Investigating Education and Support Needs of Families Who Have Children with Intellectual Disabilities[*]

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Abstract

The purpose of the study was to define families' of children with intellectual disabilities, needs on education and support services. Descriptive survey model was used in the study. Data was collected via semi-structured interviews. The study was conducted in 9 Training Application Schools (Eğitim Uygulama Okulu) that were formal special education school, governed by Ministry of Education. The schools were in Eskişehir, Ankara, İzmir, İstanbul, Denizli and Muğla. 18 administrators and teachers and 38 volunteer parents of children with intellectual disabilities participated in the study. The data were collected through semi-structured interviews. The themes defined from the interviews were: social support social support networks, personal development, skills on working with children, adjustment process, information about special education programs and school's practices, child's health. Although, there were some differences between the percentage of needs' area of administrators-teachers and parents, the needs' areas of administrators and teachers were parallel with parents'. It is thought that the results of this study can be a source for designing programs and developing present programs on the basis of the needs of families of children with intellectual disabilities.

Keywords: *Parent needs; family needs; children with intellectual disabilities.*

Introduction

Family prevails as the primary institution that forms the basis of all other communal institutions. Family could be defined as social and economic group, depends on division of work, with various types such as small, large, narrow or wide where individuals are born into, raised in or spend most of their lives in (Cavkaytar, 2010; Türk Dil Kurumu (TDK), 2010). Initially, a simple form of interaction network based on the foundation of the relationship between the couple is formed. This relationship

evolves to a different stage as a child; a new member of the family comes into the couple's world. Along with the new member, the couple, who newly became mother and father shift their expectations and roles in life, each other, occupancies, close circle and society (Akkök, Aşkar, & Karancı, 1992).

Just after the birth or in school years learning that they have a child with intellectual disability disappoints parents by shattering their feeling of "having the ideal child" and it affects negatively the family structure and operation (Eripek, 1996). While learning the evolution in their structure and operation, causes of this evolution and also learning how to live with a child with intellectual disability family members go through processes, according to O'Shea, Algozzine and Hammitte (2001) there are five stages: (1) shock, disbelief, denial, (2) anger, resentment, (3) bargaining, (4) depression and hopelessness (5) acceptance; according to Varol (2006) there are three stages: (1) shock, denial, pain, depression, (2) anger, guilt, shame, (3) acceptance and adjustment. To participate successfully in these processes, which start with the stage of shock and finish with the stage of acceptance is possible for parents with the consideration of the needs of all members of the family. This consideration is also the precondition to preserve the integrity and unity of the family (Fiedler, Clark, & Simpson, 2007).

Main purpose of evaluating family needs is to make a contribution to children with intellectual disability and to settle the type, content and quality of the service which will be given to the child and to the family (Akçamete & Kargın, 1996; Bailey & Simeonsson, 1988; Varol, 2006). For that purpose, firstly, problems that families have after they learned they have a child with intellectual disability should be determined, in addition to family needs their strong ways and their supports should be settled (Bennet, Lingerfelt, & Nelson, 1990).

Variety and variability in family needs prevent developing a universal and reliable need classification system for settling the needs of the families who has child with children with intellectual disability; but, it is thought that the problem will be solved by using different evaluation approaches (Berger, 2008). By using the techniques of observation and interview; it is possible to learn about families which could support their children and to learn roles, competence of each family member and the requirements that they need to survive, by making tests, surveys and inventories or using environmental assessment approach as base which allows to evaluate the family in its own natural environment (Bennett, Lingerfelt, & Nelson, 1990).

Winton (1986), Bailey and Simeonsson (1988), Turnbull, Turnbull, Erwin, Soodak and Shogren (2011) indicated that evaluation instruments, which are developed to determine families' needs in different domains can be used. When the evaluation instruments, which are developed to determine the needs of families, are analyzed, it is seen that the needs are discussed under specific headings (Shea & Bauer, 1991). With the Family Needs Survey of Bailey and Simeonsson (1988) it is collected under six topics; information, family and social support, financial needs, explaining child's circumstances to others, operation of the family and community services. With the Family Information Preference Inventory of Turnbull and Turnbull, it is collected under five informational areas; teaching the child at home, support and working with professionals, planning for the future, helping the whole family relax and enjoy life more, finding and using more support (Turnbull, Turnbull, Erwin, Soodak, & Shogren, 2011).

Winton (1986) indicated that to determine families' needs it should be evaluated in five informational areas; properties of child, information, help and support, nature of the interactive relation between child and parents, point of view of the family for upbringing the child and living with a child with disability and family's lifecycle and conditions.

Generally analyzed, within the needs of parents of child with intellectual disabilities, need of knowledge/education, need of support, need of performing family function properly is emphasized frequently. In need of knowledge/education category, families' need of knowledge/education takes part in these kind of subjects; nature and properties of disability, child's and family's legal rights, offer

education to the child, preparing an efficient environment for child's education at home, coping with child's behavioral problems and communication with the child (Bernstein and Barta, 1988). To be able to limit the expectations from child with intellectual disabilities as members of his family, to determine the convenient purpose and service fulfill the family's needs of information about child's disability, property and legal rights is essential (Çetinkaya & Öz, 2000). The researches show that the informative counseling for the parents' needs of knowledge/education reduces the concern and stress and help their adjustment process (Aksaz, 1992; Böcü, 1991; Çetinkaya, 1997; Hunfeld, Tempels, & Passchier, 1999; Pelchat, Jocelyn, & Nicole, 1999).

