A study on family opinions concerning services provided in special education centres

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Suggested Citation:

Received August 13, 2017; revised October 28, 2017; accepted December 22, 2017.
Selection and peer review under responsibility of Prof. Dr. Huseyin Uzunboylu & Assoc. Prof. Dr. Cigdem Hursen, Near East University.
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Abstract

This study is to diagnose and evaluate children with different special needs medically and educationally and, as a result of those evaluations, to identify families’ expectations, opinions and suggestions concerning the special education process, services and the functioning of special education institutions. The mothers of five children who attended special education centres located in Nicosia, Turkish Republic of Northern Cyprus, were included. The data were gathered through semi-structured interviews, and the study were designed with the research method qualitatively. The opinions of mothers were gathered under five main themes. The results show that children who were diagnosed/evaluated at an early stage were integrated into education earlier and benefit more from special education institutions compared with other children. This study concludes that mothers’ anxiety and stress decrease as the social support they receive increases.

Keywords: Children with special needs, family, special education support services, special education.

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1. Introduction

The family, which is one of the smallest and basic building blocks of society, plays an important role during the development and education of the child, starting from birth. A newly arrived child brings to the family many changes, whether the child has special needs or not. There are many changes that couples have to overcome such as the harmony between spouses, undertaking of new roles, changes in the professional and daily lives of spouses and economic adjustments. In addition, the dimension of changes experienced by families having children with special needs is much greater. Thus, the stress and anxiety experienced by those families increase in parallel to the severity of the change. Families need some help and support in many issues such as the child’s special needs, special problems or education. Besides, if those children need life long day care during or if they have problematic behaviours, the stress and anxiety level experienced by the family in overcoming those difficulties, and concerns regarding the child’s future, increase. On the other hand, matters such as the children’s acquisition of independent living skills, how to carry on in the absence of their mother or father, and the education or services they would receive in the future when they become adults are among the factors increasing the level of anxiety (Coskun & Akkas, 2009; Ozsoy, Ozkahraman & Calli, 2006; Schilling, Kirkham, Snow & Schinke, 1986). It seems that there are a lot of studies we have looked at in the literature about the involvement of the special need child in the family, feelings of the family, anticipations and solution ways (Evans, 2007; Hatton, Emerson, Graham, Blacher & Llewellyn, 2010; Howard, Williams & Lepper, 2010; Ristal and Singer, 2004; Yates, 2012), while in some of these studies the importance of family support services in dealing with emotional states is emphasised (Howard et al., 2010; Yates, 2012) and how they deal with these emotions, and that most families do not know how to behave in this situation and that their marriages do not continue (Hatton et al., 2009; Ristal and Singer, 2004). The importance of the family is emphasised by the importance of the family in meeting the needs of the child, and it is possible to provide early education services by emphasizing that it is a turning point for 0–6-year-old special needs children like all children, and it is stated that starting at the earliest possible time is the solution to both the family and the child (Evans, 2007; Yates, 2012).

In addition, families always need to be behind their child and provide support from birth as planning and carrying out their situation. This situation limits the functions of the family and leads to stress since many families do not have enough information on matters such as where to get guidance, what to do and how to behave. Thus, starting from the birth of their child with special needs, families face different problems in different areas with regards to information, stress, anxiety, social support and material matters (Hassal, Rose & McDonald, 2005; Kaner, 2004; Sucuoglu, 1995).

The families of children with special needs should, in order to reduce stress and worry, gain knowledge of their children’s condition, share their experience with others and work together with those concerned with their children’s education (Kucuker, Bakkaloglu & Sucuoglu, 2001). Because families help their children with special needs in fulfilling all their needs and provide them with many services as the persons in their nearest proximity. Thus, families are the fundamental factor in the lives of disabled children, and should receive knowledgeable and qualified support during the first years of their child. Families which are informed properly and which receive support provide support for their children concerning issues such as starting education at an early stage and minimizing the adverse impacts of disabilities. As we consider the importance of early childhood education, it has been determined that family support services should be of good quality (Kaner, 2004; Sucuoglu, 1995). Early childhood special education covers education services provided to children who are aged from zero to six years, who are at risk of, or have growth retardation and services to the parents of those children. Those education services develop parents’ skills in forming positive interaction with the child and also favourable learning outcomes for the child (Birkan, 2002; Harris & Handleman, 2006; Hume, Bellini & Pratt, 2005).

The sooner children with special needs start receiving education services, and the more efficient will be the support received by the family and the child. Moreover, this factor would also be effective
in the establishment of healthy interaction between the child and their environment as well as in the perception of the child as a member of the society. Furthermore, special education services received in early childhood also play an important role in planning and implementing in an efficient and effective manner than services received in the preschool and primary school education of the child as well as their education in the later years.

