EXPERIENCES AND NEEDS OF MOTHERS OF CHILDREN WITH AUTISTIC DISORDER

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Experiences and Needs of Mothers of Children with Autistic Disorder

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Thesis Abstract

Akşın Ceylan Köktürk, "Experiences and Needs of Mothers of Children with Autistic Disorder"

The purpose of this study was to understand mothers of children with autism in terms of their experiences, needs, difficulties, stress levels and supports. Thirty mothers whose children were diagnosed as autistic were interviewed individually. The children were between three to eight years old. Sixty percent of children were in the mild to moderate form of autism where fourty percent were severe.

Semi-structured interviews were implemented to mothers to get detailed information about themselves and their children. Additionally, the Questionnaire on Resources and Stress (QRS-FT) was used to see mothers' sources of stress and the Family Support Scale (FSS) was used to see mothers' support systems. Mothers also completed family information forms.

The results of interview analyses showed that there was a time interval between mothers' first recognition of a problem in their children and their application to a professional. They were mostly sad and shocked when they heard the word autism and some mothers still feel the same. The responsibility of children was mostly on the mothers. Most mothers did not have any free time to relax. Being mothers of autistic children effected the social lives of mothers negatively.

Children's communication and behavioral problems were among the top difficulties that mothers had to cope with. Mothers mostly stated needs concerning their children, like schools that would accept their children, more therapy sessions and other therapies. To be well enough to lead independent lives was the shared future expectation for their children by mothers. Lastly, mothers expected other people to be more understanding, empathic and aware of autism.

Results from quantitative data also showed that mothers of children with autism perceived middle levels of stress and support. Mothers tended to have the highest mean scores from the pessimisim factor and the lowest mean scores from the parent and family problems factor of QRS-FT. Mothers perceived emotional support the most and caregiving support the least.

(314 words)

Tez Özeti

Akşın Ceylan Köktürk, "Otistik Bozukluğa Sahip Çocuğu Olan Annelerin Deneyimleri ve Gereksinimleri"

Bu çalışmanın amacı, otizme sahip çocuğu olan anneleri deneyimleri, gereksinimleri, yaşadıkları zorluklar, gerginlik düzeyleri ve destekleri doğrultusunda anlamaktır. Çocuğu otistik tanısı almış otuz anne ile bireysel görüşmeler yapılmıştır. Çocuklar üç ile sekiz yaşları arasındadır. Çocukların %60'ı hafif-orta düzey otizme, %40'ı ise ağır otizme sahiptirler.

Annelerle kendileri ve çocukları hakkında daha ayrıntılı bilgi almak amacıyla yarı-yapılandırılmış görüşmeler yapılmıştır. Buna ek olarak, annelerin gerginlik kaynaklarını görmek amacıyla Aile Stresini Değerlendirme Ölçeği (ASDÖ) ve annelerin destek sistemlerini görmek amacıyla da Aile Destek Ölçeği (ADÖ) kullanılmıştır. Ayrıca anneler aile bilgi formlarını doldurmuşlardır.

Yapılan görüşmelerin sonuçlarına göre, annelerin çocuklarında bir sorun olduğunu ilk fark etmeleri ile bir uzmana başvurmaları arasında bir zaman aralığı bulunmaktadır. Otizm sözcüğünü duydukları anda çoğunlukla üzüntü ve şok hissetmişlerdir ve bazıları halen aynı duyguları yaşamaktadır. Çocukların sorumluluğu genellikle annelerin üzerindedir. Birçok anne rahatlamak için kendisine zaman ayıramamaktadır. Otizmli bir çocuğa sahip olmak annelerin sosyal yaşamını olumsuz etkilemektedir.

Çocuklarının iletişim ve davranış sorunları annelerin başa çıkmak zorunda oldukları en önde gelen güçlüklerdir. Anneler çocuklarını kabul edecek okul, daha çok bireysel eğitim oturumu ve başka terapiler gibi daha çok çocuklarına yönelik gereksinimler belirtmişlerdir. Annelerin çocukları için gelecekten beklentilerinin başında onların bağımsız yaşayabilecek kadar iyi olmaları gelmektedir. Son olarak anneler, diğer insanlardan daha anlayışlı, empatik ve otizmin farkında olmalarını beklemektedirler.

Niceliksel verilerin sonuçlarına göre ise, anneler orta düzeyde gerginlik ve destek algılamaktadırlar. Anneler ASDÖ'den en yüksek ortalama puanı karamsarlık etmeninden, en düşük puanı ise ana-baba ve aile sorunları etmeninden almışlardır. Anneler en çok duygusal desteği, en az bakım desteğini algılamaktadırlar.