Families need to be informed about how they should cope with their child's behavioral problems and what kind of education they should offer to their child (Kendall, 1998; Kohler, 1993; Özen, Çolak, & Acar, 2002; Page, 1993; Simpson, 1996). To fulfill this need of the family, it is expected from counselors to offer behavior management, teaching skills and service and sources for the programs that parents will apply at home (Berger, 2008). There are many surveys of family education programs -relies on talent and information gaining and emphasizing the importance of family involvement during child's growth- shows that these programs; by supplying families, their need of knowledge/education about this matter, make them effective in handling child's problems about behavior and learning; and decrease the communication problems with their child (Akköse, 2008; Altunel, 2007; Ardıç, 2008; Bakkaloğlu, 2004; Batu, 2008; Canay, 2003; Charlop-Christy, & Carpenter, 2000; Çetin, 1995; Çuhadar, 2008; Erbaş, 2001; Odluyurt, 2007; Sucuoğlu, Küçüker, & Kanık, 1993; Symon, 2005; Tekin-İftar, 2008; Vuran, 2000). In addition, these researches reveal that the education, which is instructed by families, whose needs of knowledge/education are fulfilled, has a positive effect on the child's development.

Besides, in the category of need of support, there are financial, social, emotional or psychological supports for the families with child with disability. Many families with children with intellectual disabilities have the need of emotional support, professional help for their psychological problems and resources of social support. Having a child with intellectual disability in the family is an emotional burden, a stressful life experience and a stressor that requires a constant reaction of tolerance (Freedman, Wyngaarden, & Seltzer, 1997; Yıldırım, & Conk, 2005; Yukay, 1998). This kind of stress sources make families feel inhibited and causes alteration of family roles and relationships. Furthermore, these families with children with disabilities can come across with different sources of stress and this situation can cause negative changes in ordinary family routines, roles, relationships and expectations.

When we think about the durations of the family's acknowledgement of the child, the pressure of the explanation of the child's situation to others, the care of the child after the parents die, the parents' anxiety of the child's growth, their need of knowledge, their responsibilities of the child's education and treatment, the problems about affording child's care, therapy, special education and medical expenses, the changes that the family will go through after a new member with disability, the difficulties that they will face within their social environment and common life; it is inevitable that these families will be helped all their lives for various reasons by counselors, institutions, their relatives, to cut it short: formal or informal any source (Hassall, Rose, & McDonald, 2005; Özsoy, Özkahraman, Çallı, 2006; Özşenol, Işıkhan, Ünay, Aydın, Akın, Gökçay, 2003). The support the family needs sometimes can be from a relative, sometimes from a professional and sometimes from a family who has a child with disability.

There are a lot of surveys which examine the effects of financial, social, emotional or psychological support which is offered to families on their stress, concern, sense of self-efficacy, quality of life, satisfaction of life, self-respect and their attitude. Findings of these surveys show that the support offered has positive effects on factors which are ordered by fulfilling the needs of families (Çelebi, 2003; Duygun, 2001; Dyson, 1997; Frey, Greenberg, & Fewell, 1989; Girli, Yurdakul, Sarısoy, & Özekeş, 2000; Şardağ, 2010; Tamer, 2010; Tezel, 2003).

Needs of solving the family problems which have an important role in family's function, maintenance communication in family, fulfill parent roles, planning time management, making effective decisions and the difficulties of this process that families face with takes part in family's function and need of coping with the problems which comes out while functioning category (Özbeklik, 2006). Plenty of families with a child with intellectual disabilities face with frequent crisis, disagreements and problems and to overcome these problems they need to be helped to gain the skill of solving and coping with these problems (Epstein, 1995; Schalock & Alonso, 2002).

Having a child with intellectual disability, requires solving the problems such as child care, doing the house work, coping with negative emotions that family members feel for each other, undertaking financial drain of family, fulfilling roles and duties of family members; planning the time for leisure times, relaxation, amusement events and tasks they have to do; carrying on with family intercommunication such as protecting each other, creating mutual peace atmosphere, supporting each other, being tolerant toward each other; taking true decisions for their child and family. This situation requires the need of coping with the difficulties of fulfilling family functions (Smith, Gartin, Murdrick, & Hilton, 2006).

Determining the family needs in this category; developing the personnel skills of each family member like solving the problems, making a decision, communicating; examining the way they perceive the family functions and the relation between this perception and factors is important to cope with the problems that the family have in this period and to fulfill the limited functions. By the studies which have the same aim, the relation between families' perception of family function and their level of socialization, level of solitude, life quality, level of support, difficulty that they have is examined and the relation between the factors which are ordered by the perception related with the family function is seen (Akıncı, 2007; Arslantürk, 2009; Günsel, 2010; Özşenol, Işıkhan, Ünay, Aydın, Akın, & Gökçay, 2003).