General education services provided to all children with special needs or to children having normal developmental aim to orient children according to their interests, wishes and skills and to help them in different ways to solve problems. At the end of this process, the objective is for children to attain the life of self-sufficiency, that is, independent individuals. The medical diagnosis and evaluation of children with special needs provides information to educators as well as families with regards to the identification of children’s educational needs and the monitoring of their development. Medical evaluations are conducted in hospitals and clinics, and reports are given to children at the end of those evaluations. However, it is observed that those reports do not define the performance levels of children with special needs (Altinkurt, 2008). Therefore, in addition to medical diagnosis, children with special needs shall also be evaluated from an educational point of view. In this manner, their performance shall be determined and educational objectives shall be established. The educational evaluation of children with special needs comprises the gathering of various information on children. This process shall be carried out with different objectives such as identification, classification and enrolment in a programme (Taylor, 1997).

Children in whom disabilities have been detected as a result of educational evaluations shall benefit at the maximum level from special education services in order to maximise their skills in independent living, academic development, social development and other areas of development (Erıpik, 2013). One type of education included in the field of special education is special education support services. Special education support services are defined as specialists, equipment, education and consultancy services provided to the individual child, their family, teachers and the staff of the school they attend, once the educational needs of the disabled child are determined at the end of the evaluation and diagnosis process (Batu & Kircaali-Iftar, 2005). Thus, special education support services do not only cover the education of the disabled child, but also their family, and involves the work of at least two individuals or more in cooperation. Individuals working in cooperation support the academic success and the social acceptance of the disabled child as well as their participation to society. Education institutions are a social structure and form the basis for education and training. Of course, as educational institutions have expectations from individuals, institutions also have responsibilities to the child, the family and other specialists. In this respect, the cooperation of institutions with families is important for increasing the quality of education received by children who benefit from special education services. Since, as in children exhibiting normal development, the group that best knows the characteristics of children with special needs is their mothers and fathers. Cooperating with the family enables child’s skills learned at school to be developed at home. Thus, this cooperation supports the continuity of skills and their generalisation in different environments.

Therefore, the level of knowledge of the families on the special education services provided by institutions to their children, and the level of their cooperation with the institution are of vital importance for the institution, the family and the child. Considering the importance of the family in the life of the child (Hassal et al., 2005; Howard et al., 2010; Kaner, 2004), early education services (Evans, 2007; Yates, 2012) and school–family cooperation are emphasised. It seems that it is not enough to work with what kind of problems the family has encountered, how they solve their problems and what they expect of support from their education services, starting from the way the child is diagnosed to the benefit of special education services. For this reason, this study aims to reveal the problems experienced by families with regard to their children, while the next studies to be carried out in the field are thought to shed light on the solution proposal.

The objective of this study is to diagnose and evaluate children with different special needs medically and educationally and, as a result of those evaluations, to identify families’ expectations,
opinions and suggestions concerning the special education process, services and the functioning of special education institutions.

The study reviews the problems faced by families during all the important phases of children with special needs since birth, such as diagnosis and evaluation, and the special education services they receive, and puts forth in a detailed manner the solutions families have used to overcome those difficulties. Since the findings of the study consist of opinions expressed by mothers, they are considered important. Mothers’ statements concerning special education centres which their children attend and their expectations from specialists are hoped to provide guidance for people working in this field as well as for other families.

2. Methods

2.1. Research model

The study has been designed as qualitative research to describe the opinions and expectations of families whose children attend special education centres in Cyprus, with a view to examining their living situations, medical and educational diagnosis and evaluation processes, and the institutional services they received. The data of the study were collected with semi-structured interviews. The interview technique is a process based on interaction, where the personal perceptions and experiences of participants are considered (Bogdan & Biklen, 2007). Both researchers have professional practice and academic experience in the field of special education. For this reason, the interviews were carried out by the researchers themselves and the voice recordings were carried out. This study is grounded on the perceptions and statements of mothers, and analyses in a detailed manner the opinions of mothers concerning the situations faced in the diagnosis and evaluation of children, to what extent they have benefited from special education services, and their level of knowledge and participation regarding services. The semi-structured interview forms prepared by researchers by taking the opinion of specialists were used in the collection of data.

2.2. Participants

The mothers of five children who required special education and who attended special education centres located in the city centre of Nicosia in the Turkish Republic of Northern Cyprus, were included in the study realised during the spring term of the 2016–2017 academic year. Due to the principles of confidentiality and ethical conduct, the names of mothers have not been disclosed in the study. Participation was voluntary and the codes A1, A2, A3, A4, A5 were used. Researchers first developed a plan and started the data collection process within this plan. They reached the number and addresses of private special education and rehabilitation centres in Nicosia in the TRNC, met with the director and the authorities of the institution, and made the necessary authorisation for the research.