(251 sözcük)

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Finally, I want to dedicate this work to my little angel, my niece Naz, without whom our lives would be empty and meaningless.

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CHAPTER I

INTRODUCTION

The presence of a child with a disability or a disorder can affect the daily experiences of family members both in positive and negative ways. If the disorder is life-long and caused by syndromes like autistic disorder, then parents are more deeply affected. Parenting a child with autistic disorder is a life-long responsibility, thus parents of children with autistic disorder are exposed to experiences and have needs different than other parents. They need different resources and support systems for handling everyday situations. For them, life is a different parental journey with struggles, challenges and joys. Feeling sometimes special and sometimes helpless is the basic nature of this journey.

DeMyer (1979, cited in Cantwell & Baker, p. 48) found that a child with autistic disorder affect, "each parent as an individual, the marital relationship, the parent – child relationship and the other children in the family." Yet, mothers are still the ones whose lives are most affected by the child. The responsibility of an autistic child is mostly on mothers. This is the case everywhere including Türkiye. Mothers of children with autistic disorder are the primary caregivers, spend more time with their children then fathers and are responsible for their child's education and daily activities. This is why mothers' social life is more restricted than fathers' (Eren, 1994).

As Freedman and Boyer (2000) stated, people should take a holistic approach when working with children, focusing not only on the individual with the disability, but also tuning into the needs of the entire family unit. Numerous studies have examined the experience of living with a child with autistic disorder. In all of these

studies, parents of children with autistic disorder reported more stress than parents of children with other disabilities like Down's syndrome (e.g. Dumas et. al., 1991; Rodrigue et. al., 1990; Sanders and Morgan, 1997, cited in Hastings et. al., 2005). Interestingly, however, only a few studies have examined the parents' unique needs and resources. Before implementing programs for parents, however, we first need to understand what their needs are. Only after identifying their met and unmet needs, support systems and resources, we can develop and implement effective programs for families.

The importance of the study is deeply influenced by my experiences of living and working with autistic children. My niece, Naz, who is now seven years old was diagnosed as "having some autistic features" on her second birthday. The following five years have changed lots of things in our lives. But those changes were always in a positive direction. This was partly because she was in a mild form of the spectrum and with her superior intelligence we always had wonderful surprises with her. She changed me as well because although I was determined to work with children I did not know anything about developmental disorders. After I graduated from college I began to work with these special children and their parents, who allow me to develop a better understanding of them everday.

From my own experiences I learned that if there is something beyond being a "mother," it is being a mother of a "special child." Mostly mothers do not have an opportunity to tell their stories in detail. This study aims to give them this opportunity, which in turn, may help us to understand them more deeply as a way to start finding more effective ways to support them in coping with problems.

The birth of a child with a disability can be experienced differently by parents. Some studies stated that factors like family size or socioeconomic status may effect parent's reaction and acceptance of the disability (Seligman & Benjamin – Darling, 1997). Disabilities like Down syndrome are genetic and can become apparent soon after birth. However, some disabilities like autistic disorder, language disabilities or deafness can only be discovered when the child is older (Seligman & Benjamin – Darling, 1997). Whether parents learn their child's disability at birth or later, this unexpectant event will effect them negatively.

Professionals who work with children also need to work with children's families, this is more so for children with special needs. One should be aware of the needs, expectations and resources of the family. Without overestimating or underestimating the impact of the child on the family, they can serve them better. Because effective interventions can be achieved only through parent - professional partnership. In the past, most attention was given to the needs of the child but in the last decades, professionals have began to give importance to both children and their families (Seligman & Benjamin – Darling, 1997).

Little is known about the experiences of mothers with autistic children in Türkiye. So, the main purpose of the present study is to enhance our understanding of mothers of children with autistic disorder, especially in regards to their needs, experiences and support systems.

CHAPTER II

REVIEW OF LITERATURE

This section starts with some basic information about autistic disorder; what it is, its causes, epidemiology and therapeutic methods. Then the section proceeds with how parents experience and handle the disorder, and what needs, stressors and support systems they have.

Understanding Autistic Disorder

Autistic disorder was first described by Kanner (1943), an American psychiatrist. Nearly simultaneously Hans Asperger, an Austrian psychiatrist, published a paper on related problems. They were independently describing the same disorder. However, because of World War II, Asperger's work did not become as popular as Kanner's (Frith, 1989). Today, Asperger's syndrome is a label for children who tend to have normal or high intelligence and are highly verbal, near-normal autistic (Frith, 1989).

