose children with DS aged between 36-72 months were attending preschool. The data were collected using semi-structured interview techniques in three different preschool institutions where the mainstreaming was carried out in the district center of Gaziantep, Şahinbey. Interviews were conducted with five mothers whose DS children went to the preschool institution in the spring semester during 2015-2016 academic year. Descriptive and content qualitative analyses were used to analyze the data. The findings regarding the opinions of the mothers of DS children on the quality of the mainstreaming practices revealed the following salient themes: Early experiences before mainstreaming, quality of mainstreaming at preschool and inclusion. The findings showed that inclusion practices have not been adopted in mainstreaming practices in our country; therefore, the most reliable sources mothers preferred to follow was the experienced families who had children with DS in the preschool.

Keywords: down syndrome, preschool education, parents, inclusion

1. Introduction

1.1 Introduce the Problem

1) Why is this problem important?

In the present study, considering that the preschool is the first step of education, the investigation of the problems of the special needs children with DS diagnosis in the preparation process to school in terms of the views of the parents is a distinguishing aspect. In addition, the choice of qualitative research method based on interaction and in-depth information gathering and data obtained through semi-structured interviews is also important for arrangements for preschool mainstreaming practices for DS children.

2) How does the study relate to previous work in the area? If other aspects of this study have been reported previously, how does this report differ from, and build on, the earlier report?

2013 regulation by the Ministry of National Education in our country had not brought any changes to the age of starting preschool education. Before the newly developed system, a resolution urging the children between 37-72 months to go the preschool education had been implemented. According to the 2013 regulations on 12-year compulsory education, the children who completed 36 months may start their preschool education. However, it is remarkable that in this regulation there is a change in the upper limit of continuing education due to the alteration in the age of starting compulsory primary education. Thus, as of 30 September 2012, there is a resolution ensuring that the children between 37-66 months continue the practice classes or kindergarten, and the children between 48-66 months take their preschool education in preschool classes. The same legal regulation includes continuing the mainstreaming education practices during preschool just like at other levels (MEB-Ministry of National, Education, 2012).
3) What are the primary and secondary hypotheses and objectives of the study, and what, if any, are the links to theory?

This study was conducted on the grounds that the quality of the mainstreaming practices and the views of the mothers in this respect are believed to be significant and aimed to investigate the views of the mothers of children with DS who are between the ages of 36-72 months and continue to preschool on the quality of the mainstreaming practices in preschool institutions.

The following questions were sought in line with the research aim:
- What are the mothers’ views on experience with DS children before children’s preschool education?
- What are the mothers’ views on the quality of the mainstreaming practices in the preschool institutions?
- What are the mothers’ views and recommendations for increasing the quality of preschool mainstreaming practices?

4) How do the hypotheses and research design relate to one another?

Although there are mainstreaming practices in Turkey, early intervention programs are not yet in place; therefore the institution-based and children-oriented approach of the pre-school education process, no matter how well organized the transition from home setting to pre-school education is, may become a new and challenging process for children with special needs and their families. In this regard, mothers as the primary caretakers, experience difficulties in supporting the educational and social development of their children apart from nursing (Küçüker, 2001; Metin, 2012; Freeman & Kasari, 2002). So the study is designed with a in this study, the mothers of children with DS whose children were continuing to preschool were reached with purposive sampling. The data were collected through 13 interview questions, which aimed to determine the opinions of the parents about the practices of mainstreaming training.

5) What are the theoretical and practical implications of the study?

As a result, it has been seen that when mothers of DS children feel themselves lucky when they were admitted to preschool institutions, their children were happy with this process and they described these institutions and teachers as qualified. When mothers received positive support in the family before the preschool education, it seems to be effective in accepting the DS diagnosis. The mothers needed social support out of their family, and this support was also expected from the local administrations NGO’s and associations-foundations as well as the people in their immediate surroundings. In addition, mothers needed organizations, such as arts, sports and leisure activities that empower their children’s interpersonal interactions. In this regard, families should be informed about their access to such services by making relevant regulations. The findings suggest that the transition process to the preschool institutions for mothers is difficult because there are no early intervention services in the preschool education. As a result, it is understood that inclusion practices are not yet an approach adopted in mainstreaming practices in Turkey; therefore, the most reliable sources of education, particularly the most reliable sources of maternal choice in the preschool and elementary school period are the experienced families with DS children.

1.2 Explore Importance of the Problem

Every married couple who have taken the first step towards becoming the “smallest unit” of society, the “family,” imagine having a healthy baby. Babies, however, can also come to the world with many differences specific to their development. Examinations made during pregnancy, along with advances in imaging and diagnostic techniques, provide detailed information about the kind of developmental differences that infants may experience (Farrel, Agatisa, & Nutter, 2014). Parents who are often unprepared for a negative picture have a baby with developmentally different and special needs, which also affects family patterns (Brynat, Puri, Dix, & Ahmed, 2016; Oktay & Unutkan, 2013; Skotko, 2015).