As one can see, family needs consist of many subjects which parents knowabout their children's characteristics in order to help them to preparefor the present life and life in the future. Two thousands are based on the idea of offering service to all of the family members in accordance with the family-centered approaches. The most important characteristic of the family-centered approaches is to be based on the needs of the family in offering support and the service to all of the family members (Turnbull et. al., 2011). Because of that in preparing an online parent training and support education program (Cavkaytar, Adıgüzel, Ceyhan, Uysal, & Garan, 2011) for the families with children with severe and moderate intellectual disabilities; it is aimed to present families' needs. The purpose of the survey arises from this subject.

The purpose of the present study was to determine the needs of knowledge/education and support of parents whose child has severe and moderate intellectual disabilities. In accordance with this aim, the answers of questions below are searched.

1. How do parents of child with intellectual disabilities explain their needs of education and support?
2. How do administrators and teachers explain the needs of education and support of the parents of a child with intellectual disabilities?
3. What are the similar and different opinions of parents and administrators and teachers about the needs of education and support?

Method

Research Design

To determine the needs of knowledge/education and support of parents whose child is with intellectual disabilities, which is the main aim of the research, descriptive survey model is used. Within the study, between January and March of 2011, data is collected by semi-structured interviews.

Participants

Semi-structured interviews are conducted in private and formal Training Application Schools which are connected to Ministry of National Education placed in Eskişehir, Ankara, İzmir, İstanbul, Denizli and Muğla. Among these cities nine schools are included in this study; one school each from Eskişehir, Denizli and Muğla; two schools each from Ankara, İstanbul and İzmir. The research is realized with nine school administrators and nine teachers, one from each of the schools and 38 parents who has a child with severe or moderate intellectual disability; three mothers and three fathers are from one of the Training Application School and two mothers and two fathers from each of the other Training Application Schools.

Data Collection Tools

Parent interview form and administrators-teachers interview form; two forms are prepared for the semi-structured interviews, which are realized in period of determining the needs.

Parent Interview Form (PIF). Parent Interview Form has two parts. In the first part, information about interview and in second part the questions are stated. To determine the possible areas of need and to prepare the questions of interview, primarily, related literature was reviewed. After the review of body of literature, subject areas repository is constituted, determined subjects are classified and each group is collected under one topic. All of these areas of need formed the questions to examine parent's needs. After completing the interview questions, the question forms were given to three assistant professors in special education in order to be control the validity of the interview questions.

Administrators-Teacher Interview Form (MTIF). Administrator-Teacher Interview form has two parts. In first part, information about interview and in second part the questions are stated. Questions of administrator-teacher interview form are similar which are in parent interview form. The administrator-teacher interview form is prepared by changing the structures of the questions, which are in parent interview form. This form, which is prepared by research staff, is also given to a consultant just like the parent interview form. Three assistant professors of special education have given their ideas about the semi-structured interview forms. The questions are rewritten in accordance with the opinions of the consultants.

Interviewing Process. Participants were invited to the schools as it was planned before, and the interviews were conducted as below:
   a) Semi-structured interviews, which are conducted swith the administrators and teacher interview, form are realized in a quiet place in school which is comfortable for two people's interview (principal's office, guidance service, etc.), as it was planned before. At the beginning of the interview all the instructions are given and the permission to record is get from the interviewee. All of the interviews are recorded with tape recorder. Interviews of administrators and teachers took approximately 35-45 minutes.
   b) Semi-structured interviews, which are done with the parent interview form, are realized with the parents who participate voluntarily. The semi-structured interviews with parents are done in places, which are chosen by the school administration (principal's office, guidance service, etc.). At the beginning of the interview all the instructions are given and the permission to

record is get from the interviewee. All of the interviews are recorded with tape recorder. Interviews of parents took approximately 45-55 minutes.

Data Analysis

Semi-structured interviews are analyzed with descriptive analysis method. Descriptive analysis is done by realizing the process below (Yıldırım & Şimşek, 2005; Blanchet & Gotman, 2001):
1. All interviews, without doing any change, are reported in the same order as in the form.
2. A thematic framework is formed based on the same data codes are given to determined themes. After completing the codes of interviews, reliability calculations are done inter-coders in %30 of interviews. According to that, two different coders coded the interviews that they didn't code before independently. Afterwards, the given codes are compared; points of hesitation are mutually agreed. Subject, which are emphasized frequently about questions or themes, are presented.
3. In accordance with the formed thematic framework, frequency counts are found out by reading the data. These determined themes are grouped under main topics. By forming subthemes, frequency count is found out for each student under these stated main themes. For the reliability of the data and the formed thematic framework, opinions of two consultants, who have the qualitative research and content knowledge, are asked.
4. By identifying the arranged data, these data are supported directly by quoted passage. Thus, findings are identified and interpreted.

Findings

In this part of the research, opinions of the parents of child with disability and administrators and teachers of these children about parents' education and support are placed. After analyzing the answers, which are given to the interview questions, the themes of the given answers are seen in Table 1.