Kanner (1943) described eleven children who had special features like autistic aloneness, obsessive insistence on sameness, and narrow topics of interest. Since this original work, much has been found. Now it is known that autistic disorder can be seen in families from all social classes, not only in those of well-educated or professional parents, as it was assumed then. Problems of these children are no longer linked to parental attitudes (Volkmar, Klin & Cohen, 1997). After the 1970s, studies rejected the view that parents of autistic children are cold, introverted, unempathic and overprotective. In other words, studies in the last decades have

shown that parental pathology has no effect on a child's autistic disorder (Cantwell & Baker, 1984).

It is not a coincidence that both Kanner and Asperger had chosen the term "autistic." Psychiatrist Eugen Bleuler in 1911 was the first person to introduce this label. The word "autism" came from the Greek word "autos" which means "self." Bleuler used this term as a basic disturbance in schizophrenia that involves withdrawal from social life into the self (Frith, 1989).

In the fourth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV, 1994, p. 70-71) (Table 1) autistic disorder is placed under a category called pervasive developmental disorders (PDD) along with Rett's disorder, Asperger's disorder, childhood disintegrative disorder and pervasive developmental disorder not otherwise classified (PDD-NOS). To have a diagnosis of autistic disorder one should have impairments in social interaction and communication, have restricted repetitive and stereotyped patterns of behavior, interests and activities, and an onset prior to age three (APA, 1994). Autistic disorder is seen three or four times more in boys than in girls (Korkmaz, 2000).

Parents, especially mothers, recognize something different in their children but cannot name the problem. They sometimes fear deafness and sometimes other people around them say that there is nothing to be afraid of. The mother of a child with autistic disorder says:

> I cannot now pinpoint when I first realized he was losing his language. All I know is that I took him to the doctor when he was eighteen months old to ask for a hearing test, because I feared he was deaf. We could shout his name, and he just didn't respond. It turned out his hearing was fine; it was autism that had pulled our son into his own world (Praed, 2007, p. 140).

Another mother expresses that “A wall was between us; we could see each other, yet we could not reach each other. To understand our child, we knew we had to look deeper” (Derosier, 2007, p. 293).

To develop an effective intervention program, comprehensive evaluation of a child is fundamental. While diagnosing autistic disorder it is important to observe a child both in structured and unstructured times. Areas for observation should include; social development, communication, responses to the environment, play skills, self-awareness, motor skills and problem behaviors (Sparrow, Marans, Klin, Carter, Volkmar & Cohen, 1997). To structure observations professionals use instruments. Instruments for children with autistic disorder are mostly designed for parents as informants or as observers. The Autism Diagnostic Interview- Revised (ADI-R) and Autism Diagnostic Observation Schedule (ADOS) are examples of these scales (Sparrow et al. 1997). Some instruments are developed to diagnose autistic disorder before three years of age, including The Checklist for Autism in Toddlers (CHAT) and the Symptoms of Autism in Babies (SAB) (Gillberg & Coleman, 2000).

Parents mostly recognize behavioral abnormalities in their children very early. However, sometimes the professionals’ inability to recognize autistic disorder or parents’ late application to a professional results in late identification and education. Parental delay in applications could be due to ignorance, neglect or wishful thinking that things would naturally take their normal course. The time interval between the recognition of problems by parents and the diagnosis is stated by several researchers (Young, Brewer & Pattison, 2003; Harrington, Patrick, Edwards & Brand, 2006; Siklos & Kerns, 2007).

Table 1: *Diagnostic criteria for autistic disorder*

299.00 Autistic Disorder

A. A total of six (or more) items from (1), (2), and (3), with at least two from (1), and one each from (2) and (3)

(1) qualitative impairment in social interaction, as manifested by at least two of the following:

a) marked impairments in the use of multiple nonverbal behaviors such as eye-to-eye gaze, facial expression, body posture, and gestures to regulate social interaction

b) failure to develop peer relationships appropriate to developmental level

c) a lack of spontaneous seeking to share enjoyment, interests, or achievements with other people, (e.g., by a lack of showing, bringing, or pointing out objects of interest to other people)

d) lack of social or emotional reciprocity

(2) qualitative impairments in communication as manifested by at least one of the following:

a) delay in, or total lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gesture or mime)

b) in individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others

c) stereotyped and repetitive use of language or idiosyncratic language

d) lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level

(3) restricted repetitive and stereotyped patterns of behavior, interests and activities, as manifested by at least two of the following:

a) encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus

b) apparently inflexible adherence to specific, nonfunctional routines or rituals

c) stereotyped and repetitive motor mannerisms (e.g hand or finger flapping or twisting, or complex whole body movements)

d) persistent preoccupation with parts of objects

B. Delays or abnormal functioning in at least one of the following areas, with onset prior to age 3 years:

(1) social interaction (2) language as used in social communication (3) symbolic or imaginative play