DS, a disorder characterized by the division of chromosomes, is a syndrome of mental retardation that could be seen in every part of the world (Contestabile, Benfenati, & Gasparini, 2010). DS occurs in live births in 1: 700 to 1: 1000 rates, and in three different ways: “trisomy 21, mosaic trisomy and translocation trisomy”. The most common type of DS (95%) is the type of trisomy 21 that occurs when babies have 47 chromosomes due to the presence of three chromosomes instead of two on chromosome 21st. Developmental disorders could also be seen in the areas of physical, cognitive, social, language and emotional development depending on the genetic structure of children with DS (Acarlar, 2006; Cakmak, 2009; Cohen, 1999; Küçüker, 2001) While the most widely recognized distinguishing physical features are head-to-face structures, problems, such as heart diseases, sensory deficiencies, epilepsy, immune system and endocrine system disorders, are also common in individuals
with DS (Contestabile, Benfenati, & Gasparini, 2010; Fidler, 2005; Grieco, Pulisifer, Selgshon, Skotho, & Schwartz, 2015). In addition, behavioral and psychiatric disorders could be seen in young people with DS, which limits their independence and job placement rates (Jobling & Cuskelly, 2002; Mallardo & Cuskelly, 2014). Inadequacies in expressive language development due to mental retardation also negatively affect the independent life of individuals with DS (Acarlar, 2006; Abbeduto, Warren, & Conners, 2007; Fidler, 2005; Freeman & Kasari, 2002). Among the developmental (cognitive) deficits, DS is the most common syndrome that arise from genetic disorders. Autosomal trisomy syndrome is more likely to occur in pregnant mothers at an advanced age (Daunhauer, Fidler, Hahn, Will, Raitano, & Hepburn, 2014; Kozma, 2008; Metin, 2012). Mother’s learning of having a baby with DS diagnosis is established by clinical observations immediately after birth and diagnosed by genetic tests, as can be diagnosed by screening and testing during pregnancy (Contestabile, Benfenati, & Gasparini, 2010). The studies conducted with the families and especially mothers who have infants with deficiencies reveal that open and clear diagnosis has provided psychosocial advantages in favor of the mothers (Abbeduto, Warren, & Conners, 2007; Cocchi, Gualdi, Bower, Halliday, Jonsson, Myrelid, & Annere, 2010; Contestabile, Benfenati, & Gasparini, 2010; Fidler & Nadel, 2007; Freeman & Kasari, 2002). Findings showed that well-known and early genetics diagnosis, such as DS, cause children’s mothers to reach their social support groups more quickly and have emotional comfort in permanent and significant dimensions. However, there is an emphasis in the relevant literature that the mothers of children whose diagnoses are unclear and who are hoping that perhaps one day their children can be called “normal” do not seek for social support, do not prefer to communicate with their parents of children with disabilities (Lenhard, Breitenbach, Ebert, Schindelhauer-Deutscher, & Henn, 2005; Rosenthal, Biesecker, & Biesecker, 2011) and experience negative feelings depending on their degree of disability, their problem behaviors and the level of social support they receive (Helff & Glidden, 1998). In this process, parents have experienced psychological problems, such as rejection, regret, sadness, anger, sociability, guilt, stress, anxiety, hopelessness and depression (Akkök, 1997; Kaytez, Durupal, & Kadan, 2015; Pştav-Akmeşe, Mutlu, & Kerem-Günel, 2007; Sucuoğlu, 1995). In the literature, the concept of “Down Syndrome Advantage,” which positively affects the level of social welfare of mothers, has been widely used for many years because children and young people with DS have a more harmonious and calm temperament than children with other genetic syndromes and mental deficiencies (Corrice & Glidden, 2009). Many parents of children with DS are strongly against it even if it is not valid for all parents, and parents with normal development children have had the pleasure of raising children despite the behavior problems that accompany their children’s disabilities (Glidden, Grein, & Ludwig, 2011). In addition, mothers of children with DS reported positive opinions about situations, such as stress, anxiety, and interpersonal relationships, that exemplify the concept of family welfare (Corrice & Glidden, 2009). Among the factors that account for the mothers’ positive feelings are that children with DS have cute, friendly looks and harmonious behavior, as well as the social support and economic situation they see from their environment and their spouses. However, it can also be observed that children with DS may abuse their love ties with their mother and/or family members as they grow older with various actions, such as rejecting a given task, delaying school and home affairs. Thus, parents should monitor the behaviour of their children with DS and learn under which stimuli the behaviour occur, increase or decrease to prevent the unwanted behaviour, especially in recent years, many studies have highlighted the significance of early intervention so that the small differences observed in the first period of life in babies with DS will turn into snowball effects in the coming years and make individuals incapacitate in all developmental areas (Bailey, Hebbeler, Spiker, Scarborough, Mallik, & Nelson, 2005). The most common behavioral patterns known of all children with DS are that they have the desire to participate and interact in social settings. Compared to children with other developmental disabilities, they empathize with their peers, and they are more easily adapted to social settings (Blacher & Mc. Intyre, 2006; Eisenhower, Baker, & Blacher, 2005), they maintain friendships and are selected as friends by their peers (Freeman & Kasari, 2002; Kasari & Hodapp, 1996). Guralnick, Connor, & Clark Johnson (2011) reported that children with DS should be supported by parents and teachers to strengthen their interaction with their peers.

