

ASSESSING NEEDS OF PARENTS WITH CHILDREN WITH DISABILITIES IN TURKEY

Abstract: The universal experience of parents with a child with disabilities are added responsibilities and needs in supporting the child's development. This study assessed the nature and extent of needs identified by parents of children with disabilities in Turkey using a Turkish translation of the Family Needs Survey (Bailey, Blasco & Simeonsson, 1992). The survey of 35 items and two open-ended questions was translated to reflect Turkish culture and linguistic equivalency. The psychometric properties of the Family Needs Survey were examined by administering it to 377 mothers and 297 fathers of children with disabilities, served in special education schools or rehabilitation centres. Factor analysis of data for mothers and fathers yielded a six-factor model explaining 56% and 61% of the variance, respectively. Alpha values for the factors of the survey ranged from .63 to .90 for the mother data set, and .80 to .91 for the father data set. Analyses of endorsed needs in the Family Needs Survey revealed an overall similar profile for both parents, with greater needs expressed for the factors of obtaining information, family and social support and community services than for factors pertaining to financial topics, explaining to others and child care. Mothers and fathers identified 35 additional needs reflecting themes of personal and societal concern related to parenting a child with disabilities in Turkey.

Keywords: Family Needs Survey, Turkish families, validity, reliability, children with special needs

Özaydın, Latife PhD

Associate Professor
Department of Special Education
Special Education Application and Research Center
Hasan Kalyoncu University
Gaziantep, Turkey
E-mail: latife.ozaydin@hku.edu.tr
ORCID: 0000-0002-2975-1620

Karaçul, Fikriye Eda PhD

Assistant Professor
Department of Guidance and Psychological Counseling
Mehmet Akif Ersoy University
Burdur, Turkey
E-mail: fekaracul@mehmetakif.edu.tr
ORCID: 0000-0003-0844-5904

Kayhan, Nilay PhD

Associate Professor
Department of Special Education
Ege University
İzmir, Turkey
E-mail: nilaykayhan@gmail.com
ORCID: 0000-0002-0937-8013

Büyüköztürk, Şener PhD

Professor
Department of Educational Measurement and Evaluation
Hasan Kalyoncu University
Gaziantep, Turkey
E-mail: sener.buyukozturk@hku.edu.tr
ORCID: 0000-0002-0898-1697

Karahan, Sevim PhD

PhD Candidate
Department of Special Education
Hasan Kalyoncu University
Gaziantep, Turkey
E-mail: sevim.karahan@hku.edu.tr
ORCID: 0000-0001-7753-4105

Simeonsson, Rune J. PhD

Professor
School Psychology Program
University of North Carolina
Chapel Hill, NC, USA
E-mail: rjsimeon@email.unc.edu
ORCID: 0000-0002-2181-8034

DOI: 10.52963/PERR_Biruni_V10.N3.16

INTRODUCTION

The universal experience of parents with a child with disabilities is the increase of responsibilities and needs in supporting the child's health and development. In order to meet these responsibilities families, need information, resources, support, and services for their child and themselves. The social welfare state and the community plays a role in the provision of services and education for the child, though families assume major responsibility for the child, with mothers usually taking on the primary caregiver role (Bailey, Blasco & Simeonsson, 1992; Burton-Smith, Mcvilly, Yazbeck, Parmenter & Tsutsui, 2009). In this regard, a survey on problems and expectations of individuals with disabilities in Turkey revealed that 49.6% of the care and responsibility of individuals with disabilities are undertaken by their mothers and 18.2% by their spouses (TSI, 2010). The reality that mothers being the primary caregivers for children with disabilities in Turkey improved paid leave and wage policies as well as increasing child cash assistance and kindergarten benefits for mothers. With the mother having primary responsibilities for the child with disabilities it is essential to identify not only her needs for information and services but also those of the father in his supporting role. Within a family-centered approach in the delivery of services to families in Turkey, the added needs of children and adults with disabilities have been the basis for legal regulations and development planning related to health, education, and social benefits (disability pension, the same and cash assistance) (Decree Law No. 573; Özaydın & Gallagher, 2012).

In Turkey, all public and private special education services are under the responsibility of the Ministry of National Education. To benefit from these services, children with special needs are required to get a medical diagnosis from a health institution that is also free for everybody. Based on a medical diagnosis, children are assigned to general education or Special Education Schools in accordance with special education practices. An element of the placement decision is that the children with special needs can receive educational support during out-of-school hours from Special Education and Rehabilitation Centers. Special education services are provided also to children between the ages of 0-3 with special needs and developmental disabilities by Special Education and Rehabilitation Centers. Children with special needs between the ages of 0-3 in Turkey are provided special education services even though not enforced and these services do not focus on their families (Ertem, 2005; Özaydın & Gallagher, 2012). The adoption of an approach based on inadequacies in the national education system that focuses on the individual leads to the provision of services for children, however, leaves families one step behind their children. There are other countries in similar situation where priorities of the families are considered as secondary importance (Ertem, 2017; McWilliam, 2010; Ueda et al., 2013). Families' involvement in their children's education and social services is supported in Turkey. In this context, many institutions providing social services and assistance are grouped under a single roof by the Ministry of Family, Labor, and Social Services. Thus, education, health, social services for individuals with special needs and their families are guaranteed by the official system in Turkey.