C. The disturbance is not better accounted for by Rett's Disorder or Childhood Disintegrative Disorder

Probable Causes of Autistic Disorder

Autistic disorder is a developmental disorder that can be seen in every culture, region or social class (Seligman & Benjamin – Darling, 1997). In the early years, parents, especially mothers were blamed with being "refrigerator parents" due to their poor parenting. According to Bettelheim (1967) the negative, ambivalent or indifferent feelings of mothers explain infantile autism. In his view, negative feelings of parents can result in autistic diorder (Bettelheim, 1967). In the 1960s a neurologically based approach became popular. Rimland, who was the father of a child with autistic disorder, criticized the psychogenic and psychological views (1964, cited in Olley & Gutentag, 1999). According to him, parental attitudes were not responsible for autistic disorder. With this new sight, Rimland removed the feelings of guilt from parents for causing autistic disorder. Today the neurobiological factors underlying autistic disorder are found to be more important in the onset of autistic disorder (Siegel, 1997; Sigman & Capps, 1997). But there is still limited information about the probable causes of autistic disorder. "In fact, autism is not a unitary disease with a single etiology. It is a heterogeneous behavioral syndrome found in association with many etiologies." (Sigman & Capps, 1997, p. 171).

Most mothers do not see autistic disorder as a result of a particular cause, while some of them blame themselves or external sources like MMR vaccine (Dale, Jahoda & Knott, 2006). However, in another survey with sixty-two parents of children with autism, 26% of parents believed that something had caused or contributed to the causation of their child's autistic disorder. 45% of them answered "maybe" to that question. Immunizations, genetic predisposition and environmental

exposure of the mother or the child were stated as causes by parents (Harrington, Patrick, Edwards & Brand, 2006).

There are family and twin studies showing the importance of genetic factors in autistic disorder. In these studies, the frequency of autistic disorder among siblings was two to five percent more frequent than in the general population (Gillberg & Coleman, 2000). While sixty percent of monozygotic twins were suffering from autistic disorder, less than five percent of dizygotic twins suffered from autistic disorder (Sigman & Capps, 1997). The fact that autistic disorder is seen more in males than females also suggests that autistic disorder is heritable (Baron-Cohen, 2003).

Baron-Cohen (2003) calls autistic disorder a condition of "mindblindness." According to him it is an "empathy disorder" because people who have autistic disorder "have difficulties in mindreading or putting themselves into someone else's shoes, imagining the world through someone else's eyes and responding appropriately to someone else's feelings." (Baron-Cohen, 2003, p.137).

Prevalence of Autistic Disorder

In the late 1970s the prevalence of autistic disorder was 4.9 per 10.000. In the 1980s, higher rates of autistic disorder like 7.7 per 10.000 were reported. In the 1990s the mean prevalence reached 9.6 per 10.000 (Gillberg & Coleman, 2000). According to Gillberg and Coleman (2000), autistic disorder is more common than 2 – 5 in 10.000 children. Rates in the most reasonable, conservative estimate is about 1 in 1.000 children. The prevalence of all PDDs is at least 4 to 5 in 1.000 children.

In a research by Fombonne (2003), thirty-two surveys published between 1966 and 2001 in 13 countries were described in detail. Fombonne (2003) reported that, 10/10.000 could be the base rate for the current prevalence of autistic disorder and 27.5/10.000 for the combination of all PDDs. Croen, Grether, Hoogstrate and Selvin (2002) studied children who were born in California between 1987 and 1994 and were enrolled in the Department of Developmental Services (DDS) with a diagnosis of autistic disorder. They found 5,038 children who had a diagnosis of autistic disorder with a prevalence of 11 per 10.000.