Table 1. Distribution of the Semi-structured Interview to Themes

Themes	*Parents' Opinions*		Administrator's and teacher's opinions	
	f	**%**	**f**	**%**
Social Support Network (SSN)	151	22	62	23
Personal Development (PD)	143	21	70	26
Working with Child Skills	100	15	50	18
Acceptance process (AP)	98	15	50	18
Information about special education programs and schooling practices (ÖB)	93	14	14	5
Children's Health (CH)	89	13	25	9
Total	**674**	**100**	**271**	**100**

As in Table 1, in interviews with parents, the opinions that parents stated on their needs are detected to be focused on %22 social support network, %21 personal developments. Besides these two main need domains, parents stated in their interviews that they have needs in knowledge and skill about working with children (%15); acceptance process (%14); information about special education programs and school practices (%14); children's health (%13). Findings which were gained by

interviews, are parallel to literature on family needs of children with disabilities (Bernstein and Barta, 1988).

In interviews which are done with administrators and teachers it is detected that even though there are differences in percentages, the needs which are emphasized are parallel with the parents'. From the point of view of the administrators and teachers, needs of parents with a child with disability consist of %23 personal development; %23 social support network; %18 working with children skills; %18 acceptance process; %9 children's health, %5 information about special education and school practices.

It is seen in Table 1, opinions of both parents and administrators and teachers are pointed the two main need domains primarily; personal development and social support network. That's why, these two domains are firstly examined in detail below and then analyses are developed about other need domains.

Needs of parents about social support network

As it is seen in Table 2, after the analyses, it is determined that need of parents about social support network is formed by five main topics. Among these needs "Legal rights, socio-economic needs which are provided by public and private sector, needs of information about new services" is the most emphasized one. It is detected that 34 out of 38 parents don't have enough information about their legal rights, socio-economic needs which are provided by public and private sector and needs of information about new services. Besides, 32 of the parents stated that they are in need of information about how their child's future would be; 28 of the parents stated that they need information about non-governmental organizations and voluntary agency and information about participation and creating social network; 26 of the parents stated that they need information about supports after school.

Table 2. Needs of Parents about Social Support Network

Social support network	Number of Parents' Opinions	Number of Administrator's and Teacher's Opinion
a- Need of information about from whom parents would get support	31	11
b- Need of information about supports after school	26	6
c- Legal rights, socio-economic needs which are provided by public and private sector, needs of information about new services	34	18
d- Need of information about non-governmental organizations and voluntary agency, information about participation and creating social network	28	13
e- Need of information about the future life of the child	32	14

The finding acquired show consistency with other findings in literature (Hassall, Rose, & McDonald, 2005; Özsoy, Özkahraman, & Çallı, 2006; Özşenol, et. al., 2003) opinions which support these results of some parents are given below:

City code-35, participant code-D102; Line number-L: 35D102; L388-389- *"we have no idea about any of these. Hardly, hearsay. But just if someone has done it."* (The answer given to the question, which aims to determine the need of information about legal rights).

34K104; L556-561- "*In fact, my child grow up, sexuality, in future, my child is a boy, even a girl or a boy sexuality, you can explain it to a healthy being but when it comes to my son's sexuality, in short, i don't know how will i treat him"* (The answer given to the question which aims to determine the need of information about the child's future life).

06D104; L572-573- "*In truth I really don't know from where I can get information"* (The answer given to the question which aims to determine the need of information about from whom parents would get support).

35D104; L420-425- "*can't know, can't know it. We are here all day long. We know nothing. In short I don't know it either, if there were, will it be bad? It will be better. If we have gone through a bad patch we would go and learn and take support but now, we don't have that opportunity"* (The answer given to the question which aims to determine the need of information about non-governmental organizations and voluntary agency, information about participation and creating social network).

06D101; L300 "*No, we don't have information about out-of-school supports"* (The answer given to the question which aims to determine the need of information about supports after school).

After the analyses, opinions of administrators and teachers and opinions of parents are determined to be in the same direction. Administrators and teachers too emphasized "Legal rights, socio-economic needs which are provided by public and private sector, needs of information about new services" the most (all of the 18 administrators and teachers). Besides that, 14 of the administrators and teachers determined that parents need information about the future life of their child; 13 of the administrators and teachers determined that parents need information about non-governmental organizations and voluntary agency, information about participation and creating social network; 11 of the administrators and teachers determined that parents need information about from whom they can get support; 6 of the administrators and teachers determined that parents need information about support after school.

06Köğr.; L430-431- "*generally speaking, like about these legal rights our people don't know a lot, unfortunately"* (The answer given to the question which aims to determine the need of information about parents' legal rights).

06Döğr.; L453-455- "*namely, in short we don't have a lot, they are not informed about any non-governmental establishment or institution"* (The answer given to the question which aims to determine the need of information about parents' knowledge and participation to non-governmental and/or voluntary establishments).

48Ö102; L172 "*They are not really informed. I think they should be informed. I mean, they really need an enormous support"* (The answer given to the question which aims to determine the need of information about from whom, parents can get support).