EI programs based on the developmental and environmentalist approach have adopted the principle of supporting parents to enable them as effective actors in the development of special needs children (Bronfenbrenner & Ceci, 1994; Guralnick, 2008; Sameroff & Rosenblum, 2006). The main philosophy of EI programs is to focus on the family as the primary caregiver and protector of the child, to strengthen the parent-child interaction, to provide guidance, and to direct them in the right directions about their children's health and safety (Guralnick, 2011; McWilliam, 2010). For this reason, in a family-centered approach to serve children with special needs and their families Bailey and Simeonsson (1988) emphasize the need to assess the strengths and weaknesses of the family, the parent-child interaction, the developmental characteristics of the child and the needs of the parents. Identifying the needs of families with

children with disabilities therefore becomes a priority to define and achieve program and service goals. A widely used tool to assess the needs of families of children with disabilities was the Family Needs Survey -1988 which had six subscales (Bailey & Simeonsson, 1988) and was adapted to investigate the services and needs of Australian family carers (Burton-Smith et al., 2009). The initial version of the Family Needs Survey (Bailey & Simeonsson, 1988) was adapted to Turkish by Sucuoğlu (Sucuoğlu, 1995). Turkish version of the Family Needs Survey was used to determine the needs of parents of children with intellectual disabilities (Evcimen, 1996), mothers with hearing-impaired children (Akçamete & Kargın, 1996), and of mothers with premature-low birth weight children (Sola & Diken, 2008) in Turkey. In addition, Mert (1997) examined its factor structure and used it to compare the needs of parents with children in different disability groups. An update of the validity and reliability of the survey adapted by Sucuoğlu was made by Cavkaytar, Ardiç, & Aksoy (2014).

The Family Needs Survey -1988 was revised by Bailey and Simeonsson in 1990 and was renewed with 7 sub-dimensions and 2 open-ended questions by adding 1 open-ended question (Bailey et al., 1992). The 35 items of the Family Needs Survey yielded subscales of; Obtaining Information (seven items), Family & Social Support (eight items), Financial Topics (six items), Explaining to Others (five items), Child Care (three items), Professional Support (three items), and Community Services (three items). The questionnaire format of the revised Family Needs Survey was well received by parents and also provided useful information for professionals (Bailey & Blasco, 1990). Findings with the revised Family Needs Survey revealed that the primary needs expressed by mothers and fathers were to have information about the services that their children may need in the current and future services, and how to teach them (Bailey et al., 1992).

The Family Needs Survey -1990 has been adapted for use in many countries (Bailey et al., 1999; Chen & Simeonsson, 1994; Granlund & Roll-Pettersson, 2001; Ueda et al., 2013). There is a need to adapt the Family Needs Survey -1990 considering changes in the globalizing world, technological developments, legal regulations, and the results of evidence-based research on adaptation of the Family Needs Survey to other cultures (Chen & Simeonsson, 1994; Ueda et al., 2013). The aim of this study was to examine the needs identified by Turkish mothers and fathers of children with special needs with a revised adaptation of the Family Needs Survey -1990 for Turkish culture and language. Using the revised Family Needs Survey, this study addressed four research questions: (1) What is the validity of the Turkish adaptation of the Family Needs Survey? (2) What is the nature and intensity of needs on the Family Needs Survey endorsed by mothers and fathers? (3) In addition to Family Needs Survey, what are additional needs expressed by parents beyond the items already in the Family Needs Survey? (4) What priorities do parents identify for professional support to meet the needs of their children with special needs? An important and distinctive feature of this study is that the final version of the survey will be published online for the first time within the scope of this article.

METHOD

PARTICIPANTS AND SETTING

The participants of the study were 644 parents (355 mothers and 289 fathers) of children with disabilities between 18 month-15 years of age who attended Special Education Schools or Special Education and Rehabilitation Centers in the six central districts of Ankara during the 2014-2015 academic year. The criterion sampling method was used in sample selection. The criteria used for the recruitment of the sample were the following: a) being parents of children between the age of 0 and 15 attending Special Education Schools or Special Education and Rehabilitation Centers in six districts in Ankara representing different socio-economic status b) being parents of children who had a medical diagnosis from a health institution and were placed

in Special Education Schools or Special Education and Rehabilitation Centers and c) being volunteered to participate in the study.

School administrators sent the questionnaires to 1114 parents who met the sampling criteria. These included two-parent families, one-parent families, or households in which only one parent chose to participate. Among them, 379 out of 557 mothers and 300 out of 557 fathers answered the questionnaire and returned the forms. Five forms were completed by individuals who were not parents of children (mother form, n= 2; father form, n= 3) and were excluded from the data set. The total number of participants in the analysis was 674 parents (377 mothers and 297 fathers). Of the parents who answered the Turkish version of the Family Needs Survey, 275 were mother-father couples, 95 of them were mothers only, and 29 of them were fathers only. The mean age of the mothers was 36.35 years, SD = 6.94 (range 21-41 +years) and that of fathers was 40.49, SD = 6.85 (range 26-41+). The demographic characteristics of the parents are presented in Table 1. The mean age of the participant children with special needs (n=399) represented by the parents was 11.9 and their characteristics were presented in Table 2 which was based on the classification system of the Special Education Services Regulation (2012).