Lower rates found in earlier studies can be due to the use of different diagnostic criteria like Kanner's. Differences in social interaction, communication and focused interest were being categorized by Leo Kanner as autism. Nowadays, rates of children who suffer from autistic disorder have increased. According to the statistics of U. S. Department of Education, between the years 1993 to 2003 the nationwide rate of autistic disorder increased 657 percent (Lilienfeld & Arkowitz, 2007). Investigators have turned to environmental factors for such an increase, like the use of antibiotics, viruses, allergies, television viewing in infancy and vaccines containing thimerosal (a preservative containing mercury). Some of these factors remain speculative and had not been investigated and some are even rejected (Lilienfeld & Arkowitz, 2007). Especially vaccine-autism link is investigated in some countries. Although MMR vaccinations remained constant or declined, the rate of autistic disorder diagnoses continued to rise. For example, in Denmark in 1992, mercury-containing vaccines were not used, but the incidence of autistic disorder still increased (Madsen et al. 2003, as cited in Pavone & Ruggieri, 2005).

Gillberg (2005) mentioned the possible reasons for the increase in autistic disorder. According to him, the conceptualization of the disorder has changed over the last decades and the diagnostic criteria are more detailed now. He also pointed to the environmental factors and the awareness in the community about autistic disorder. The public's increased familiarity was also stated by Lilienfeld and Arkowitz (2007) who claimed that movies like "Rain Man" played an important role in this awareness. According to Baron-Cohen (2003) one in 200 children has one of the autism spectrum conditions and this is the result of better awareness and broader diagnosis. Recent studies have shown that the prevalence of autism spectrum disorders (ASD) is 6.6 per 1.000 or 1 in 152 for 8 year old children in 2002 in the United States. They estimate that 560.000 individuals between the ages 0 to 21 have an ASD (Autism and Developmental Disabilities Monitoring Network, 2002). Still, it is unclear whether this increase is due to changes in the diagnostic criteria or due to a true increase in prevalence.

Therapeutic Approaches to Autistic Disorder

Parents choose and use many treatment methods for their children with autism spectrum disorders. Some of these methods do not have any empirical evidence while some others are supported by research. "Which educational method is appropriate for my child?" is a question frequently asked by parents of children with autistic disorder. Wiseman (2006, p. 165) gave two key answers to this question which are; to know your child and to know the treatments. She also added that keeping in mind the child's strengths and weaknesses is very important.

An early education program starting with early diagnosis is very important in the development of children with autistic disorder. An individualized educational program is the best known effective intervention for children with autistic disorder. These programs include every developmental area; socialization, communication, motor and daily living skills. It is hard for these children to learn naturally in social settings. They need instruction and adult guidance in learning skills.

The most popular and well known behavioral educational program was developed by Ivar Lovaas and his colleagues' (cited in Sigman & Capps, 1997). It is an early intervention program in which the child is in a 40 hours weekly program. The follow–up effectiveness studies of this program showed great improvements in children's skills and behaviors, to a level that some showed few remaining signs of autistic disorder. The Lovaas approach is based on applied behavioral analysis (ABA) (Thomas, Morrissey & McLaurin, 2007).

Floor-Time and the Denver Model are developmental in nature (Thomas, Morrissey & McLaurin, 2007). Floor time "takes a child back to the very first milestone he may have missed and begins the developmental progress anew." (Greenspan, Wieder & Simons, 1998, p.121).

Another approach is the TEACCH approach (Treatment and Education of Autistic and related Communication handicapped CHildren) which integrates developmental, social cognition, behavioral and neuropsychological perspectives (Thomas, Morrissey & McLaurin, 2007).

Speech and language therapy are also the most frequently used intervention techniques for communication problems of children with autistic disorder. Picture Exchange Communication System (PECS) is another technique used for a way of

communication. In this system, children are prompted to give the picture of the desired object (Bondy & Frost, 1994, cited in Durand, 1999).

Medication is another means of helping children with autistic disorder. However, the purpose in medical treatment is not to treat autistic disorder but to reduce behavioral problems that coexist with it (Olley & Gutentag, 1999). For example, comorbidities like depression or hyperactivity in autistic disorder can be treated by pharmacological cures/ therapies (Zappella, 2005).

Alternative treatments have been widely used by parents over many decades. But there is still limited or nonexistent evidence for their effectiveness in the literature. Gluten - casein free diet for children with ASDs is one of them. Millward et al. (2004, as cited in Pavone & Ruggieri, 2005) searched the abstracts from several sources about Gluten – casein (GC) free diets and their effectiveness between the 1960s and 2000s. They found the positive effects of GC - free diet for children with ASDs in only one study.

Vitamins, especially vitamin B6 is also used as an alternative treatment for autistic children. Because of the studies' limitations or the absence of controlled studies, there are no clear results about the effects of vitamins on autistic features (Pavone & Ruggieri, 2005).