Need of parents about personal development

Table 3. Need of Parents about Personal Development

Personal development	Number of Parents' Opinions	Number of Administrator's and Teacher's Opinion
a- Need of information about problem solving skills	25	12
b- Need of information about communication skills	27	12
c- Need of information about decision-making skills	27	17
d- Need of information about time management skills	34	15
e- Need of information about coping with stress skills	30	14

As it is seen in Table 3, after the analyses, it is determined that need of parents about personal development is formed by five main topics. Among these needs "need of information about time management skills" is the most emphasized one. 34 parents out of 38 pointed out their need by determining that they have problems about planning and managing. Besides that, 30 of the parents determined that they need information about coping with stress skills; 27 of the parents determined that they need information about decision-making and communication skills; 25 of the parents determined that they need information about problem-solving skills. These needs which are obtained by series of analysis, show consistency with the needs about personal development, which are presented by Özbeklik (2006), Epstein (1995) and Schalock and Alonso (2002).

06K102, L228-233- *"I can not catch up. Although I am a quick-fingered person in all other things, you can guess it in my manner of speaking, I can not catch up. Even the day time is not enough for me. There are loads of things that I can't cope with"* (The answer given to the question which aims to determine the need of information about time management skills).

34K103; L294-295- *"But sometimes I come to the boil, I trash and smash"* (The answer given to the question which aims to determine the need of information about coping with stress skills).

35D102; L265-274- *"one knows his own child, indeed. Knows what he would and won't do. In my personal decision, it would be better for him to not to go. But community affects your decisions. Therefore I feel I am obliged to make him go there ... community forces you"* (The answer given to the question which aims to determine the need of information about decision-making skills).

20D101; L77-78- *"sometimes they don't get it because they didn't live through it but the ones that pass through understand it. The others don't get, hardly understand it"* (The answer given to the question which aims to determine the need of information about communication skills).

48K102; L163-164 *"...there may be some points that we come to a deadlock, in that point I really need someone to help me"* (The answer given to the question which aims to determine the need of information about problem-solving skills).

After the analyses, it is determined that opinions of administrators and teachers are parallel with the opinions of parents but they have changed the order of importance. Administrators and teachers emphasized "decision-making skills" the most (17 administrators and teachers out of 18). Besides that 15 of the administrators and teachers determined that parents need of information about time

management skills; 14 of the administrators and teachers determined that parents need information about coping with stress skills; 17 of the administrators and teacher determined that parents need information about problem-solving and communication skills.

06Köğr.; L255-259- *"they hesitate about making a decision, they can't maintain their decision, more precisely they decide, they say they are going to do that but they change that process negative if child rise to the top"* (The answer given to the question which aims to determine the need of information about parents' decision-making skills).

48Köğr.; L134 *"they can't use the time. Because it is so hard, they are wrapped in school in any case, they also want to come to school and most of them attend. They stay and wait in school all day long. And after that, their only child is not just the one they have in this school. Sometimes I ask, how many kids they have, they say 2, 3 some say 4. They have a child waiting for them, their partners waiting for the food to be prepared. They have housework but because they are here all day long they can't do it I guess"* (The answer given to the question which aims to determine the need of information about parents' time management skills).

48Köğr.; L160 *"Obviously, they really need a giant support, they need it so as they want to come and explain it the following day, in the first place. In the morning, for example, we come to school they are in need of telling what happened like they looked us like that, they said that. And we feel we need to smooth them down"* (The answer given to the question which aims to determine the need of information about parents' coping with stress skills).

20Döğr.; L71-72- *"when they determine the problem, they first talk with their school teachers, if they can't solve it they take the child to a rehabilitation center. They try to solve it there. If they can't solve it there too, it remains as a problem"* (The answer given to the question which aims to determine the need of information about parents' problem solving skills).

20Döğr.; L79-80- *"In communicating, because they have a child with disability, the parents absent their selves. Generally it starts with not going on a visit and continues with not visiting their relatives. Because they have a child with disability they thing there will be a different environment or they will have negative reactions and they take their selves off the community"* (The answer given to the question which aims to determine the need of information about parents' communication skills).

Need of parents about becoming skillful about working with their child

Table 4. Need of Parents about Becoming Skillful about Working with their Child

Becoming skillful at working with their child	Number of Parents' Opinions	Number of Administrators' and Teachers' Opinions
a- Need of information about skills education	28	14
b- Need of information about supporting what their child learn at school at home	23	12
c- Behavioral control/need of information about changing behavior	29	14
d- Need of information about social skills education	20	10

As it is seen in Table 4, after the analyses, it is determined that need of parents about becoming skillful at working with their child is formed by four main topics. Among these needs "behavioral control/ need of information about changing behavior" is the most emphasized one. 29 parents out of

38 pointed out their need by determining that they have problems about controlling and changing behaviors. Besides that, 28 of the parents determined that they need information about skills education; 23 of the parents determined that they need information about supporting what their child learn at school at home; 20 of the parents determined that they need information about social skills education. These needs which are about parents' skills on working with their child are presented before by Kendal (1998), Kohler (1999), Özen, Çolak and Acar (2002).

06K101; L440-448- *"Because B. is too familiar with me at home, he ignore the things I say, we did that mistake when he was young. We showed him our love and now he is at a point where he believes we will love him no matter what he does. I consulted the psychologists at the special education center in order to change his behavior, but we did not succeed in the matter because if he wants to do something, he will do it in a week if not now"* (The answer given to the question which aims to determine the need of information about behavioral control/changing behavior).