Table 1. Demographics of Parent Participants

	Mothers (n=377)		Fathers (n=297)	
	n	%	n	%
Age				
21 & under	5	1.3	-	-
22-25	16	4.2	-	-
26-30	58	15.4	17	5.7
31-35	87	23.1	48	16.2
36-40	80	21.2	64	21.5
41 & above	81	21.5	107	36.0
No response	50	13.3	61	20.6
Educational Level				
Illiterate	6	1.6	2	0.7
Elementary&Middle School	188	50.0	106	35.7
High School	94	25.0	69	23.2
University	50	13.1	65	21.9
Masters Degree	9	2.3	13	4.3
No response	30	8.0	42	14.2
Occupation				
Housewife/No job	296	78.5	32	10.8
Has a job	40	10.6	213	71.7
No response	41	10.9	52	17.5

Table 2. Special Education Services Classification of Children

Conditions of the Children	N=399	
	n	%
Intellectual disability	118	28.02
Autism	76	19.04
CP	46	11.52
Chronic illness	44	11.02
Learning disorders	23	5.26
Cognitive developmental disability	22	5.51
Speech and language disorders	18	4.51
Visual impairment	16	4.01
Attention deficit hyperactivity disorder	10	2.50
Orthopedic disorders	10	2.50
Hearing impairment	9	2.25
Emotional / behavioral disorders	7	1.75

PROCEDURES

The process proposed for survey adaptation by Hambleton and Patsula (1999) was carried out in three stages; (1) Translation and back translation of the survey, (2) Pre-pilot study, (3) Pilot study, and psychometric analysis. These studies, respectively, are explained in the following. Initially, during the adaptation process, the Family Needs Survey -1990 was translated from English to Turkish by three field experts and two foreign language experts. In the process of translating the items into Turkish, field experts preferred the phrase “I need” used in the first version of the survey (Bailey & Simeonsson, 1988), as it was more appropriate for the Turkish language. The translated forms were arranged in a single form reflecting the consensus of researchers, and suggestions of a Turkish language expert. The final Turkish language version of the survey was sent to 10 professionals in the field of special education who were familiar with both languages and cultures for review. Based on the suggestions of the field professionals, item (# 4), which was not in the original survey, “I need convenient care services for my child during tasks such as shopping, personal medical checks, or going to hair-dresser” was added to the Child Care dimension. The reverse translation of the survey was finalized by the researchers in consultation with the author of the original survey. In this process, 36 items in Turkish form were re-reviewed. Parents responded to each item on a three-point rating scale similar to the original scale. In addition, the researchers added items about child and parent demographic information. The two open-ended questions (“Please list other topics or provide any other information that you would like to discuss” and “Is there a particular person with whom you would prefer to meet?”) were also included.

After the Turkish Family Needs Survey is finalized, permission was obtained from the Provincial Directorate of National Education in order to conduct the study in 12 Special Education Schools and 32 Special Education and Rehabilitation Centers in six districts of Ankara, Turkey. For the pilot study, the Turkish form of the Family Needs Survey was administered to 25 mother-father couples before administering it to larger groups. Based on the pilot study results, the Turkish version of the Family Needs Survey was considered satisfactory semantically, conceptually, and inapplicability. Researchers distributed the printed Turkish Family Needs Survey questionnaire to the administrators in the chosen schools after the pilot phase. The questionnaire was enveloped separately for mother and father of each child. The school administrators gave the instructions to parents who agreed to answer the questionnaires and parents returned filled forms to the administrators. Data sets were checked for missing data and incorrect input, outlier values before proceeding to psychometric analysis (Büyüköztürk, 2002; Kline, 2005; Steiger, 2007). Forms with missing data (22 mothers, 8 fathers) were excluded and analyzes were performed on the data obtained from a total of 644 participants. Thus, the pilot study and psychometric analyses were performed on data obtained from a total of 644 participants (355 mothers and 289 fathers).

DATA ANALYSIS

Data sets were analyzed to confirm the factor structure. Cronbach's Alpha internal consistency coefficient was calculated separately for the data set for mothers and fathers. Given the original seven-factor structure of the survey, Confirmatory Factor Analysis was used LISREL 8.71 version and applied to assess whether the same factor structure applied to data for responses for mothers and fathers in the Turkish culture. These findings indicate that the original 7-factor measurement model of the survey does not adequately fit the data collected in Turkish culture. In that case, Exploratory Factor Analysis was used SPSS 25 version applied to the data sets for both.

Parents answered the first open-ended question by identifying issues not included in the Family Needs Survey. The responses were evaluated by descriptive analysis (Yıldırım & Şimşek, 2018). All of the statements were reviewed by the researchers, and assigned to one of three codes based on the content: (a) covered the same topics as in the Family Needs Survey, (b)

described/exemplified existing items in the Family Needs Survey, or (c) reflected new topics (Bailey & Simeonsson, 1988). For the second open-ended question, parents identified the top five of 16 professionals who they felt could provide information and support about their needs: (Primary Care Physician, Pediatrician, Child Neurologist, Physical Therapist, Dentist, Nurse, Psychiatrist, Psychologist, Social Worker, School Principal, Special education teacher, Classroom teacher, School). These positions are defined by the State Personnel Presidency in Turkey (State Personnel Presidency, 2021).

RESULTS

WHAT IS THE EVIDENCE FOR THE RELIABILITY AND VALIDITY OF THE TURKISH ADAPTATION OF THE FAMILY NEEDS SURVEY?

As an initial step, Cronbach's Alpha internal consistency coefficient was calculated separately for the data set for mothers and fathers. Alpha values range from 0.63 to .90 for the mother data set, and .80 to .91 for the father data set. Given the original seven-factor structure of the survey, Confirmatory Factor Analysis was applied to assess whether the same factor structure applied to data for responses for mothers and fathers in the Turkish culture. The principal fit indices for the maternal data set of CMIN / df = 2.192, RMSEA = .058. - square / sd), were acceptable while GFI = .838, AGFI = .810, NFI = .804, CFI = .882, values were found to be outside the acceptable limits for model data compliance. Confirmatory Factor Analysis results based on the father data set yielded similar results (CMIN / df = 2.435, $p < 0.001$, GFI = .796, AGFI = .760, NFI = .784, CFI = .859, RMSEA = .071). These findings indicate that the original 7-factor measurement model of the survey does not adequately fit the data collected in Turkish culture. In that case, Exploratory Factor Analysis was applied to the data sets for both. Varimax rotation was the method of use in Exploratory Factor Analysis with the reliability of the survey scores calculated with Cronbach's alpha (Büyüköztürk, 2002).