2.3. Data collection tool

Data for this study were collected by researchers who used the interview form and the demographic information form prepared in consultation with specialists. The 11 questions in the form were asked sequentially to participant mothers during the interviews and their answers were recorded with an audio recorder. Only interviews with the researcher and mother have been made to the interviews made using the voice recorder. After completing the interviews with each mother, the voice recordings were listened and written by two different researchers. Basic information such as age, gender, educational status and income level of mothers was gathered in the demographic information form used in the study. Furthermore, this form contained information on the gender and age of children and reports for how many years the children have education support, and in which area they required the most support. The demographic information of participants is given in Table 1.
As seen in Table 1, children with special needs are in the age range of 6–18 years and they have received supportive education from 1 to 15 years. Three of the children with special needs are boys and 2 are girls. One child was diagnosed with a need for special education services from birth. Three children were diagnosed for special education at age 2, and one child was diagnosed for special education at age 5. The areas where children needed the most support were determined to be the acquisition of independent living skills for two children and the acquisition of literacy skills for three children. As we see in the table the years during which support was received, we see that special education support has been received from 1 to 15 years.

As we see in Table 1 the general characteristics of mothers who are the participants of the study, we see that 3 have graduated from primary school and 2 from high school. The age of mothers at the birth of these children varies between 18 and 30. One family has a medium level of income, while four families have a low level of income. Four mothers declared that their teacher changed during the education process of their children and that they previously received support from a place different from the institution they currently attend. Two mothers declared they received support at home from a private teacher.
2.4. Data collection tools/techniques

The questions taking place in the semi-structured interview form were prepared by taking the opinion of specialists working in the special education departments of two different public universities in Turkey and holding a doctoral degree in the field of special education. Participating parents were asked about the level of clarity and clarity in the interviews, the academicians working in the Department of Education Faculty, Turkish education were shown and the final form was given after their opinions were received. The answers given to questions were analysed with the inductive approach in order to reach a deep meaning (Creswell, 2005; Ergenekon, 2007). Researchers have made a detailed literature review while preparing the questions and have evaluated the accessibility of children with special needs with regards to special education centres. Then, in all the important stages such as diagnosis, evaluation and special education services from the birth of children with special needs in different areas, the difficulties they face with these processes, the solutions they use to overcome these difficulties, the special education centres their children attend and open-ended questions that questioned the perceptions/opinions of the experts on duty and the support services they received. Then researchers prepared open-ended questions in order to examine the difficulties faced by families during all the important phases of children with special needs such as the diagnosis and evaluation phases starting from their birth and the special education services they receive; the solutions families have used to overcome those difficulties; their expectations with regards to the special education centres attended by their child, the education programmes that are implemented and the specialists working in those centres; and their perceptions and opinions on the support services they receive. Afterwards, two specialists contributed opinions on validating the draft form that had been prepared. Then the draft form was revised according to the corrections and suggestions from specialists and revised into its final format. Examples of questions used in the interview are taking place in Table 2.

<table>
<thead>
<tr>
<th>Table 2. Semi-structured interview question examples</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. When did you first notice that your child had special needs? What kind of orientation has been made for the evaluation?</td>
</tr>
<tr>
<td>2. What kind of approaches did you come across within the family, from peers and from brothers–sisters up until the diagnosis and the evaluation were made?</td>
</tr>
<tr>
<td>3. How did you decide to have your child start education support (rehabilitation institution)? What kind of situations did you face during the orientation process?</td>
</tr>
<tr>
<td>4. What do you think a class environment should be like for your child to receive education that is appropriate to his/her characteristics?</td>
</tr>
<tr>
<td>5. Is the education institution presently attended by your child adequate from the physical point of view and with regards to training programmes?</td>
</tr>
<tr>
<td>6. When you think about the general education and/or education support, what kind of problems do you think your child has faced at school (attitudes, physical adaptation and environment participation in social activities)?</td>
</tr>
</tbody>
</table>

2.5. Data collection process

2.5.1. Implementation of semi-structured interviews

Before starting the data collection process, mothers were informed about the study to be conducted. After taking their consent to participate, the demographic information of mothers and children was taken. Following the collection of demographic information, interview questions prepared by researchers were addressed to mothers in the Teachers’ Lounge or in the individual education room. During the interview conducted with each mother in the special education institution attended by her child, researchers tried to pose comprehensible questions and abstained from steering the responses. The average duration of interviews was 19 minutes. Audio recordings were made after receiving consent from the mothers participating in the interview. Also the contract text
was read before the meeting and approval was started. The context information for the interviews is given in Table 3.

Table 3. Context information of interviews

<table>
<thead>
<tr>
<th>Researchers</th>
<th>Participants place</th>
<th>Date</th>
<th>Duration</th>
</tr>
</thead>
<tbody>
<tr>
<td>Researcher 1</td>
<td>Teachers’ lounge</td>
<td>March 15, 2017</td>
<td>15 minute 17 second</td>
</tr>
<tr>
<td>Researcher 1</td>
<td>Individual education room</td>
<td>March 15, 2017</td>
<td>17 minute 42 second</td>
</tr>
<tr>
<td>Researcher 1</td>
<td>Individual education room</td>
<td>March 15, 2017</td>
<td>23 minute 45 second</td>
</tr>
<tr>
<td>Researcher 1</td>
<td>Individual education room</td>
<td>March 16, 2017</td>
<td>18 minute 8 second</td>
</tr>
<tr>
<td>Researcher 1</td>
<td>Individual education room</td>
<td>March 16, 2017</td>
<td>21 minute 22 second</td>
</tr>
</tbody>
</table>

As seen in Table 3, the first author (researcher 1) carried out the interview phase with mothers on March 15, 2017 and March 16, 2017. Four of those interviews were made in the individual education rooms of rehabilitation centres, while one has been made in the teachers’ lounge while teachers were absent. As we examine the duration, it is seen that the shortest interview was with Subject A1 (15 minutes 17 seconds), while the longest was with Subject A3 (23 minutes 45 seconds).