Negative emotional moments are experienced by the mothers intensely (Beckman, 1991) since the tendency to take responsibility for care and development of their children is usually mother’s responsibility (McConachie, 1989). Among these intense feelings, mothers are also responsible for providing needs for their children, such as special education support, searching for a suitable preschool institution to accept their children, a doctor who understands their medical needs, dentist and reliable caregiver (Bailey, 1988). As parents receive social support from close families, family members and other families with DS children, positive expectations and moods increase, and attempts to meet their needs are also increasing (Cavkaytar, Ardu, & Aksoy, 2014; Guralnick & Albertini, 2006). To meet these needs on time and with correct intervention, the developmental evaluation of children with DS should be followed from early on, and expert support should be provided to their parents. The
training should be implemented on the basis of home and/or institution in the form of early intervention programs to support children’s cognitive, emotional, social and behavioral development (Bailey, Hebbeler, Spiker, Scarborough, Mallik, & Nelson, 2005; Dunst, Trivette, Hamby, Raab, & Bruder, 2000; Sucuoğlu, 1995). Early intervention programs advocate that children aged 0-36 months should be able to reach health, nutrition and development support as early as possible, strengthen their families and regulate the environment in which their children live with their families (Ertem, 2005; Ertem, Doğan, Gök, Kizilates, Çalışkan, Atay, & Cicchetti, 2008). Early intervention programs are carried out in a natural setting, such as a home environment the child and his family live, a home of the caregiver, a children’s park, and a shopping mall to prepare the families and children for education programs in multi-directional ways. The transition process is a long-term arrangement that helps special needs children acquire the necessary skills from the home environment to the school environment and then to the professional life (Bakkaloglu, 2013; MEB, 2012). Although there are mainstreaming practices in Turkey, early intervention programs are not yet in place; therefore the institution-based and children-oriented approach of the preschool education process, no matter how well organized the transition from home setting to preschool education is, may become a new and challenging process for children with special needs and their families. In this regard, mothers as the primary caretakers, experience difficulties in supporting the educational and social development of their children apart from nursing (Cohen, 1999; Freman & Kasari, 2002; Küçüker, 2001; Metin, 2012).

The term mainstreaming appears to have been used to place special needs children in the same classrooms with their peers until the 1990s (Odom & McEvoy, 1988; Odom & Speltz, 1983). The inclusion term used today is defined as being accessible to the social community like everyone else and being a part of social and social systems, beyond the fact that children with special needs need to be placed in educational settings together with their peers (Odom, Buysse, & Soukakou, 2011). Even if the term changes, games, and peer groups are expressed as the environments in which the social interaction of the special needs children develops the most. Social interaction between peers has been a subject of interest and work for many years due to its importance (Guralnick, Connor, & Johnson, 2011). The National Association for the Education of Young Children has also emphasized the importance of educating preschoolers about gaming activities to assess, support and monitor the development of all children and has shown it as among the indispensable values in the child’s life (National Association for the Education of Young Children, NAEYC) (Division for Early Childhood National Association for the Education for Young Children, DEC, 2009). The presence of children with DS with their peers in the mainstreaming classes of preschools will enable them to experience social interaction skills through life experiences more often through peer and adult interaction (Guralnick, 2000).

The services of preschool education are supporting the child and the family and strengthening the intra-family patterns at the same time. It is therefore seen as a necessity to benefit from preschool education services for children with special needs and to have access to support services in all developmental areas together with their peers (Mahoney, 1990; Mc Naughton, 1994). However, in recent years, that special needs children in preschool mainstreaming practice could not reach the desired achievements unless the systematic teacher interventions put re-examining the mainstreaming practices on the agenda (Özaydın & Çolak, 2011; Özaydın, Tekin-Iftar, & Kaner, 2008). When children’s mainstreaming experiences are examined, social and academic acquisitions of them, just as children with other disabilities, are limited (Rietveld, 2014; Macartney & Morton, 2013) and since they are excluded by normal children, they cannot benefit from peer-mediated social interaction opportunities (Guralnick, 2000). The proceeding on what quality mainstreaming is and how it should be applied resulting from the long-lasting experiences based on preschool mainstreaming practices, prepared by the two major organizations, namely DEC and NAEYC, have been put in the literature (Division for Early Childhood National Association for the Education for Young Children, 2009). With this proceeding, the concepts of “Access, Participation and Support” that determine the quality of mainstreaming practices in preschool education have been explained, and field experts have agreed on a common opinion on their placement in preschool education standards (Larocco & Barton, 2016; Odom, Buysse, & Soukakou, 2011; Soukakou, Winton, West, Sideris, & Rucker, 2015).

Among the concepts that determine the nature of mainstreaming practices in preschool education, Access is defined as the facilitation of access to opportunities, environments, and activities that support children’s learning and development, and the realization of universal learning standards (Universal Design for Learning). For example, the problem of access could be solved by removing the physical and structural obstacles that make it difficult for children to reach an activity, environment or material, and providing a new order. Participation is defined as the amount of time when children with special needs meet together (teachers, peers, materials) in accordance with children’s age, competence and medium of living. Some special needs children need routine
teaching or individual arrangements and support from embedded teaching to fully involve their peers and adults with learning and play activities by organizing environmental regulations and program even if access to preschool classes is provided (Mc William & Casey, 2008; Shonkoff, & Phillips, 2010).

The concept of Support is defined as the provision of continuity and support to individuals, family members, practitioners, experts and administrators who provide services to families and children, even if access and participation of special needs children are provided, through the necessary background for effective mainstreaming (DEC, 2009). Especially, the fact that preschool teachers are not trained to meet the learning needs of children with disabilities (Chang, Early, & Winton, 2005) has frequently been reported. In this context, proposals for solutions seem to focus on re-examining the approach of raising preschool teachers. Another important point that should be supported in mainstreaming practices is the family-school cooperation, that is, the participation of the family in the early childhood education. Active participation in the family’s education process affects children positively, promotes social and linguistic development, and maintains learning in the home environment (IDEA-Individuals with Disabilities Education Improvement Act, 2004). In this regard, school and/or home-based instructional programs are valued for children with special needs in the preschool period, and the family is consulted for their views on current education practices (Council Exceptional Children) (CEC-Council for Exceptional Children, 2010).