Varimax vertical rotation of the data set for mothers yielded a 6-factor structure accounting for 56.43% of the total variance of the survey. Exploratory Factor Analysis of the data set for fathers with rotation also yielded a 6-factor structure accounting for 61.41% of the total variance of the survey. The variance explained by the factors for mothers after rotation is 11.99% (Financial Topics (FT), factor I); 10.58% (Obtaining Information (OI), factor II); 10.32% (Child Care (CC), factor III); 10.04% (Family and Social support (FS), factor IV); 7.62% (Explaining to Others (EO), factor V) and 5.88% (Community Services (CS), factor VI). The corresponding factors and variance explained for fathers after rotation are 12.83% (Financial Topics, factor I), 11.34% (Obtaining Information, factor II), 8.29% (Child Care, factor III), 11.69% (Family and Social support, factor IV), 8.05% (Explaining to Others, factor V) and 9.23% (Community Services, factor VI).

The Turkish version of the Family Needs Survey has six factors and the item factor loadings for the data set for mothers and fathers are presented in Table 3. An examination of Table 3 revealed item loadings for factors mother and father data sets on the factor of economic issues for items range from .57 to .84, for the factor of Financial Topics; .61 to .78, for Obtaining Information, .43 to .73 for Family and Social Support; .58 to .74 for Child Care; .57 to .70 for Explaining to Others and .44 to .58 for Community Services. The item factor load values for the data set for fathers are presented in Table 3 for comparison with the factor loadings for the data for the mothers. Examination of Table 3 for item loadings on the father's data set on the factor of economic issues for items range from .65 to .83 for Financial Topics; .58 to .79 for Obtaining Information; .58 and .71 for Family and Social Support; .66 to .71 for Child Care; .61 to .69 for Explaining to Others and .47 to .74 for Community Services. Cronbach alpha values for the six factors ranged from .63 to .90 for surveys completed by mothers and .82 to .91 for fathers.

Table 3. The Results of the Exploratory Factor Analysis: Item Factor Loadings for Mother and Father Data

	Mother n=377	Father n=297
Financial Topics		
FT1. I need financial support to cover the expenses such as food, housing, clothing, medical care, or transportation.	.84	.82
FT5. I need financial support to pay for therapy, daycare, and other services my child needs	.81	.83
FT3. I need financial support to pay for the caregiving of my child	.81	.79
FT6. I need financial support to pay for toys that my child needs	.77	.80
FT2. I need support for providing any special equipment my child needs.	.75	.79
FT4. I need counseling or help in getting a job	.57	.65
Obtaining information		
OI3. I feel the need to obtain information about what and how to teach my child	.78	.79
OI4. I feel the need to learn about how to handle my child's behavior	.73	.75
OI5. I feel the need to obtain information about any condition or disability my child might have	.72	.78
OI2. I feel the need to learn how to play and talk with my child	.69	.69
OI6. I feel the need to obtain information about services that are presently available for my child.	.64	.69
OI7. I feel the need to be informed about the services my child can receive in the future.	.63	.69
OI1. I feel the need to learn how children grow and develop	.61	.58
Family and Social Support		
FS2. I would like to have friends to talk to.	.73	.67
FS1. I feel the need to talk with someone in my family about my concerns.	.67	.63
FS5. Our family needs help in order to discuss our problems and reach solutions.	.64	.60
FS6. I need help supporting each other during difficult times in our family.	.64	.66
FS3. I would like to have more time for myself	.60	.71
FS4. I would like to help my spouse accept any condition or disability our child might have	.58	.58
FS8. I need help planning and doing family recreational times	.47	.66
FS7. I need help deciding who will do household chores, childcare, and other family tasks.	.43	.63
Child Care		
CC1. I need support locating care providers who are willing and able to care for my child.	.74	.71
CC4. I need convenient care services for my child during tasks such as shopping, personal medical checks, or going to hairdresser.	.71	.71
CC3. I need appropriate care services for my child in centers such as mosques, masjid, or Quran courses during religious services (prayers, fasting, going on a pilgrimage, religious conversations, etc.).	.62	.66
CS3. <i>I feel the need to locate a dentist who will be able to examine my child.</i>	.60	---
CC2. I need support locating a daycare program or preschool for my child.	.58	.70
Explaining to Others		
EO2. I need support to explain my child's condition to his or her siblings.	.70	.62
EO1. I need support to explain my child's condition to my parents or my spouse's parents.	.67	.61
EO3. I would like to know how to respond when friends, neighbors, or strangers ask questions about my child.	.66	.69
EO4. I would like to know how to explain my child's condition to other children	.57	.63
Community Services		
CS2. I feel the need to locate a doctor who understands me and my child's needs.	.58	.74
CS1. I feel the need to meet and talk with other parents who have a child like mine.	.55	.70
CS3. <i>I feel the need to locate a dentist who will be able to examine my child.</i>	---	.58
EO5. I would like to reach reading materials (books and magazines, etc.) about other families who have a child like mine.	.53	.47
PS 2. I feel the need to meet with a counselor (psychologist, social worker, psychiatrist.	.48	.66
PS 3. I feel the need to be able to talk to my child's teacher or therapist for longer periods of time.	.44	.67