Here are some other alternative therapies used in the treatment of autistic disorder; detoxification of mercury, music therapy, holding therapy, osteopathy/craniosacial therapy, horse and pony riding and dolphin therapy. Other therapeutic methods include; facilitated communication, auditory integration training and sensory-motor therapies. These have been either found to have little or no

effectiveness, or have never been objectively evaluated (Gillberg & Coleman, 2000; Olley & Gutentag, 1999).

Although there is no or little evidence about the effectiveness of alternative treatments, nowadays they are very popular among parents of children with autistic disorder. Sixty two parents were asked what complementary or alternative therapies, diets or medications they have tried for their children. Eighty seven percent of parents reported that they have used at least one complementary and alternative medicine (CAM). Sixty nine percent reported that they have tried at least one dietary restriction and sixty percent tried at least one dietary supplement (Harrington, Patrick, Edwards & Brand, 2006).

Green, Pituch, Itchon, Choi, O'Reilly and Sigafoos (2006) made an internet survey with 552 parents to explore the intervention programs and therapies used in the treatment of their children with autistic disorder. Speech therapy was the therapy (70%) used most often by parents. Visual schedules were the next (43.2%), sensory integration (38.2%) and social stories (36.1%) were the other commonly used treatment methods. Most parents were using multiple treatments (the mean number was 7). Green et al. (2006) also grouped 108 treatments into eleven categories. The most common category used by parents was "standard therapies" which include therapies like speech and music. Skills based treatments like social stories and ABA were also commonly used. Another category of treatment was medications and it was used by 52.5 % of parents. It was also found that if the child had severe autistic disorder, his/her parents were using more treatment methods than the parents of children with mild autistic disorder or Asperger's syndrome. Also, parents of

younger children were using more methods than parents with older children (Green, et al., 2006).

Goin-Kochel, Myers and Mackintosh (2007) also searched the treatments used by parents of children with autism spectrum disorders via internet survey. Like Green et al. (2006) they found that younger children were undergoing more treatments than the older children.

However, older children were undergoing more drug treatments. From 479 participants, 42.8 % had tried pharmacological treatments and 31.9 % tried special diets. Behavioral/educational/ alternative treatments (ABA, Floor Time, sensory integration, speech therapy etc.) were being tried more by children with autistic disorder and PDD-NOS than children with Asperger's syndrome.

There is no cure for autistic disorder now. However, with early identification, education and appropriate intervention methods, improvement can be achieved. Parent involvement in the education of children with autistic disorder is crucial because parents spend more time with their children than anyone else and without parental involvement nothing will be gained. "Professionals cannot help children without the help of families. Only through a professional-family partnership can effective interventions occur. Professionals, then, must work to understand the world in which a child lives- the world of the family." (Seligman & Darling,1997, p. 278).

"Should it be cured?" is another question because it is debatable that curing autistic disorder can prevent genius people as well. This can be looked at from the view of a person who is in this spectrum.

I love my autism. I shout it out for everyone to know. I'm quite thoroughly against research to find it is cure or prevention. I don't believe it can ever be cured because it isn't an abnormality or sickness. It is a distinct difference. It cunningly escapes complete understanding. The autistic one remains a mystery, a puzzle. That

is delightful. This type of individual is simply one who lives apart in his or her own way from the masses (O'Neill, 1998, p. 199).

Temple Grandin, who is well known by her own accounts of having autistic disorder, stated something similar in her book: "If I could snap my fingers and be non-autistic, I would not. Autism is part of what I am" (Grandin, 1996, p. 60).

Parents of Children with Autistic Disorder

Psychological Well-Being of Parents of Children with Autistic Disorder

Parents experience various kinds of feelings when they realize that their child has some developmental delay. They sometimes blame themselves, or go through feelings of guilt and anger or shock or denial. In the early stages of that process, parents may be depressed and overwhelmed (Greenspan & Wieder, 1998). They may feel unsupported, left to face the crisis on their own. Guilt and sadness, anger and exhaustion may spin them into paralysis. Parents of children with autistic disorder may experience burnout through their lives and some factors can increase this possibility of burnout. The unrelieved care of the child, not obtaining an accurate diagnosis, isolation from the social world, inadequate supportive services and neglect of needs of parents are among these factors (Marcus, 1984).

Mothers of children with disabilities experience increased moodiness, are more prone to illness. They also describe themselves as unable to pursue personal goals and having little free time (Holroyd, 1974 cited in Weiss, 2002).

There are some factors which have been associated with the well-being of mothers. Perceived self-efficacy is one of them (Ozer, 1995; Sahu & Rath, 2003 cited in Kuhn & Carter, 2006). Kuhn & Carter (2006) studied the associations between self-efficacy and parenting cognitions of agency, feelings of guilt and

autism knowledge among mothers of children with autistic disorder. They found that mothers who take an active role in her child's development reported higher levels of maternal self-efficacy. On the other hand, mothers who have feelings of guilt reported lower levels of maternal self-efficacy.