There are published studies into the views of parents of children with DS on mainstreaming and inclusion practices. The study that investigated the views of the families of children with DS and children with autism on inclusion practices found out that mothers of child with DS were happy that their children would be placed in full-time preschool classes by inclusion practices, therefore, they supported this placement practice as an ideal method as opposed to mothers with autistic children. In the study, when parents’ views on inclusion were evaluated in terms of children’s age groups, the parents of small children with DS regarded the inclusive preschool classes as an advantage for their children. Parents’ accounts highlighted that their young children with DS have the desire to interact with peers and adults and that they can take advantage of these interaction opportunities (Marshall, Tanner, Kozyr, & Kirby, 2014). Researchers emphasized the issues that parents want to change, which included the need for more inclusion, the need for support for the transition to school, placement to the neighborhood school, the need for additional services and support, the effects of peers, parents’ financial resources and decision-making and continuity of receiving information. The results of two studies reported above were supported by a recent study (Freeman, Alkin, & Kasari, 1999; Marshall, Tanner, Kozyr, & Kirby, 2014) argued that parents of a child with DS had trouble accessing reliable information and services about the DS, while positive relationships and family cohesion was observed in families of the children with DS and between siblings. Parents were advised to improve their formal and informal support services that their children needed to maintain a quality life (Marshall, Tanner, Kozyr, & Kirby, 2014).

There is a limited number of studies on the mainstreaming practices in preschool for children with DS in our country, Turkey (Baysal-Metin, 1989), which remained under-researched. There is very few studies on the supporting preschool teachers’ professional qualifications and knowledge levels and teaching of academic and social skills to special needs individuals continuing to mainstreaming. In 2004, Bakkalöğlu developed an intervention program on an activity-based education and examined the effect of this program on the transfer skills of children with developmental retardation in the age range of 3-6 years and completed the scale development study to evaluate preschool transition skills in 2007 (Bakkaloglu, 2004). Another study on skill teaching belongs to Odluyurt & Batu (2010) which focused on the teaching of preparation skills for mainstreaming of individuals with developmental disabilities (Odluyurt & Batu, 2010).

Research on the qualification levels of the teachers working in the kindergartens (Kaya, 2005) and evaluation of the preschool mainstreaming practices was performed with the scanning method (Yavuz, 2005). Using semi-structured interview Özen, Ergenekon, Kürkçüoğlu, & Genç (2013) conducted research to determine the teaching practices in the preschool teachers’ classrooms who had mainstreaming students (Özen, Ergenekon, Kürkçüoğlu, & Genç, 2013). In another study, the level of knowledge about the mainstreaming of teachers in charge of the school was examined (n=169) The knowledge level of the teachers’ mainstreaming in preschool education was evaluated by using “Mainstreaming Information Test” (Sucuoğlu, Bakkaloğlu, İçen-Karasu, Demir, & Akalın, 2014). There is an experimental study on children with DS among the studies on mainstreaming in preschool (Metin, 2012). As highlighted above, we should note that scant research is available on the mainstreaming practices in preschool for children with DS in Turkey.
1.3 State Hypotheses and Their Correspondence to Research Design

The case study was chosen because we had the opportunity to elaborate the quality of mainstreaming practices, which is a current phenomenon nowadays, in the light of the opinions of the mothers with DS children who are going to the preschool mainstreaming classes in the real-life area (Bakkaloglu, 2013; DEC-NAEYC, 2009; Guralnick, 1999). Using semi-structured interview (Yildirim & Simsek, 2013; Ergenekon, 2007), the data were collected from the mothers of DS children attending three different preschool institutions where the mainstreaming practices in the district center of Gaziantep, Sahinbey.

2. Method

In this study, the mothers of children with DS whose children were continuing to preschool were reached with purposive sampling. As a result of the interviews conducted with the managers and employees of Guidance Research Center of Gaziantep, we learned that there were children with DS diagnosis and placed in mainstreaming; however, the decision of families is important. In other words, children with DS and their mothers who are recommended to mainstreaming could be reached by applying to the preschool. Seven children with DS and mothers were reached through the administrators and teachers of the preschool. The interviews were conducted with five mothers of children with DS were at the preschool during the spring semester of the 2015-2016 academic year. For the confidentiality (Bogdan & Biklen, 2007), pseudonyms were used. Demographic information of mothers and children is given in Table 1.

2.1 Identify Subsections

The themes that were revealed in the interview data about the views of the mother’s children with DS on the quality of mainstreaming practices are explained under three main themes: early life before mainstreaming, quality of mainstreaming in preschool and inclusion. Mothers’ early life-based views were pointed out in the sub-theme of acceptance process of children with DS, social support the children had during this process, and guiding them to educational institutions they received in the process. The views of the mothers on the quality of the mainstreaming practices were explained in the proceeding, published in 2009, which represents the conditions of a quality inclusion with the dimensions: Access, participation, and support (DEC-NAEYC, 2009). Under the inclusion, which is the last theme of the study, the opinions of the mothers about the transition from preschool mainstreaming education to later education levels and social inclusion were included. The themes and sub-themes obtained in the research are given in Figure 1.

2.2 Participant (Subject) Characteristics

In this study, the mothers of children with DS whose children were continuing to preschool were reached with purposive sampling. As a result of the interviews conducted with the managers and employees of Guidance Research Center of Gaziantep, we learned that there were children with DS diagnosis and placed in mainstreaming; however, the decision of families is important. In other words, children with DS and their mothers who are recommended to mainstreaming could be reached by applying to the preschool.