WHAT IS THE NATURE AND INTENSITY OF FAMILY NEEDS IDENTIFIED BY MOTHERS AND FATHERS? For each item in the Turkish Family Needs Survey form, the percentages of the parents' "Yes" answers to the question for "Do you need information or support on this subject?" are presented in Figure 1. In the original survey, the CS3 (I feel the need to locate a dentist who will be able to examine my child) was found under the same factor in the father form, while it was in the Child Care dimension in the mother form. Two items with the highest percentage of endorsement by both parents are the 6th and 7th items of Obtaining Information dimension as seen in Figure 1. These items are "I feel the need to obtain information about services that are presently available for my child", and "I feel the need to be informed about the services my child can receive in the future". It is noteworthy that mothers and fathers responded "Yes" at the highest rate to the other items of the Obtaining Information suggesting that the most intensive needs of Turkish parents are in this dimension. The items that parents endorsed the least are the first two items of Explaining to Others (I need to explain my child's condition to his or her siblings, and I need support to explain my child's condition or my spouse's parents). While the rate of mothers who answered yes to these two items is 26%, the yes rate of fathers is 28% and 27%, respectively. This finding suggests that Turkish mothers and fathers do not have difficulty in explaining the situation of their children to others.

One of the items with the greatest difference between endorsed needs by Turkish parents is the 4th item of Child Care (I need convenient care services for my child during tasks such as shopping, personal medical checks, or going to a hair-dresser). While the percentage of mothers who endorsed this item was 50%, the percentage of fathers was 36%. The other item with the biggest difference between the parents is the second item of the Family and Social Support (I would like to have friends to talk to). The yes rate for mothers for this item was 60% and the rate of fathers was 48% suggesting that compared to fathers, mothers are more responsible for the care of their children, need convenient care services for their children, and need friends to take social support. The only item that both mothers and fathers endorsed at the same rate (32%) was the first item of Child Care (I need support locating care providers who are willing and able to care for my child).

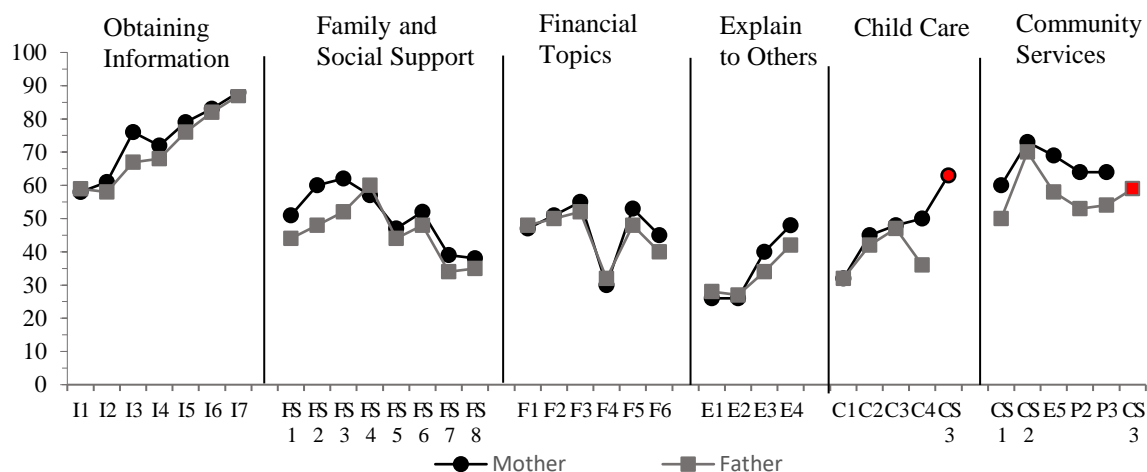


Figure 1. Percentage of Needs of Parents Answered Yes in Original Form of Family Needs Questionnaire

WHAT ARE THE ADDITIONAL NEEDS EXPRESSED BY PARENTS ABOVE EXISTING ITEMS IN THE FAMILY NEEDS SURVEY?

The first open-ended question in the Turkish Family Needs Survey was answered by 107 mothers and 85 fathers resulting in a total of 227 statements that the parents felt were not included in the survey. All of the statements were reviewed by the researchers, and assigned to one of three codes based on the content: (a) covered the same topics as in the Family Needs Survey, (b) described / exemplified existing items in the Family Needs Survey, or (c) reflected

new topics (Bailey & Simeonsson, 1988). Of the statements, 192 simply described/exemplified existing items in the Turkish Family Needs Survey form but 35 statements reflected new needs not included in the Turkish Family Needs Survey. As shown in Table 4, mothers, in general, considered new subjects as more of a need than fathers. The primary theme that 18% of the mothers need was what the situation of their children will be after the death of the parents and who will they be protected by. The same theme was expressed by 17% of fathers. The primary need of 19% of the fathers was to solve problems they face while obtaining their children's health reports. The same theme was expressed by 16% of mothers. In this situation in the Turkish family, it can be stated that fathers assume more responsibility than mothers for their children's health and education in official contexts. The theme that was endorsed equally by both parents was about increased access to parks, sports areas, and swimming pools in their vicinity that were free of charge for their children. Other needs of Turkish parents are social support, home regulations, community awareness, and a positive attitude expectation from health personnel.