Greenspan and Wieder (1998) stated that parents experience conflicting feelings, anger and estrangement, eagerness to blame themselves and each other as they try to cope with their child's developmental problems.

While examining the factors that affect the psycho-social well-being of parents of children with autistic disorder, the amount of social support and the sex of the parent were found to be significant determinants of parental depression, anxiety and anger. Mothers of children with autistic disorder were experiencing more distress than fathers were (Gray & Holden, 1992). Moes, Koegel, Schreibman and Loos (1992) found differences in the stress levels of mothers as well as fathers. Mothers were experiencing more stress than fathers about themselves, other family members and the family as a whole, and they were also at a greater risk for depression than fathers. As mentioned by Moes and his colleagues (1992) the reason of these gender differences can be due to the primary caretaker role of the mothers who spend more time at home with their children.

Hastings (2003) searched fathers' and mothers' mental health and stress levels. Eighteen married couples with children who have autistic disorder were included in this research. Mothers' and fathers' scores were similar on stress and mental health but mothers' anxiety levels were higher than fathers. Also, mothers were found to be more affected by child's behavioral problems and fathers' mental health. In contrast, fathers' stress was not associated with the same factors.

According to Hastings (2003) this is due to the time that mothers spend with their children. In other words, the caregiving burden of mothers is more than that of fathers. This finding is also supported by Olsson and Hwang (2001) who investigated parental depression in a larger sample (N=216) of both mothers and fathers who have children with autistic disorder or intellectual disability and in 214 control families. As it was expected, mothers of children with autistic disorder had higher scores on the depression inventory than mothers of children with intellectual disability. Fathers of children with autistic disorder and intellectual disability came next in their depression scores. The reason of this difference was again found to be associated with mothers' caregiving burden.

Although having a child with autistic disorder is the main factor responsible for parental stress or depression, research also found additional factors influential in increasing stress levels. Duarte, Bordin, Yazıgı and Money (2005) claimed that poor expression of affect, little interest in people, being an older mother and having a younger child contributed to increased stress levels in mothers of children with autistic disorder. Other studies found strong negative associations between the abilities and behaviors of the child and the emotional distress of mothers (Bromley, Hare, Davison & Emerson, 2004). Emotional distress was associated with unmet needs like break from caring and planning for the future (Hare, Pratt, Burton, Bromley & Emerson, 2004).

In a study with a Turkish sample (Fırat, Diler, Avcı & Seydaoğlu, 2002) mothers of autistic children were compared with mothers of mentally retarded children on their anxiety, depression, alexithymia (unawareness of cognitive aspects of motional responses) and general psychological symptoms. Results showed that

mothers of autistic children had significantly higher depression, state anxiety and general symptom scores.

Abbeduto and his colleagues (2003) examined the mothers of children with Down syndrome, autistic disorder and Fragile X syndromes in terms of their psychological well-being. Mothers of adolescents and young adults with autistic disorder reported significantly higher levels of depressive symptoms than did mothers of those with Down syndrome. It was also found that mothers tended to be more depressed if they had lower family income, other children with disabilities, if the children had a greater number of behavioral problems and if the mother reported less use of problem-focused and greater use of emotional–focused coping. Psychological functioning of mothers of autistic children were compared with mothers of normally developing children and mothers of children with Down syndrome by Rodrigue, Morgan and Geffken (1990). Frustration, anxiety and tenseness were found to be common feelings among mothers of autistic children. Mothers also reported lower perceived parenting competence and less marital satisfaction than the other two groups.

In another study, Turkish mothers of children with autistic disorder (N=43) and attention deficit hyperactivity disorder (ADHD) (N=32) were compared according to their stress levels. Both mothers had higher stress levels than the normal mean (which was 24,62). However, mothers of children with autistic disorder also had higher stress levels (M=32,37) than mothers of children with ADHD (M=28,22) (Esenler, 2001).

Studies of Bristol (1979, as cited in Bebko, Konstantareas & Springer, 1987) and DeMyer and Goldberg (1983, as cited in Bebko, Konstantareas & Springer,

1987) stated age related stress for mothers. They found that mothers who had older children with autistic disorder found the situation more stressful than mothers of younger children. However, contrasting results were found by Bebko, Konstantareas and Springer (1987). Young children's parents did not differ in how stressful they found the child's characteristics. Also, mothers of older children with autistic disorder reported less stress than fathers. Some behaviours of children with autistic disorder are more stressful for mothers when the children are older. For example, stereotypic behaviour and inappropriate speech are excusable when the child is young (Tomanik, Harris & Hawkins, 2004).