2.6. Data analysis

The study was designed using an inductive approach. A descriptive analysis technique was used for the interview data. Data obtained from the mothers were coded for each subject from ‘A1’ to ‘A5’. After the coding process, interview records were transcribed and labelled as descriptive index, descriptive data, interviewer comment and page comment. The records were transcribed on the computer, and their descriptive inventory and coding were entered. The reason why the descriptive analysis technique of the data is analysed in this research is the analysis of the similarities and differences between the statements made by participants in the qualitative researches and the statements they made about any topic (Bogdan & Biklen, 2007). For this reason, the discourse of the mothers was taken into account in the study and both the deduction and the induction methods were used together. After coding the data, it was grouped for identifying patterns and the data was aggregated. Ten different types of coding representing each category were used. Calculations on the reliability of the study, its replicability as well as calculations on the reliability between coders were made. The fact that the consistency ratio between coders is high in this calculation shows that the reliability is high. Reliability was determined by using the formula \([\text{Consensus} / (\text{Consensus} + \text{Divergence})] \times 100\) (Miles & Huberman, 1994). In the study, the reliability coefficient was calculated to be 90%, indicating that the reliability of study has been accepted as reliable.

3. Findings

The objective of this study is to diagnose and evaluate children with different special needs medically and educationally and, as a result of those evaluations, to identify families’ expectations, opinions and suggestions concerning the special education process, services and the functioning of special education institutions. In this respect, mothers indicated their opinions and suggestions concerning 11 questions and the interviews were recorded with an audio recorder. A descriptive inventory of interview records was made. Then records were analysed according to the qualitative analysis method, and main themes and sub-themes were obtained within categories. The main themes and sub-themes that were established are taking place in Table 4.
Table 4. Main and sub-themes

<table>
<thead>
<tr>
<th>Theme</th>
<th>F</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Opinions on intra-familial patterns following the birth of the disabled child</td>
<td>5</td>
<td>100</td>
</tr>
<tr>
<td>1.1. Opinions on the experiences of the family during the acknowledgment phase of the disability</td>
<td>5</td>
<td>100</td>
</tr>
<tr>
<td>1.2. Opinions on the acknowledgment, orientation and social support process</td>
<td>5</td>
<td>100</td>
</tr>
<tr>
<td>2. Opinions on the diagnosis and evaluation processes of the disabled child</td>
<td>5</td>
<td>100</td>
</tr>
<tr>
<td>2.1. Opinions on the diagnosis process and the provision of health services</td>
<td>5</td>
<td>100</td>
</tr>
<tr>
<td>2.2. Opinions on the process concerning the enrolment in the institution and the access to the support services</td>
<td>5</td>
<td>100</td>
</tr>
<tr>
<td>3. Opinions on the programme implemented in special education institutions</td>
<td>4</td>
<td>80</td>
</tr>
<tr>
<td>3.1. Opinions on the effectiveness of the programme implemented in special education institutions</td>
<td>5</td>
<td>100</td>
</tr>
<tr>
<td>3.2. Opinions on the problems faced in the implementation of support services</td>
<td>5</td>
<td>100</td>
</tr>
<tr>
<td>4. Opinions on the staff working in the delivery of support services</td>
<td>5</td>
<td>100</td>
</tr>
<tr>
<td>4.1. Opinions on the cooperation between the family and the staff working in the special education centre</td>
<td>5</td>
<td>100</td>
</tr>
<tr>
<td>4.2. Opinions concerning the impact of the cooperation made by the staff working in special education and general education institutions on delivery of education support</td>
<td>5</td>
<td>100</td>
</tr>
<tr>
<td>5. Opinions on the legal regulations concerning the delivery of support services</td>
<td>5</td>
<td>100</td>
</tr>
<tr>
<td>5.1. Opinions on the changes made in support services provided in special education centres</td>
<td>5</td>
<td>100</td>
</tr>
<tr>
<td>5.2. Expectations of the family from the institution and suggestions</td>
<td>4</td>
<td>80</td>
</tr>
<tr>
<td>5.3. Differentiations in the professional competencies of the staff working in special education institutions</td>
<td>5</td>
<td>100</td>
</tr>
</tbody>
</table>

As seen in Table 4, the opinions of mothers who have children with different types and levels of disability and who attend special education institutions were gathered under 5 main themes and 11 sub-themes: ‘Intrafamilial patterns in conjunction with the birth of the disabled child, diagnosis and evaluation processes of the child, the program implemented in special education institutions, qualifications of the staff working in the supportive service process and legal regulations concerning the supportive service process’. Those themes, consisting of mothers’ opinions, have been gathered in 53 frequency intervals. The frequency values calculated for the sub-themes, indicate the number of mothers who stated their opinion on this theme.