2.3 Sampling Procedures

Seven children with DS and mothers were reached through the administrators and teachers of the preschool. The interviews were conducted with five mothers of children with DS were at the preschool during the spring semester of the 2015-2106 academic year. For the confidentiality (Bogdan & Biklen, 2007), pseudonyms were used. Demographic information of mothers and children is given in Table 1.

2.3.1 Measures and Covariates

The data were collected through 13 interview questions, which aimed to determine the opinions of the parents about the practices of mainstreaming training and information form aiming to obtain demographic information. Some of the 10 questions included in the written interview form are presented in Appendix A.

2.3.2 Research Design

An inductive approach was adopted, and descriptive and content analysis were carried out in the data analysis that included the perceptions and expressions of the mothers. In a holistic and detailed descriptive analysis, it is our aim was determine the similarities and differences between the answers of the interviewees (Bogdan & Biklen, 2007). During the preparation phase, coding was done for each mother, and descriptive manifestations of her responses were extracted. The patterns between the data were divided into categories by the authors, the codes representing each category were formed, and finally, the main theme and the sub-themes were reached. Authors determined the inter-reliability of the coding by calculating the repeatability and reliability between the
Reliability was calculated according to the formula: Reliability = \( \frac{\text{Agreement}}{\text{Agreement} + \text{Disagreement}} \) \times 100 (Miles & Huberman, 1994). The inter-coder reliability was calculated as 96% and considered reliable.

2.3.3 Experimental Manipulations or Interventions

The thirteen (13) questions in the interview form are given in Table 3. The identified questions were asked in the same order to the participants, and the mothers were given the opportunity to respond to the questions as long as they wish. Voice recordings were taken at all interviews and also recorded in writing with the participants’ consent. The study focuses on the opinions of mothers of children with DS. Children with DS were continuing to mainstreaming in preschool. The present research investigated the quality of mainstreaming in preschools and children’s needs using semi-structured interview. The interviews lasted average 30-46 minutes. Interviews with the parents were conducted in the guidance room of the preschool institutions where children continued and in individual education and support education rooms. Before the interviews, the school administrators, the teacher and the guidance counselor responsible for the room were informed by the researchers. Face-to-face interviews were performed at the times when children were in the classes and when the physical properties, such as sound, heat, and light were appropriate.

3. Results

The opinions of mothers participating in the study were gathered under three main themes: “early life, quality of mainstreaming practices and inclusion”

3.1 Early Life

The acceptance of the diagnosis, the social support they receive from the family and its close surroundings and the kind of directions given to their children’s education process were identified as the sub-themes of early life, starting with the DS diagnosis of the interviewed mothers. The expressions of the mother’s own experiences and perceptions in these three sub-themes, including “acceptance process, social support and guiding” are described below.

3.1.1 Acceptance Process

While all of the mothers stated that they managed this process with difficulty, they reported the factors that made the process difficult, which included the way the diagnosis was explained by the medical personnel, helplessness that children experienced, and the positive and negative aspects of sharing diagnosis and health condition with family members and close relatives. The excerpts from the views of the mothers are given below.

Nazan: Mehmet had to have heart surgery and had a chance to be once. If it’s just a problem in your heart, it’s nothing. The doctors told me that he could only have one operation because he is DS. He was seven-and-a-half-months when he had the surgery. This is a very difficult. I did not see any help from anyone then. Everyone even my relatives loved him from a distance.

Leyla: We learned in the pregnancy that he would have DS. We have accepted this situation easier with my partner. It did not take long for our parents to get used to this situation. But I was saddened by the fact that some doctors were constantly talking about difficulties during pregnancy. I wanted to know more about what will happen and what I am going to do.

The two mothers who stated that another problem they have experienced during the admission process is the sayings of relatives and friends declared that they had a lot of difficulties in this process. Here are excerpts from the interview data collected from mothers who had a child with DS:

Zeynep: Nobody excluded my child. DS was easily accepted by your relatives and brothers. Doctors did not tell us anything, so we did not know. We learned one month after birth. Then we realized that DS was everywhere but we did not know. First, when we accept that we thought what our relatives would think about it. I think my greatest advantage is that the ages of my other children are higher.

3.1.2 Social Support

The mothers said that they received favorable support from their children, their spouses and their parents in the first years of birth of their child with DS, respectively. Nazan stated that she did not see the closeness of her neighbour from her relatives in her first years of the baby; however, all of her mothers expected a more positive sense of support from their immediate surroundings.

Gülay: Nobody supported. I also experienced the education process alone. Everybody was looking at Mert as if he can not do anything I have always struggled so that I can take a step. There is a ladder in front of me, and I have to go out these stairs. In fact, when they see the differences in Mert, they start to support me.
3.1.3 Guiding

Another important finding is that under the early life theme emerging from mothers’ views, their children could not find any official source or institution to guide them on early education and preschool education. While two mothers said that they were called for support from special education services by special education and rehabilitation centers while their children were before three years old, a mother shared that they acted after their pediatrician’s recommendation on starting the child a nursery. The other two mothers stated that they met with the experiences of the mothers of children with DS and they went to search for special education support and preschool institution. Even if the parents received information from different people and institutions, they found the greatest support for education from other families with DS children and followed the path they follow.