Table 4. Topics that Parents Describe as Needs

	Topics of 35 new needs identified by mothers and fathers	Mother		Father	
		N=50	%	N=36	%
1.	Status of children after the death of parents	9	18	6	17
2.	Solving the difficulties parents face while getting their children's health reports	8	16	7	19
3.	Children having a pleasant time in educational environments	8	16	2	6
4.	Free parking, sports area, and swimming pool nearby	7	14	5	14
5.	Social support to mother and father	6	12	4	11
6.	Domestic and external needs (Elevator, garden, ground floor)	5	10	4	11
7.	Society's sensitiveness to children with special needs and their families	4	8	4	11
8.	Health personnel demonstrating understanding and positive attitude to parents	3	6	4	11

WHAT PRIORITIES DO PARENTS IDENTIFY FOR RESOURCES AND PROFESSIONAL SUPPORT TO MEET THE NEEDS OF THEIR CHILDREN WITH SPECIAL NEEDS?

The second open-ended question in the Turkish Family Needs Survey regarding parent preference for interaction and support with 16 professionals was answered by 318 mothers and 305 fathers. Both mothers and fathers identified members of the health profession (child neurologist, psychiatrist, primary care physician, pediatrician) as their top choices for information and support. Fathers (17%) preferred primary care physicians more than mothers (6%) whereas school principals, social workers, religion officers, nurses, and experienced parents were preferred in similar percentages.

DISCUSSION

Factor analytic studies of the Family Needs Survey with various item sets across countries have resulted in a range of different factor structures from three to seven (Burton-Smith et al., 2009; Chen & Simeonsson, 1994; Granlund & Roll-Pettersson, 2001; Ueda et al., 2013). Although the number of factors varies across cultures, the similarity of dimensions supports the findings of similar and continuing needs of families with children with disabilities.

This study examined the use of a Turkish translation of the Family Needs Survey to identify the nature and intensity of needs of mothers and fathers raising children with disabilities. Validity and reliability analyses of the final version with 36 items of the survey were performed on a data set of 674 participants. Application of Confirmatory Factor Analysis for a seven-factor structure showed that the model was not compatible with the mother and father data sets. Application of Exploratory Factor Analysis for six-factor structure yielded a KMO value of .911 indicating the suitability of the data for factor analysis. The fit indexes were within limits after testing this model, indicating the compatibility of the model (Büyüköztürk, 2002; Kline,

2005; Steiger, 2007). The values of the fit indices indicated that the mother data set was compatible with the factorial structure of the father data set. In the 6-factor structure of the Turkish

In the Family Needs Survey, the needs of mothers and fathers were distributed in the same factor structure. Of note is the fact that the item (I feel the need to meet with a religious commissary, mufti, or prayer leader), had a factor loading less than 0.40 and was removed from the Turkish Family Needs Survey mother and father forms. The low factor loading on this item suggests that Turkish parents meet their information and support needs for their children with special needs by the widespread and free health care system in Turkey. The system includes newborn screening, medical diagnostics, and treatment therefore, child health monitoring and follow-up may be the reason for parents' preference.

As in previous studies, Turkish parents' main need was reflected in the dimension of Obtaining Information. This finding was also evident in the initial Turkish Family Needs Survey adaptation (Sucuoğlu, 1995) and in Japanese (Ueda et al., 2013), Australian (Burton-Smith et al., 2009), Chinese (Chen & Simeonsson, 1994), Swedish (Granlund & Roll-Pettersson, 2001) and U.S. families (Bailey et al., 1992). These prove that parents' need for information continues depending on the diversity and intensity of each family's needs and with the growth and development of the child. For Turkish mothers and fathers the item "I feel the need to know about the services my child can receive in the future" in the factor Obtaining Information was the most endorsed information item. The same item is also the highest endorsed need by families in the United States (Bailey & Simeonsson, 1988; Bailey et al., 1992), Sweden, China, and Australia. The children of the parents who participated in this study are groups that benefit from Special Education Schools or Special Education and Rehabilitation Centers. Nevertheless, based on the focus of special education services on the disabilities of children with special needs, families fall outside of these services in Turkey. This situation relates to the lack of full participation of the family in special education services within the Turkish education system (Ertem, 2017; Özaydın & Gallagher, 2012) also mentioned in Japanese culture (Ueda et al., 2013). As with all disadvantaged groups in Turkey, social welfare services and social assistance create a degree of trust and prosperity for children with special needs and their families. The same is true for the health system. Although there is a comprehensive healthcare system, these services are mostly center-based and focus on the child's disability. Therefore, the families of children with special needs are also unable to reach sufficient information about their children's health and cannot find solutions to their needs outside of the institutions (McWilliam, 2010; Sucuoğlu, 1995; TSI, 2010; Ueda et al., 2013).

The items that parents endorsed the least are the first two items (E1, E2) of explaining their children's situation to others. Among all, 26% of mothers endorsed both items while 28% and 27% of fathers endorsed those items. This suggests that Turkish mothers and fathers do not experience difficulties in explaining the situation of their children to others. Although the difference between Turkish mothers and fathers is not high in this dimension, it was observed that in other cultures fathers had more "Yes" answers than mothers (Ueda et al., 2013).

One of the items in the Child Care (CC4) factor presented the difference between the needs of Turkish mothers and fathers. Among our participants, a significantly higher percentage of mothers (50%) endorsed this item than fathers (36%). This was similar to that in the Australian culture, where 85% of the participants are mothers. The majority of mothers in Turkey receive respite care services for their children with special needs, however, mothers would like alternative services that are easily accessible. The results suggest that mothers would like more respite care services such as after-school care, alternative support on holidays, short-term, and sometimes long-term services at home or in different institutions (Burton-Smith et al., 2009). Item 2 of the Family and Social Support factor which differentiates the needs of parents was endorsed by 60% of mothers and 48% of fathers. Mothers feel more responsible for the care of

their children. They need care services for their children that are also convenient and need friends to provide social support. Even though the warm interpersonal relations in Turkish society are common, mothers in this study may not be receiving social support in these environments. Thus, this item which is not in the original form of the Family Needs Survey reflects Turkish culture.