The first theme of the findings is ‘Opinions on intrafamilial patterns following the birth of the disabled child’. Under this theme, there are two sub-themes as ‘Opinions on the experiences of the family during the acknowledgment phase of the disability’ and ‘Opinions on the acknowledgment, orientation and social support process’. Four of the mothers (A1, A3, A4 and A5) stated that their intrafamilial patterns changed upon the birth of their children and that their support needs have not been met during this process. On the other hand, one mother (A1) indicated that she was feeling responsible with regards to access to services since she had not accepted the fact that her child had special needs for a long time. Mothers stated that, depending on whether the disability was diagnosed at birth or later, they have faced problems such as getting divorced from their spouse, leaving home and cutting off communication with their relatives who had children of similar ages (such as a sister). Mothers also indicated that the two problems where they felt most alone were the access to health and education services and the acknowledgment of their child.

A1 ‘I had noticed since his babyhood but I guessed that he would overcome the disease. I don’t know. I thought that he would recover but I was afraid anyway’.

A2 ‘We knew right away that he had a disease. Anyway Huseyin’s problems started from birth. He had problems since his birth’.
A3 ‘In fact I had not noticed, her doctor did. My daughter was born orthopedically handicapped. In fact we did not know that she was autistic’.

A3 ‘First there was no problem. She only had a very small foot. The son of the elder sister of the doctor who operated on her was autistic. We were going regularly once every two or three days to check the cast. My daughter had nearly turned one year old. Her doctor said, I mean he said your daughter is autistic. I could not accept that…’

A4 ‘We noticed when she was 4 years old, when school time came’

Mothers pointed out that the fact that doctors gave exact information during the diagnosis phase of the disability was important. Mothers indicated that they received the most positive support from the families of children having special needs in similar or different areas.

A3 ‘The child was anesthetised once every two or three months. Until the first 6 months, we did not notice anything. But later I realised that she was not reacting to voices. Sometimes I was getting very nervous. I was throwing vases at the walls. She was not afraid at all. Then one day she heard advertisements on TV, she ran to the television with the baby-walker. I said ‘My God’, I was so surprised. We thought she was deaf but she was not deaf’.

A3 ‘My sister has a daughter of the same age. The child was not coming to our home because of her mother. That’s why I did not receive much support while she was small. But she has a friend who was our opposite neighbour in the neighbourhood. They have become friends with my daughter after they were 4,5 years old. When they were children they used to play in front of the house. When she went to primary school, all the children started to stay away from her or they were afraid. Autistic persons scream. There are ten or fifteen girls her age in the neighbourhood, only this child, the child of a family from Nigde. Even today they don’t leave her alone. When my daughter is upset, they leave their work and come’.

A3 ‘I get the most important support now. My husband and I both went into depression. I was separated from my husband at that time. When we were separated my daughter was two years old’.

A1 ‘My friend’s son had a baby of 5 months. He was sending the baby to special education since the baby was 5 months old. After I met him he said there was special education. I knew it was fee-based education. I said we cannot afford it. They said the state also provided such education. I mean it has been with the guidance of my friend’.

A3 ‘A lady helped us with education. In fact, when she learned that the child was autistic, she told us to take the child to the doctor. She said that these children received special education. We met Mrs. Senem when my daughter was two years old. Her child was also autistic’.

The opinions stated by the mothers show how important it is to get information support when they became aware of the handicap of their child. Mothers pointed out that besides the problems they faced with their spouses and other children at home, they also could not receive the support they expected from their close relatives. Mothers also indicated that neighbours who had a disabled child provided them some positive social support. Mothers stated that relationships within the neighbourhood and with close neighbours were important with regards to social acceptance and said that this situation was an advantage of attending a school that was near their house.

The second theme of the findings is ‘Opinions on the provision of diagnosis and evaluation of disabled children’. Under this main theme, we have two sub-themes, which are ‘Opinions on the diagnosis process and the provision of health services’ and ‘Opinions on the process of enrolment in the institution and access to the support services’. All the mothers emphasised the importance of early education in this process. However, they mentioned that inadequacies in the area of health had an adverse impact on the diagnosis process as well as on access to services (A1, A2, A3, A4 and A5). Under the sub-theme entitled ‘Opinions on the diagnosis process and the provision of health services’, mothers generally mentioned that the statements of doctors were very important. Mothers specified
that they could not acquire enough information when they were anxious about the developmental process of their child and pointed out that the language used was important.

A1 ‘I brought the child to the doctor. He said there was growth retardation. They said the head was small. They referred us to a neurologist who also said that there was growth retardation. At this moment you are shocked’.