Nazan: They came from a rehabilitation center when he was one and a half years old, and they told me to take him to the office by service bus. Mehmet could not walk then. We were trying to make him walk better. I was going to training twice a week with him. They were throwing toys in front of him. I was doing the things I saw there at home. His walking slowly after the surgery. He was afraid more. Gülçay: I went to the hospital to have Mert’s report. After that there is RAM, and they said that he should have mainstreaming. He’s six years old now. Maybe after a year, he will start primary school. They said it. Otherwise, I thought it was too early for kindergarten. Everyone said that I registered Mert here, “it is too early, so early, do not register for kindergarten.”

Here are excerpts from the mothers about guiding to special education and early intervention process: It seems that mothers do not have enough information about Special Education and Rehabilitation Centers or what kind of training the preschool institutions will provide for special education support. While a mother who applied to a private nursery recommended, she did not have a problem during her application to preschool institutions, other mothers stated that they faced school principals and/or teachers’ negative attitudes, did not want to register and had to change the preschool institution during their application to official preschools.

Zeynep: She’s old enough. We contacted families with other older children with DS, and we sought the institution and the teacher they were pleased. When we experienced negativity in some institutions, we were so hesitant. We always thought if it is ok or not, but the teachers helped a lot. We tried our schools close to our home, but we had the response “no”.

3.2 Quality of Mainstreaming in Preschool

The opinions of the mothers regarding the quality of mainstreaming practices in the institutions their children went, and how they evaluated them are described under the concepts of “access, participation, and support” (DEC/ NAECY, 2009, p. 2) below, which define qualified inclusion at the preschool.

3.2.1 Access

Special Education and Rehabilitation Centers in terms of access to special education are the first centers to reach mothers. After the children were 36 months old, the parents visited more than one institution but were not accepted, and their children started a preschool education late due to the search of an experienced teacher. The excerpts of the mothers regarding the access to education process are provided below:

Nazan: His teacher loves him very much. Therefore, the other children are also more interested in him. If his friends do not understand what he says, he always gets angry. Then, he stays on the teacher’s side. Our teacher recognizes us from a distance.

Ayla: When I was looking for an institution for my child, I looked for the best teachers and good institutions. In this regard, I care about the parents’ opinions who have had previous experiences.

It is understood that the general opinions of mothers regarding access were related to staff competencies. Mothers generally think that school administration staff’s attitudes towards children with DS play a significant role in the quality of mainstreaming. Excerpts of the mothers’ view are given below.

3.2.2 Participation

The findings showed that mothers’ views on participation in preschool education were that the mothers were pleased that their children participated in class activities, in which they felt that independence and individuality were supported. It was understood that they even shared the fact that their children were able to transfer what they had learned in school to the home.

Gülay: I think the class at the moment is quite enough and efficient [...] At least he knows he can share something. So everybody will sit in this table, everyone will paint this, so he knows it. He’s learning to share. He’s going very well with personal independence.
All the mothers who stated that there were negative experiences as well as positive about the participation in class stated that the biggest problem was the reactions due to the negative attitudes of the children’s peers and families. The excerpts from mothers’ views are given below:

Ayla: There are adults who are negative examples to children, but if the family uses a language that is mocking at home for the disabled child.

3.2.3 Support

Mothers stated that their children’s first days in the preschool institution was a supportive and informative environment for them. Two mothers expressed that they wanted support from whoever came to the class to help the teacher and that this practice was an advantage for the children:

Gülay: The school principal and assistant manager said that they could accept him. Until now, from the moment Mert never knew, they always thought I should I accept Mert, they always wondered whether Mert would learn or not. Mert learns. Mert cannot do this year, but Mert can do the next year. They told me that wait, never mind, but he will make it better if he goes.

The findings indicated that mothers benefitted from the experience of mothers who had children with DS and that even their search for special education and preschool education institutions and teacher searches acted in accordance with their suggestions. In addition, a mother expressed the need for associations and support of non-governmental organizations (NGO).

3.3 Inclusion

The experiences of the interviewed mothers after the preschool and the social life were reported with their opinions about their expectations. In line with the information gained, inter-institutional transition and social inclusion sub-themes were obtained.

3.3.1 Inter-Institutional Transition

All of the mothers stated that a successful mainstreaming was implemented in the institution where their children were present, that they did not want to change the institution, and that their children’s participation in preschool facilitated their participation in social activities, too, such as sports and arts. Mothers noted that the skills that children could gain in such events would prepare them for the future and how important preschool education was regarding this benefit. Three parents stated that they had had negative experiences when they took their children to such centers, while they expressed that they were often informed about the out-of-school activities by other mothers. Three of the mothers (Ayla, Gülay, & Zeynep) stated that NGO’s and local administrations are effective intermediaries in organizing such activities.

Gülay: As my child continued to study, he got more active outside. He developed himself through observing how children behave outside. Her communication has become stronger. He has adapted more easily to other institutions for sports. So, she has become to be able to continue.

Leyla: I never thought which school he would start. There is a family we are very close. We met at this school. He left here two years ago. Their children started primary school before. Then, I heard that he was in special education class.

3.3.2 Social Inclusion

All of the mothers have expressed that their children gained some skills in social life but that their inadequacy in terms of social-communication and self-care skills continues that the findings showed that children with DS were demanding the organization for more social activities with the cooperation of local administrations and NGO. In this process, mothers stated that they were informed about their children’s social skills from other experienced mothers, preschool teachers, and internet sources.