20D104; L52-53- *"You seem to be forcing him when he doesn't lean over it, he cries because he doesn't want and the subject changes. That's why we feel suffocated like he does, we feel suffocated because we are not quiet educated in that subject. For the sake of keeping him loose we can't be successful in lessons, we are not successful in education"* (The answer given to the question which aims to determine the need of information about skills education).

06D102; L1023-1028- *"My child can react if I give the same education at home as they give at school. That's why I don't give the same education that they gave at school, at home. For example, learning a letter, learning a number, I don't do it"* (The answer given to the question which aims to determine the need of information about supporting what their child learns at school at home).

35D104; L601-603- *"when he goes somewhere, okay, he says, good morning good evening, even it is morning time. Both good morning and good evening"* (The answer given to the question which aims to determine the need of information about social skills education).

After the analyses, it is determined that administrators and teachers emphasized their parallel opinions in same way with parents. 14 of the administrators and teachers determined that parents need of information about behavioral control/changing behavior; 12 of the administrators and teachers determined that parents need information about supporting what their child learn at school at home; 10 of the administrators and teacher determined that parents need information about social skills education.

20Döğr.; L200-201- *"We tell how to change behaviors when they come to us, we give advices, we tell what we perform at the school and we suggest them to do so but they spend 1 or 2 days at home, then they say that they could not do it to the teachers and they quit."* (The answer given to the question which aims to determine the need of information about parents' behavioral control/changing behavior).

34Kidr.; L478-479- *"The number of parents are very limited who study the thing, the subject which are between teacher and parents"* (The answer given to the question which aims to determine the need of information about parents' supporting what their child learn at school at home).

06Didr.; L918-919 *"The more the child goes out in public, the more he socializes and learns social skills. They learn what to do, where and how to behave. But if you do not take him to the shopping mall or somewhere else like markets when you take him you to the shopping center for the first time, if he does messy things or else he tries to touch everything, it shows he couldn't win social skills."* (The answer given to the question which aims to determine the need of information about parents' social skills education).

Needs of parents about acceptance process of their child with disability

Table 5. Needs of Parents about Acceptance Process of their Child with Disability

Acceptance process	Number of Parents' Opinions	Number of Administrators' and Teachers' Opinions
a- Need of information about nature of disability and its properties	37	17
b- Need of information about skill of accepting the disability, adjustment process of the family and accepting process	30	18
c- Need of information about child's situation and explaining the needs as parents to other family members and attitude in asking for help	31	15

As it is seen in Table 5, after the analyses, it is determined that need of parents about their skills in working with their child formed by three main topics. Among these needs "need of information about nature of disability and its properties" is the most emphasized one. 37 parents out of 38 pointed out their need by determining that they are insufficient in information about nature of disability and its properties. Besides that, 31 of the parents determined that they need information about child's situation and explaining the needs as parents to other family members and attitude in asking for help; 30 of the parents determined that they need information about skill of accepting the disability, adjustment process of the family and accepting process.

48K101; L38- *"no, I don't have much information, to the limit that I heard, that I can comprehend, to the limit that I can have education"* (The answer given to the question which aims to determine the need of information about nature of disability and its properties).

35K101; L758-762- *"hmm, my daughter, my difficulty right now is my daughter for example. She always tells that. I wish I had not given birth to E. for example. Look... we won't live a normal life. When I say it this way my hearth sinks, off course. I am insufficient."* (The answer given to the question which aims to determine the need of information about explaining child's situation to other members and attitude in asking for help).

34K101; L97-100- *"there were difficulties, yes... and you don't want to believe it, you see. I mean, you don't want to accept."* (The answer given to the question which aims to determine the need of information about skill of accepting the disability).

After the analyses, it is determined that administrators and teachers emphasized their parallel opinions in same way with parents but they have differences in order of importance. 18 of the administrators and teachers determined that parents need of information about skill of accepting the disability, adjustment process of the family and accepting process; 17 of the administrators and teachers determined that parents need information about nature of disability and its properties; 15 of the administrators and teacher determined that parents need information about child's situation and explaining needs as parents to other members of the family and attitude in asking for help.

06Didr.; L68-70- *"parents still couldn't accept it, we have more problems with parents rather that children, I mean parents who couldn't accept, we have difficulties with them more than children."* (The answer given to the question which aims to determine the need of information about parents' skill of accepting the disability).

06Döğr.; L90-93- *"they can continue without learning a thing about their own child's disability or they have shallow information or they learn it from the net so, they are not really knowledgeable."* (The answer given to the question which aims to determine the need of information about nature of disability and its properties for parents).

35Döğr.; L174-184- *"in the beginning, when children take a bus, everyone was moving away like it was epidemic. Ten years ago, one of the parents explained me this: they don't want me, she explained, neither my sisters nor other people. Take your small fry with you don't come to see us again. Ostracization is seen a lot."* (The answer given to the question, which aims to determine the need of information about parents' explaining child's situation to other members and attitude in asking for help).