A4 ‘We had been too late. The teacher noticed when she was 4 years old. She was not sitting at the table like her peers. She was interested in television. She was turning and looking in the direction where voices were coming from but there was no reaction. When the teacher told us, we went to the doctor’.

A2 ‘Yes, I mean, first we were not aware but Huseyin was born premature due to this genetic ailment. He was born by cesarean. I mean he stayed in the incubator for 15 days. The time he was in the hospital actually started when he was born, Huseyin was taken to the hospital in an ambulance right away. This was not a disease that we knew. Similarly, since my brother was in London he asked who might have this disease in the family and said that some convulsions would occur. When my brother said my sister also has it, we understood that we had a genetic disease’

As to the access to educational support services in special education centres and the orientation of children to health and education services, mothers stated that they received the most adequate support during the pre-school period, and benefited from the experiences of teachers, school directors and mothers who had disabled children.

A1 ‘My friend referred us. We did not know what was special education. We started with the referral of my friend’

A3 ‘A lady helped us with education. In fact, she told us that the child was autistic and asked us to take the child to the doctor. She said that those children received special education’.

A4 ‘We went to the doctor. The diagnosis took 10 months at the doctor. On the contrary, the situation of this child has strengthened our connection to each other. We thought how can we help her. As to personal friends, neighbours have excluded us but no one from the family has’.

A3 stated that children could not receive appropriate education as a result of incorrect referrals and placements. She also indicated that the assessment system was insufficient at this point.

A3 ‘I mean we brought her to this school and to that one but they did not accept her. I went to the Ministry. The authorised man at the ministry helped us. We started to go there once a week for only 40 minutes. Then we went 2 days and finally 5 days. We also experienced many problems there. My daughter started acting strangely. Then I took my child from there. I think she was 5 years old by that time. My father was then hospitalised at the intensive care unit. I have suffered a lot. I took her out of special education; we restarted at home.

On the other hand, A5 gave some more detailed information on the evaluation process and explained the experience gained in health institutions.

... My son was not 2 years old yet. I researched and tried to find the best doctor on the island. I brought my son to Mr. Aslan (not his real name); a pediatrician. If you ask me how I understood that he was the best doctor? According to me, if a doctor shows the same interest at the hospital and at his private clinic, then this is a good doctor. That’s why I tried to reach him. A5 indicated that her own observations and her close friends have helped her in finding a doctor.

‘A person in my social circles knew this doctor. This person has helped me. As soon as he saw he asked me a question’. “He said ‘can the child’ say the syllables of ‘mother’, this is very important”. He said “the child would say the word ‘father’, although badly”. He said “the syllables of ‘mother’, those two syllables are important”. I said “No, doctor, he says ‘father’ but he cannot say ‘mother’.
With regards to the main theme entitled ‘Opinions on the programme implemented in special education institutions’ the opinions of a total of five parents in both sub-themes are in nine frequency intervals. As to their opinions on the effectiveness of the programme implemented in special education institutions, four of the mothers (A2, A3, A4, A5) pointed out that the attitudes of teachers affected the programme. They also mentioned that the perspective determined by institutions was determinant on the staff working there and their educational practices. Mothers think that when their children change the education institutions they attend, this decreases their performance and they cannot benefit from education opportunities sufficiently.

A2 ‘At the beginning he went to nursery school when he was 4 years old and then he went to primary school. Thanks to the help of our director, he went to the source school, we were seeing the language therapist. They referred us again. We started at this school with the help of our instructors, our teacher and the director of school. I mean, there was a teacher at the special education institution we attended. He was a very good teacher, Huseyin had made progress’.

A3 ‘Special education is not sufficient in our country. Because we learn most everything from here and there. Instructors do not even know the disability of disabled children. I learned from a friend of my doctor how to deal with the education of my child’.

A3 ‘... There is no support, there is no support at school. How come there is no support? For example my daughter has graduated from primary school. We came here. Since we came, we hear that the Ministry would provide support to families. But there is no support’.

A3 ‘...My daughter participates very well in some classes. She had not participated in the last one or two classes but her teacher provided her some support. We have changed institutions. We came here. They said to us ‘we will help you, we will educate you’ etc. They brought us a school counselor. He was a very good teacher; he was helping us outside of classes. However, during the meetings he showed more interest in the education of small children. Still, no service for adults. They are talking about education that starts in infancy. Anyway there is still no education for adolescents or adults. I have participated in so many seminars but there was nothing for us. The most important requirement is family education”

A4 ‘The evaluation process is really insufficient. I am always anxious about where to send the child. The child is also fed up. They said first the child should attend regular primary school, she should study there 15 to 20 days. They said there they would draw a report and then the child would pass another examination from the rehabilitation of the state. The child does not go to primary school, what can I do if they do not get a report? In our institution the last year was paid education but the second year we came here’.

A5 ‘We have had many troubles in the evaluation. My son walked but he is not talking. He does not make any eye contact. Our daughter-in-law had noticed it, as well as my brother. They are graduated from the special education teaching department. I even got angry, I mean I have been vexed with them’.