Zeynep: There must be times when the mothers will take for themselves. For example, I can take her with me wherever I go, she does not have a problem. I say that sometimes we get bored, we get overwhelmed. For example, I say you can take care of her, I want to go out as I wish or and go shopping. So, those people need to know. They should empathize with me and put themselves in my shoes and think what I can do, how I can reduce the burden.

4. Discussion

The salient themes revealed in the interviews with mothers who were attending preschool mainstreaming classes were under three themes: the early life of mothers before mainstreaming, quality of mainstreaming at preschool and inclusion. Mothers’ early-life-based views were pointed out in the sub-theme of the acceptance process, the
social support they received in the process and guiding children with DS to the educational institutions. Mothers’ views on the quality of the mainstreaming applications were summarized in the context of a proceeding that explained the characteristics of the qualified inclusion practices with the concepts of access, participation, and support (DEC, 2009; McWilliam & Casey, 2008). Under the inclusion theme, which was the last theme, mothers’ views were described with the subthemes of transition to next education levels and social inclusion.

The participation of the mothers’ children with DS was an indispensable factor, and the mothers were seen as a member of the team in special education at preschool. Our insightful findings could contribute significantly to the literature in terms of the quality of mainstreaming practices. At the same time, short and long-term proposals will be offered to the education system by reviewing early childhood education and mainstreaming practices at preschool for the children who have special needs through the experiences and expectations of the mothers regarding their experiences with children in a mainstreaming class now and before.

The mothers stated that they learned that they were going to have a child with DS during pregnancy and/or the following birth and accepted easily. They expressed that they had the greatest support from their husbands, their children, and their parents. DS is a well-known and early genetic diagnosis that affects the acceptance process of mothers positively and provides psychosocial advantages for mothers (Lenhard, Breitenbach, & Ebert, 200; Oktay & Unutkan, 2013). Even though the mothers stated that the process was accepted easily within the family, they described that there were two important factors that make it difficult: their children had health problems (e.g., congenital heart failure), and how the health problems children suffer could be addressed by health personnel (Brynat, Puri, Dix, & Ahmed, 2016; Skotko, 2005). However, in this process, the mothers stated that they were expecting health personnel to guide themselves on what to do and where to obtain information (Skotko, 2005). This finding was consistent with the previous studies (Cavkaytar, Arıç, & Aksoy, 2014; Guralnick & Albertini, 2009). The health system has the most extensive social service network in Turkey. However, we should highlight that the health personnel does not have sufficient knowledge about the evaluation and monitoring of the development areas of children who have special needs (Ertem, 2005). In line with our findings, there are studies which found out that when mothers were informed about DS, the health personnel often used negative expressions about DS, did not provide information sources to families, and did not help how to reach families with DS (Skotko, 2005). All mothers in the present research stated that they expected to see the same support they received from the family members from the neighbors, relatives, and people they meet in the community; however, unfortunately, they did not. Mothers said that they received the first information about DS from health personnel’s. They stated that their children contacted health personnel (doctor, nurse) during routine health checks or during the treatment process to get information about DS. Mothers who stated that they met families’ children with DS like themselves in health centers and hospitals after the first years of difficulty, expressed their confidence in the views and suggestions of these experienced families. In the main time, they stated that the special education and rehabilitation centers in their surroundings also tried to provide special education support for them and facilitates the process of receiving educational evaluation reports from Guidance Research Centers by providing access to make their children have special education support. The mothers believed that their most reliable source was experienced families who had children with DS; therefore, they consider experienced families’ views and suggestions when they sought special education support for their children, also, the preschool institution that would accept their children and a preschool teacher.

This research also showed similarities with the literature on the finding of positive effects of the social support that the mothers received during the DS admission process. It is seen that the well-known and early genetic diagnosis, such as the DS, made the mothers reach social support groups more quickly and provided an emotional comfort (Contestabile, Benfenati, & Gasparini, 2010) while the social and economic support from their husbands strengthened their positive feelings. In fact, the mothers stated that they perceived normal to have a child with DS as well as having a normal development child. For example, they stated that they would not have an abortion or taking they learned that their babies have DS diagnosis or they would quit their jobs even they had a child with normal development. This finding in accordance with the finding in the previous literature which showed that parents of children with DS enjoyed pleasure without parenting (Glidden, Grein, & Ludwig, 2011) as well as parents with normally developing children (Esbensen & Seltzer, 2011). The mothers were aware of the early childhood special education services by the reaching of the Special Education and Rehabilitation Centers in their surroundings and the suggestions of other families’ children with DS and health personals.

When the mothers’ early experiences about their children with DS were examined holistically, our findings showed that between 0-36 months a systematic application did not reach them. Also, health personnel working in the health system which is the most common system in our country, families with DS children like them and Special Education and Rehabilitation Centers providing special education support were the mothers’ sources of
information in this period. The finding that is the fact that health personnel does not have sufficient information about monitoring the development of children, early education and family support is in line with the previous literature (Ertem, 2005; Ertem, Doğan, Gök, Kızıltale, Çalışkan, Atay, & Cicchetti, 2008). However, early intervention services advocate that children aged 0-36 months will reach health, nutrition and development support as early as possible, strengthen their families and regulate the environment in which their children live with their families (Guralnick, 2000). If early intervention services are implemented as a systematic service, these problems that families encounter are highly likely to diminish. Unfortunately, the fact that early intervention services could easily strengthen these groups with DS advantages by reaching the families and the child early (Corrice & Glidden, 2009; Esbensen & Seltzer, 2011) show that this advantage cannot be evaluated. Beyond the ineffectiveness of this advantage, this situation will negatively affect the fact that children with DS will face with health problems in the following years, acquire problematic behavior, adversely affect language learning and live independently away from the social life (Acarlar, 2006; Fidler, 2005) and it will turn into a disadvantage for the society.