Needs of parents about special education programs and schooling practices

Table 6. Need of Parents about Special Education Programs and Schooling Practices

Information about special education and schooling practices (ÖB)	Number of Parents' Opinions	Number of Administrators' and Teachers' Opinions
a- Need of information about the subjects of curriculum	29	9
b- Need of information about comparing the existing curriculum and special education programs	31	3
c- Need of information about individualized education plans	33	2

As it is seen in Table 6, after the analyses, it is determined that need of parents about special education programs and schooling practices formed by three main topics. Among these needs "need of information about individualized education plans" is the most emphasized one. 33 parents out of 38 pointed out their need by determining that they are not enough knowledgeable in information about individualized education plans. Besides that, 31 of the parents determined that they need information about comparing the existing curriculum and special education programs; 29 of the parents determined that they need information about the subjects of curriculum.

06K104; L538- *"I don't have IEP information, young lady"* (The answer given to the question which aims to determine the need of information about individualized education plans).

20D103; L196- *"I don't know the similarities"* (The answer given to the question which aims to determine the need of information about comparing the existing curriculum and special education programs).

35D101; L731-734- *"how should I know it, they have music, they have maths, so to say they have PE. I don't know, don't know a lot."* (The answer given to the question which aims to determine the need of information about the subjects of curriculum).

After the analyses, it is determined that even though it is a few, administrators and teachers stated parallel opinions but they have differences in order of importance. 9 of the administrators and teachers determined that parents need of information about the subjects of curriculum; 3 of the administrators and teachers determined that parents need information about comparing the existing curriculum and special education programs; 2 of the administrators and teacher determined that parents need information about individualized education plans.

34idr.; L440-441- *"it doesn't exist, they don't know it, their child goes to school but what kind of education they have there, no one asks that"* (The answer given to the question which aims to determine the need of information of parents about the subjects of curriculum).

35Döğr.; L955-956- *"there are differences but they don't accept it. They don't accept it."* (The answer given to the question which aims to determine parents' need of information about comparing the existing curriculum and special education programs).

34Köğr.; L564-569- *"while preparing individualization education program you know we call the family … we explain, but before we finish they ask us where to sign and close the case. They don't have any expectation like we have in this subject"* (The answer given to the question which aims to determine parents' need of information about individualized education plans).

Need of parents about children's health

Table 7. Need of Parents about Children's Health

Children's health	Number of Parents' Opinions	Number of Administrators' and Teachers' Opinions
a- Need of information about child's existing health status like mouth and dental health, alimentation, intestinal problems, excessive weight, sleep, visual, hearing, mental health	22	7
b- Need of information about problems that child will go through	25	10
c- Need of information which will help to cope with the health problems that child has	24	8
d- Need of information about the tools that will help the child	18	-

As it is seen in Table 7, after the analyses, it is determined that need of parents about children's health formed by four main topics. Among these needs "need of information about problems that child will go through" is the most emphasized one. 25 parents out of 38 pointed out their need by determining that they are not enough knowledgeable in information about the problems that child will go through. Besides that, 24 of the parents determined that they need information which will help to cope with the health problems that child has; 22 of the parents determined that they need information about child's existing health status like mouth and dental health, alimentation, intestinal problems, excessive weight, sleep, visual, hearing, mental health; 18 of the parents determined that they need information about the tools that will help to child.

34D101; L411-413- *"I don't know what to say actually, he can be better or worse, that's why we will be ready for everything, I don't know."* (The answer given to the question which aims to determine the need of information about problems that child will go through).

34D101; L844-845- *"for example, when he is sick, when he run a fever or when he has an attack, what should I do"* (The answer given to the question which aims to determine the need of information which will help to cope with the health problems that child has).

35D102; L467-470- *"for example, for these two years, S. has an abdominal distension. For example, I always take him to the doctor. Neither can they help him, nor me."* (The answer given to the question, which aims to determine the need of information about child's existing health status).

After the analyses, administrators and teachers unlike parents didn't determine the domain of the need about the tools that will help the child. Apart from that, they stated parallel opinions with parents in other domains of need. 10 of the administrators and teachers determined parents' need of information about problems of health that child will go through; 8 of the administrators and teachers determined that parents need information about coping with health problems that child has; 7 of the administrators and teacher determined that parents need information about child's existing health status like mouth and dental health, alimentation, intestinal problems, excessive weight, sleep, visual, hearing, mental health.

06Köğr.; L504-506 - *"in small cities these opportunities are not that vast and if you go to villages this awareness completely decreases."* (The answer given to the question, which aims to determine the need of information about parents' coping skills with child's health problems).

20Döğr.; L173-174 - *"largely, health problems are pushed into background. If there is an unseenable health problem parents mostly make no account of that, in general our children have another health problem. For example, if he is not able to walk, parents in any case make an effort for that. But if he has dental problems, it is pushed into background because the first one is counted to be a disability and when it starts to effect the child negatively the researches begin."* (The answer given to the question which aims to determine the need of information of parents' about child's existing health status).

Discussion

Studies done with the families of children with special needs should be approached in a broad perspective that starts with studies regarding the characteristics and psychological status of the family towards practical studies. Especially the studies held to determine the needs of families incorporates different subjects from the family's basic living requirements to planning the future of the child with special need.