As we examine the opinions of mothers regarding the problems faced during the implementation of support services, we see that they mainly pointed out that there was a lack of cooperation that the number of specialist teachers providing services in the institution in the field of special education was limited and that there was a difference in the quality of services from one institution to another. Mothers (A2, A3, A4 and A5) have intensely mentioned the effect of teacher changes. They indicated that as they attended special education institutions, the two main topics they were paying attention to were the teachers and the opinions of former parents.

For example;

A3 said the following concerning the adverse impacts of teacher changes on themselves. ‘Special education is surely necessary. I am satisfied but our teacher is temporary. Since Huseyin started to attend this school, teachers are constantly replaced. Just when the child is getting used to an
environment, the teacher changes. Then the new teacher starts over and I have not seen any progress in Huseyin’.

A3 “I cannot follow up the program implemented by the teacher. We started with some problems this year. There has been a teacher change. How many years did they change her teacher? My daughter picked a quarrel at school, she threw the tables etc. at school. She was so deeply attached to her teacher. She pointed out that teachers should continue education for a while with the child they are working with and said ‘she is still complaining even at home but they have established communication with her current teacher’”.

As we examine the opinions of mothers with regards to the staff working in the delivery of support services, we observed that mothers focus on the professional competencies of the staff working in special education centres and their attitudes concerning their cooperation with the family. Mothers mentioned that the cooperation of the staff working in special education and general education institutions would have a positive effect on the support education. They indicated that they were especially holding responsible teachers and school directors for the non-acceptance of their child to primary school. The opinions concerning this matter are as follows:

A4 ‘Anyway the primary school does not accept them Even now when the children enter the class they want the shadow teacher with the child. They do not accept; they want the shadow teacher with them; and the child attends school one or two days a week. Also the child does not get the same lessons. I think this is also wrong. If we want children to live independently we have to see that they sit alone in the class. Right now the child does not have any shadow teacher in this class. There is a teacher and a teacher trainee’.

A2 ‘I started bringing Huseyin here from the first, second grade. Because when he attended the first grade there were 10 students. His teachers were not showing enough interest. Huseyin was generally at the back of the classroom because the child can’t do it We went to receive the special education support from the centre. Similarly, the teacher also changed there. I mean we could not get much’.

As we examine the ‘Opinions on the legal regulations concerning the delivery of support services’, we observe that anxiety is one of the feelings most intensely experienced by mothers. Mothers are highly anxious about the inclusion of their child in adequate education; their efforts for building independent living skills and finally the life to be experienced by their child in their absence. Mothers stated that the services provided by the institution affected their anxiety levels during this process and indicated that they especially paid attention to cooperation with the institution staff and the progress of their child in their participation in social life. For example

A5 said ‘There must be better qualified support services. Physically it is not very adequate. Furthermore, the child would live in a group in his outside life. But here the education received is so limited on an hourly basis. Also, the individual and group education are not preparing them for real life. I think they can’t receive enough education’.

We observe that mothers’ expectations from the institutions and their suggestions were centred on physical competency, education material and staff qualification. Four of the mothers (A1, A3, A4 and A5) indicated that they wished that their child would acquire independent living skills, social skills and communication skills. Moreover, mothers also made some suggestions to the institution directors with regards to the physical optimisation of institutions. They especially gave negative opinions on the lack of educational materials and the quality of play equipment.

A5 ‘The education given by the class teacher shouldn’t be given without any play equipment. Besides the group class teacher and the individual class teacher, the institution must be developed. Play equipment is missing. I don’t find them adequate enough to the activity. I don’t like at all the play room downstairs’.

The totality of mothers (five mothers) responded in the sub-theme entitled ‘differentiations in the professional competencies of the staff working in special education institutions’
A4 ‘My child has a shadow teacher that has to sit behind her. This practice is not working in the classroom. It would be better if the class teacher focused only on her. Teachers can not follow each other’. I

A2 ‘I started bringing my son here since the first, second grade. I mean we could not get much. Some teachers show more interest’.

4. Conclusion and discussion

As we examine the findings of the study, we observe that the opinions of mothers who have children with different types and levels of disability who attend special education institutions are grouped under five main themes: ‘Intra-familial patterns accompanying the birth of the disabled child, diagnosis and evaluation processes, the program implemented in special education institutions, qualifications of the staff working in the support services, and legal regulations concerning the delivery of support services’.