Child Neurologist, Psychiatrist, Primary Care Physician, and Pediatrician were parents' top four choices of staff to talk about their children and children's needs. As healthcare is the most widespread service received, parents may wish to acquire information and support from them. It can also be said that parents trust the opinions of health personnel about what kind of vital problems and needs their children may have in the future. It is similar in Chinese culture that medical doctors are their most preferred and needed staff (Chen & Simeonsson, 1994). The fact that the second most preferred and needed staff of the families to talk about their children is special education teachers, indicates that they can easily reach and trust them about their children's education.

An interesting finding of the study was the identification of an additional item "I need convenient care services for my child during shopping, personal medical checks, or going to hair-dresser". Parents proposed more than 200 items but only 35 of these were not a duplication of existing items. There was a limited number of new topics that Turkish parents would want to include in the survey. This suggests that Turkish parents consider the survey to include the majority of the needs of parents. The new topics that parents expressed are; anxiety about the future, difficulties in bureaucratic procedures, social acceptance, and social needs of their children. Parents worried about future prospects of their children in the future even though they do have access to health benefits, education, and social services. A reason for this concern may be that there is an age limit of 23 years for the maximum benefit of Special Education Schools for students with special needs and limitations on accessing educational services later on and the participants' children age ranged between 18 months to 15 years in this study.

Another important finding of this study is that parents care about the quality of life of children as well as access to health, education, and social assistance besides expressing the need for increased access to parks, sports areas, and swimming pools where social integration will be supported. It is also a distinctive finding that Turkish mothers expect their children to have a pleasant life with their peers, teachers, and educators in their educational settings. In Japanese culture issues such as being prudent were among the added items (Ueda et al., 2013), while in Turkish culture, parents expect tolerance from society and a positive attitude from healthcare. In Australian culture, participants, mostly mothers, stated that they received respite care services for family members with disabilities, but still needed after-school care and vacation care and more qualified daycare services. They stated that respite care services are vital for family relationships and wellbeing (Burton-Smith et al., 2009). Chinese families expressed more family concerns, such as stress and feelings (Chen & Simeonsson, 1994).

In summary, the need for information was the most expressed need by Turkish parents who have children with special needs related to their children's education, disability, and to their future living with a disability. The findings indicate that parents have a higher level of need for Family and Social Support and Community Services besides Obtaining Information. This shows that parents continue to need support in meeting their children's needs outside of school. In Turkey, as well as other countries using the Family Needs Survey, identification of such continuing needs can serve as the basis for insuring that needs unique to individual families or common to families caring for children with disabilities.