Studies on the requirements of families with children with special needs accelerated after 1980's (Winton; 1986; Bailey & Simeonsson, 1988). Studies in those years show that informing the families should be prioritized. Accordingly, results also proved that the need to develop their social networks ranked on top for the most of the families. This is thought to be linked with the increased support provided for the families with children in need after 1980's in Turkey and visible as the history of special education is explored. The first law about the education of individuals with special needs was passed in 1987 (Cavkaytar & Diken, 2005) and special education was identified. Also, the family's participation was accepted as a principle of special education (Milli Eğitim Bakanlığı (MEB), 1987). Therefore, the first step was taken to fulfill the requirements of the children in special need and their families.

In their studies, Bernstein and Barta (1988) searched for the mostly needed knowledge that the parents needed and found out that despite the importance of technical knowledge, families needed information on their children. Initiating language development, strengthening the sense of self, reasons of children's incompatibility were among the subjects that families wanted to know the most whereas the physical structure of the child or the anatomy were listed as less important. Additionally the family's need for knowledge on education and discipline was also detected. Similarly, Sucuoğlu (1995) in her studies on the validity and reliability of Family Requirements Detection Tool (FRDT) that was developed by Bailey and Simeonsson (1988) has confirmed that the need of knowledge as one of the basic requirements that parents have while looking into the tools efficiency to determine the requirements of the parents of children with special needs.

It was noticed that the mothers rank the need to read written material about parents with similar children on top while fathers prioritize the need of knowledge to teach some skills to their children. Another research held by Evcimen (1996) showed that parents with mentally incompatible children

require knowledge on how to solve children's problems, to read written material on other families with similar lives, to share the problem with a specialist and asking for more time from the teachers to discuss the child's status.

Within the scope of this research the need that is highly prioritized among the parents with mentally incompatible children was the need for social support. This need field was followed by individual development, skills to work with children, the adjustment process, schooling practices and children's health. Directors and teachers on the other hand have prioritized the need for individual development to be followed by social support, process of acceptance, and skills to work with children, children's health and schooling practices. The needs of parents therefore align with the needs of directors and teachers.

Parents prioritizing the need for social support could be taken as a sign showing that the families are aware of the services provided and they have more knowledge about what to do. Among the needs for social support networks, legal rights of the family, future of the child, to whom they should consult to, how to collaborate are the needs that still stand out. This situation proves that despite the implementations, families are not sufficiently aware of the legal regulations. What families mention during the interviews also prove that they provide all their time and energy to their children and unless there is an external support they remain uninformed.

A study by Meral (2011) verifies that mothers of children with moderate and severe intellectual disabilities and children with autism perceive their quality of life above the average and this is explained by the social support they perceive. Therefore, as shown by the results of this research social support takes its place among the important variables to understand the families.

When the studies done in Turkey related to families are analyzed, it can be seen that the most of the research was focused on determining the stress levels and lowering the stress levels following specific interventions (Ardıç, 2010). The need for time management skills before stress management is encountered as a subject that was never studied before. Again, on the subjects of decision making, communication and problem solving skills there are just a few studies conducted in the literature (Costigan, Floyd, Harter, & McClintock, 1997; Goldberg-Arnold, 1998). Consequently the results of this research, putting out the needs of parents' individual development fields determined by themselves is considered to be important for bringing out a new point of view on family studies.

In researches which aim to determine parents' needs both parents of the child with intellectual disabilities (Evcimen, 1996; Sucuoğlu, 1995) and parents of the child with hearing impairment (Akçamete & Kargın, 1996) show that they have profound need of knowledge and need of information about how participants can teach some of the skills at home. In this research, it is seen that one of the most emphasized subject is to be knowledgeable with behavioral control of the child and skills education at home. Akkök, (1984), who did the first study about families having information about changing behaviors of the child and teaching skills to the child, show that parents can be educatory for their child. Afterwards, Cavkaytar (1999; 2007), Cavkaytar and Pollard (2009), Özcan and Cavkaytar (2009) have done researches with families about teaching skills to their child at home and showed that families can teach self-care and life skills. These research findings show again that parents require information about nature of disability, adjustment process, coping with the disability. These findings prove clearly the need of increasing and efficient continuation of studies about informing the families. That's why; plenty of techniques, which are proved to be efficient, will help families to teach daily life skills to their children and by this way to fulfill the need of information.

While administrators and teachers are not mentioning a lot about parents' needs of information about curriculum, parents' mentioning about education and curriculum for children is a significant finding. In the light of this finding, it can be a clear indicator that the subjects, which are not a need from administrators' and teachers' point of view can be substantial for parents.

When the opinions about children's health are analyzed, parents' mentioning their need but administrators and teachers not expressing a lot about parents' need of that is a significant finding. This finding shows that family needs differ from the ones, which are presented by Sucuoğlu (1995) and Evcimen (1996).

As a conclusion, the studies that aim to determine the needs of the families of a child with intellectual disability prove that the most the family needs is information about child's diagnosis, its properties, progress and education and support from consultants and social surroundings. Planning the programs, which aim to fulfill family needs can effect positively the communication between parents and their children and by decreasing the level of anxiety and stress it can ease the adjustment process. That's why these research findings are thought to be the source of planning new programs and developing the existing programs, which are based upon needs of families of children with intellectual disability.

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