According to the findings of the study, mothers stated that their intra-familial patterns changed upon the birth of their children and that their support needs have not been met. Mothers declared that they faced problems such as being divorced from their spouse, leaving home and cutting off communication with their relatives after the birth of their child. Mothers also indicated that they had problems regarding their access to health and education services concerning their child. The literature is similar to the findings of the study and puts forth that problems arise in the functions of the family and marital relations together upon the birth of a child with special needs. These problems might arise from the other siblings of the child, the relatives and spouses of mothers as well as from the disabled child (Freedman, Krauss & Seltzer, 1997; Ozsenol et al., 2003; Risdal & Singer, 2004). According to the study’s findings, the mothers of disabled children express that they cannot get satisfactory information, education and health services regarding the situation of their children from family, close environment and other spheres of the society. This finding supports the literature and in other studies that have been conducted, in that mothers stated that they could not receive support from their close relatives and acquaintances and that their stress, anxiety and burnout levels were high starting from the birth of their child with special needs (Kaner, 2003; Cavkaytar, Batu and Cetin, 2008). Furthermore, the conclusion that mothers’ anxiety and stress levels decrease as the social supports they receive increase is also in parallel with the literature (Howard et al., 2010; Kaner, 2004; Yates, 2012). It is thought that the education provided by the family plays an important role in helping the families cope with the problems experienced by the parents in the direction of this information and it is thought that the more information about the family child and the support from the environment, the more satisfied it will reach and the positive attitude towards the child will be developed.

The study findings show that children who have been diagnosed/evaluated at an early stage are integrated into their education earlier, that they have more interactive relations with the family and benefit more from special education institutions compared to other children. All the mothers emphasised the importance of early education and mentioned that inadequacies in the area of health had an adverse impact on the diagnosis process as well as on the access to services. In fact, special education in early childhood is accepted to be very important. In another study, Kucuker, Ceber-Bakkaloglu and Sucuoglu (2001) indicated that early education programmes regulated the interaction behaviours between mothers and fathers and their children. On the other hand, Diken, Batu and Kurtyilmaz (2010) pointed out that early childhood education programmes had positive impacts on preventing problematic behaviours. With regards to special education services in early childhood, McConnell (2000) indicated that screening systems for children took place in each state of the USA. He mentioned that after the screening procedures, children were evaluated in all fields by specialists and that appropriate individualised family service plans were prepared. It is seen that the early provision of education and health services provided to the family in the direction of these results are positive effects between the child and the family in two directions. It is thought that the family will benefit from many positive effects of early education such as education, improvement of social behaviour,
increase of social acceptance while children gain information and skills and communicate positively with their children.

The way education, health and support services provided to children with special needs obtained is a matter as important as the provision of those services. Mothers declared what concerns the access to supportive services and the orientation of children to health and education services; they received the most important support from teachers, school directors and other parents who had disabled children. Hallahan and Kauffman (2003) have put forth the importance of family support groups in the use of special education services by disabled children. They mentioned that the impact of family support groups might vary according to the personality characteristics of mothers and fathers. Ersoy and Curuk (2009) have referred to the significance of other parents as well as of the internet with regards to the social supports provided to families. Furthermore, they also specified that it is possible to raise individuals in peace and harmony with society as families of disabled children come together with other families, exchange opinions and relax by participating in recreation. As we take a look at the results of this study concerning the problems faced in the implementation of support services in special education centres, mothers indicated that the most important deficiencies were the insufficient level of cooperation among the family, the general education teacher and the special education teacher and the insufficient number of teachers providing services. Cooperation forms the basis of education support services that enable disabled children to fully benefit from special education services. As we take a look at literature studies pointing out the importance of cooperation in special education support services, we observe that these studies mention that cooperation should be extended as it would have positive impacts such as increasing the academic success and social acceptance of disabled children as well as their participation in society. Besides, it is also indicated that the type and intensity of support services provided would vary according to the general characteristics of the disabled child, teachers and the family (Batu, 2013; Batu & Kircaali-Iftar, 2005; Friend & Bursuck, 2006). With regards to the legal regulations concerning the delivery of support services, mothers stated that they were highly anxious about where and how their children would receive education and whether they would be able to develop independent living skills. It was observed that mothers are desperate and anxious about how their children will struggle in their life after them or whether their children would always continue in a similar way of life. As we examine the other studies made on this topic, we observe that they are in parallel with the findings of this study and that the parents of disabled children have some worries about the future and that they share negative thoughts (Coskun & Akkas, 2009; Ozsoy et al., 2006; Schilling et al., 1986). The reasons for these concerns may be explained by different possibilities. The first is that there is no institution to support, or access to such institutions, that can provide, support or have a job/profession for their children. The second is that children are caused by problems with how to meet the educational needs at home after school life. Another and important is the concern that children can survive independently if they are left alone in life.

5. Recommendations

Finally, families who are with children with special needs in all phases starting from their birth should participate fully in the evaluation, enrolment and education process. The findings of the study are similar to those of the related literature with regards to the importance of early education and the emotional state of families with disabled children. Thus, the medical/educational diagnosis and evaluation of children with special needs should be made as soon as possible and they should benefit from appropriate education services. A well-qualified special education service might decrease the stress and anxiety levels of families and might give them the courage for supporting their children. Another interesting result of the study is that the cooperation between special education institutions, general education institutions and families would increase the success of children with special needs in all the fields. Staff should be given in-service training regarding the principles of cooperating with families. The dialogues between the staff and the family should be followed up professionally by
administrators. The communication of mothers within their family, with their relatives or with their close friends, should be strengthened and mutual social support should be ensured.

References