REFERENCES

- Akçamete, Gönül and Kargın, Tevhide. “İşitme engelli çocuğa sahip annelerin gereksinimlerinin belirlenmesi” [Determining the Needs of Mothers with Hearing Impaired Children]. *Ankara University Faculty of Educational Sciences Journal of Special Education*, 2 (2) (1996): 7-24. Retrieved from <https://dspace.ankara.edu.tr/xmlui/bitstream/handle/20.500.12575/47171/378.pdf?sequence=1&isAllowed=y>
- Bailey, Donald B. & Simeonsson, Rune J. “Assessing needs of families handicapped infants”. *The Journal of Special Education*, 22 (1) (1988): 117-127. <https://doi.org/10.1177/002246698802200113>
- Bailey, Donald B. and Blasco, Patricia. M. “Parents’ perspectives on a written survey of family needs”. *Journal of Early Intervention*, 14 (3) (1990): 196–203. Retrieved from <http://citeseerx.ist.psu.edu/viewdoc/download?doi=10.1.1.826.8234&rep=rep1&type=pdf>
- Bailey, Donald B., Blasco, Patricia M. and Simeonsson, Rune J. “Needs expressed by mothers and fathers of young children with disabilities”. *American Journal of Mental Retardation*, 97 (1) (1992): 1–10. Retrieved from <https://www.researchgate.net/publication/21768452>
- Bailey, Donald B., et.al. “Needs and supports reported by Latino families of young children with developmental disabilities”. *American Journal on Mental Retardation*, 104 (5) (1999): 437- 451. [https://doi.org/10.1352/0895-8017\(1999\)104%3C0437:NASRBL%3E2.0.CO;2](https://doi.org/10.1352/0895-8017(1999)104%3C0437:NASRBL%3E2.0.CO;2)
- Bronfenbrenner, Urie & Ceci, Stephen J. “Nature–nurture reconceptualized in developmental perspective: A bioecological model”. *Psychological Review*, 101 (1994): 568–86. <https://doi.org/10.1037/0033-295x.101.4.568>
- Burton-Smith, Rosanne, et.al. “Service and support needs of Australian carers supporting a family member with disability at home”. *Journal of Intellectual & Developmental Disability*, 34 (2009): 239–247. <https://doi.org/10.1080/13668250903103668>
- Büyüköztürk, Şener. “Faktör analizi: temel kavramlar ve ölçek geliştirmede kullanımı (Factor analysis: Basic concepts and using to development survey)”. *Educational Administration in Theory & Practices*, 32 (2002): 470-483. Retrieved from <https://dergipark.org.tr/en/download/article-file/108451>
- Cavkaytar, Atila, Ardiç, Avşar and Aksoy, Veysel. “Aile gereksinimlerini belirleme aracının geçerlik ve güvenilirliğinin güncellenmesi (Family Needs Survey: The study of updating of validity and reliability)”. *Ankara University Faculty of Educational Sciences Journal of Special Education*, 15 (2014): 1–14. https://doi.org/10.1501/Ozlegt_0000000195
- Chen, Jianhua & Simeonsson, Rune J. “Child disability and family needs in the people’s republic of China”. *International Journal of Rehabilitation Research*, 17 (1994): 25–37. doi: 10.1097/00004356-199403000-00003
- Decree-Law on Special Education. Official Gazette (Number: 23011). 1997. Access address: https://orgm.meb.gov.tr/meb_ys_dosyalar/2012_10/10111011_ozel_egitim_kanun_hukmunda_kararname.pdf
- Evcimen, Emirali. “Zihin engelli çocuğu olan ailelerin (anne babaların) gereksinimlerinin belirlenmesi (The determine of needs of family (mother and father) who have children with mental retardation)” Unpublished Master Thesis. Anadolu University, Eskişehir, 1996.
- Ertem, İlgi, Öztürk. “Uluslararası çocuk gelişimi izleme rehberi: Bireyselleştirilmiş müdahalelerin sağlanması (The international guide for monitoring child development: enabling individualised interventions)”. *Early Childhood Matters. Bernard van Leer Foundation*. 2017. Retrieved from https://bernardvanleer.org/app/uploads/2017/06/BVL18_TR_artikel_Ertem_v4.pdf
- Granlund, Mats & Roll-Pettersson, Lise. “The perceived needs of support of parents and classroom teachers-A comparison of needs in to microsystems”. *European Journal of Special Needs Education*, 16 (3) (2001): 225–244. <https://doi.org/10.1080/08856250110074382>
- Guralnick, Micheal J. “International perspectives on early intervention: A search for common ground”. *Journal of Early Intervention*, 30 (2) (2008): 90–101. <https://doi.org/10.1177/1053815107313483>
- Guralnick, Micheal J. “Why early intervention works: A system perspective”. *Infants and Young Children*, 24, (2011):6-28. <https://dx.doi.org/10.1097%2FIYC.0b013e3182002cfe>
- Hambleton, Ronald K. & Patsula, Liane. “Increasing the validity of adapted tests: Myths to be avoided and guidelines for improving test adaptation practices”. *Applied Testing Technology Journal*. 1999. Retrieved from <http://www.jattjournal.com/index.php/atp/article/view/48345/39215>
- Kline, Rex B. Principles and Practice of Structural Equation Modeling (2nd Edition ed.). New York: The Guilford Press. 2005.
- McWilliam, Robin A. *Routines-based early intervention: Supporting young children and their families*. Paul H. Brookes Publishing Co. Baltimore, Maryland, USA. 2010.
- Mert, Emine. “Farklı engel grubunda çocuğu olan anne ve babaların gereksinimlerinin karşılaştırılması (Compare of mothers’ and fathers’ needs on different disability types)” Unpublished Master Thesis. Abant İzzet Baysal University, Bolu, 1997.

- Özaydın, Latife & Gallagher, Peggy A. “Georgia’s Early Intervention program: Recommendations for a system of early intervention in Turkey”. *Procedia-Social and Behavioral Sciences Journal*, 46 (2012): 5610 – 5621. <https://doi.org/10.1016/j.sbspro.2012.06.483>
- Sameroff, Arnold J. & Rosenblum, Katherina L. “Psychosocial constraints on the development of resilience”. *Annals of the New York Academy of Sciences*, 1094 (2006): 116-124. <https://doi.org/10.1196/annals.1376.010>
- Sola, Canan and Diken, Ibrahim Halil. “Gelişimsel gerilik riski altındaki prematüre ve düşük doğum ağırlıklı çocuğa sahip annelerin gereksinimlerinin belirlenmesi (*Investigating the needs of mothers who have at-risk premature and low-birth-weight infants and toddlers for development delays*)”. *Ankara University, Journal of Faculty of Educational Sciences*, 9 (2) (2008): 21-36.
- Steiger, James H. Understanding the limitations of global fit assessment in structural equation modeling. *Personality and Individual Differences*, 42 (5) (2007): 893-98. Doi: 10.1016/j.paid.2006.09.017
- Sucuoğlu, Bülbin. “Özürü çocuğu olan anne-babaların gereksinimlerinin belirlenmesi. (Determination of parents' needs who have children with mental retardation)”. *Turkish Journal of Child Adolescent Mental Health*, 2 (1) (1995): 10-18.
- Türkiye İstatistik Kurumu (Turkish Statistical Institute-TSI) (2010). *Özürüli Sorun ve Beklentileri Araştırması* (Survey on Problems and Expectations of Disabled People). (Published Number: 3636). Retrieved from TURKSTAT website: <https://ailevecalisma.gov.tr/media/5602/ozurlulerin-sorun-ve-beklentileri-arastirmasi-2010.pdf>
- Ueda, Kimiko, et.al. “Validity and reliability of the Japanese version of the family needs survey”. *Research in Development Disorders*, 34 (2013): 3596-3606. <http://dx.doi.org/10.1016/j.ridd.2013.07.024>
- Yıldırım, Ali and Şimşek, Hasan. “*Sosyal bilimlerde nitel araştırma yöntemleri (Qualitative research methods in the social sciences)*”. Ankara: Seçkin Yayıncılık, 2018.