Some studies showed that that the families of children with DS found inclusion classes at preschool appropriate, however, they did not accept since the mainstreaming classes did not provide appropriate opportunities for their children (Freeman, Alkin, & Kasari, 1999; Guralnick, Connor, & Johnson, 2011; Kasari, Freeman, Bauminger, & Alkin, 1999). When the findings of this research are examined, it is seen that there is a lack of a circular on how to apply the mainstreaming practices at the beginning of the school year. It is believed that the present Circular 60 on Mainstreaming (MEB, 2008) does not bring any special proposals specific to the preschool and is behind the literature because it covers all levels of education. The finding that the satisfaction of both the mothers and their children with their children’s participation in the class activities was consistent with the previous studies (Kasari, Freeman, Bauminger, & Alkin, 1999).

Informational meetings could be held in cooperation with universities, governmental institutions, local administrations NGO and organizations on the legal rights of the special needs children and their families. Social support groups could be created to facilitate interactions between the parents. In this respect, support can be provided by local authorities and municipalities. Collaboration with the Ministry of Health could be arranged, and in-service training for health personnel could be arranged in the DS’s diagnostic process, follow-ups for mother and child before delivery and guidance. Arrangements could be made for early childhood guiding services for families in terms of access, participation and continuing education for children with DS and other special needs children, primarily in preschool, primary school, and other educational levels. In addition to the views of families’ children with DS, a study may be conducted to examine the views of preschool teachers’ students with DS in their classroom. Another study that examines the views of undergraduate students attending preschool on practical experiences on their work with children in need of special education in their institutional internships could be conducted.

References


Ertem, İ. Ö. (2005). Children with development problems in the first three years: Three problems and three solutions. *Ankara University Faculty of Educational Sciences Journal of Special Education, 6*(2), 13-25


**Appendix A**

**Parent Interview Questions**

Q-1) What kind of attitudes have you met from your family, peer, and sister during the time until your child starts school? In this process, who do you think provided you and your child with most important support? Why?

Q-2) How did you decide that your child should start school? What kind of guidance about this issue was provided to you and from whom? (Prompts: Doctor, relative, friend, other families)

Q-3) What kind of attitudes did you meet in the school environment your child was present? (School management, teacher, other parents, peers)

Q-4) When you think about your child’s characteristics, what kind of classroom environment do you think he needs to be trained? Is the classroom environment he/she is currently studying sufficiently in terms of its characteristics (teacher, other students, physical characteristics)?

Q-5) What do you think about mainstreaming (strengths and weaknesses)? Do you think this model is applied correctly for your child?

Q-6) What are the most positive practices for your child in the school environment? (Prompts: Program, teacher-friend relations, social, game activities)

Q-7) What are the similarities and differences between your child and his classmates?

Q-8) What kind of difficulties does your child face in your school environment? (Prompts: Service, food, classroom environment, attitudes and approaches)

Q-9) Are there any areas your child has difficulty? If so, what? Are you cooperating with his teacher in these areas?

Q-10) Who do you think the most intensive come from in his school life? Do the support type and level meet your expectations?

Q-11) What are your views and expectations so that the integration program becomes more useful for your child? (Prompts: Program, school management, teacher friends, and other families) if you were wanted to make arrangements in the program, in which areas, to whom, and what kind of suggestions would you have?

Q-12) What are your child’s needs out of school life? What sort of arrangements do you recommend for out of school life?

Q-13) Do you think that the program and institution you are continuing prepare your child sufficiently to the primary school? What are your suggestions in this regard.
Appendix B

Table 1. Demographic information of mothers and children with DS

<table>
<thead>
<tr>
<th>Participants</th>
<th>Mean±SS</th>
<th>Min-Max</th>
</tr>
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<tbody>
<tr>
<td>Mothers’ average age</td>
<td>37</td>
<td>28-45</td>
</tr>
<tr>
<td>Children’ average age</td>
<td>5 age 4 month</td>
<td>5-6</td>
</tr>
<tr>
<td>Mothers’ first birth age average</td>
<td>21</td>
<td>18-23</td>
</tr>
<tr>
<td>Mothers’ average age at the birth for a child with DS</td>
<td>31.4</td>
<td>22-40</td>
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<tr>
<td>Number of children the family has</td>
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<td></td>
</tr>
<tr>
<td>Gülay</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Zeynep</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Ayla</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td>Nazan</td>
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<tr>
<td>Leyla</td>
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<tr>
<td>Socio-economic level of the family</td>
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<td>Median</td>
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<tr>
<td>Good</td>
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<td>Education Level of mother</td>
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<tr>
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<tr>
<td>Education Level of father</td>
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<tr>
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<tr>
<td>Duration of preschool education of the children with DS</td>
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</tr>
<tr>
<td></td>
<td>2</td>
<td>2 year</td>
</tr>
<tr>
<td>Areas where the mothers want the child with DS to be supported for development</td>
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<td></td>
</tr>
<tr>
<td>1-Language development and communication skills</td>
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<td>2-Social skills</td>
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</tr>
<tr>
<td>3-Academic skill</td>
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<td>State of the children with DS receiving support outside the school</td>
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<td>The type and institution of the received support</td>
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<td>Special education support / Special education rehabilitation center</td>
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<tr>
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<tr>
<td>Under the supervision of parents</td>
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