Eren (1994) found that mothers leave their jobs to spend more time with their autistic children. Whether a mother is working or not can also effect the stress level of a mother. Elçi (2004) showed that mothers who did not work had significantly higher scores on the stress level, emotional exhaustion and total burnout dimensions. According to the researcher this is because working mothers are less involved in their child's caregiving. Mothers who work also perceive more social support than mothers who do not work (Görgü, 2005). Görgü (2005) found that mothers who have higher income levels and look after their child with the help of a spouse, a grandparent or a babysitter have lower depression scores.

Child characteristics such as responsiveness, temperament, repetitive behaviour and caregiving demands from parents are found to be related to parental stress levels (Baker, 1993, as cited in Tomanik, Harris & Hawkins, 2004). Severity of the child's autistic disorder also had an effect on the stress levels of parents (Bebko, Konstantareas & Springer, 1987). The more severe the symptoms were, the more stressful it was for parents.

A stressor in one area of one's life may result in stressors in other areas too and this is known as 'stress proliferation' (Benson, 2006). So while parenting a child with autistic disorder stress proliferation may occur. Benson (2006) searched the mediating role of stress proliferation among parents of children with autism spectrum disorders (ASD). It was found that stress proliferation was a powerful predictor of parental depression. Parents of children who had higher levels of child symptom severity also had higher levels of stress proliferation which in turn resulted in higher levels of depression (Benson, 2006).

Autistic disorder effects marital relationship and family functioning as well. Higgins, Bailey and Pearce (2005) surveyed parents of children with autism spectrum disorders (ASD) to examine family functioning and coping strategies. They found that in comparison to normative data, parents of children with ASD reported lower marital happiness, family adaptability and family cohesion.

The role of the temperament of the child is another factor in maternal stress as stated by Konstantareas and Papageorgiou (2006). Forty-three Greek mothers and their children were included in their study. The children were between two to twenty-six years of age. They found that high activity level, high rigidity and low mood of the children are the predictors of maternal stress. Symptom severity was a weaker predictor of maternal stress than the previous ones. Also mothers of non-verbal children were found to be more stressed compared to verbal children's mothers.

The relationship between maternal stress and adaptive and maladaptive behaviours of autistic children was investigated in another study with sixty mothers (Tomanik, Harris & Hawkins, 2004). In this work children were between two and eight years of age. Mothers reported the greatest stress when their children were

more irritable, hyperactive, unable to take care of themselves, nonverbal and unsocial (Tomanik, Harris & Hawkins, 2004).

Maternal burden in families with children with autism spectrum disorders was also investigated by Fitzgerald, Birkbeck and Matthews (2002). One hundred mothers were included in the study and it was found that two thirds of those mothers were experiencing high levels of burden. The child's dependency and the ability to care for his or her own needs had a great impact on maternal well-being, family burden and social problems like isolation from friends and relatives and marital problems (Fitzgerald, Birkbeck & Matthews, 2002).

Lecavalier, Leone and Wiltz (2006) conducted a study with a large sample of children and adolescents with autistic disorder (N= 293). They searched for the impact of behavioral problems of children (mean age was 9.0 years) on both parental and teacher stress. As it was expected, behavioral problems were found to be more associated with stress than any other characteristic. Conduct problems and lack of prosocial behaviors were most strongly associated with caregiver stress. For teachers, the child's chronological age was another indicator of stress. They also examined the stability of behavioral problems and caregiver stress. This was supported only for parents in which parental reports of behavioral problems and stress were found stable over a one year period (Lecavalier, Leone & Wiltz, 2006).

Gray's (2002) longitudinal study of families of children with autistic disorder showed that in eight to ten years most parents made improvements in terms of their psychological well-being and social experiences. The original study, which was conducted a decade ago, started with thirty-five parents, twenty-eight of them participated in the following research. The results showed that parents' level of

emotional distress was less than at the beginning but parents of children with severe obsessions and aggressive behaviors were experiencing the greatest amount of distress. The study also showed changes in the parents' social experiences like problem behaviors of children, coping strategies and the social life of parents. Parents were not viewing communication, problem behaviors in public, obsessions and toileting as coping problems anymore. Their child's future residential location became more important to them. Follow-up research results did not show any difference in parents' socializing problems. They still had problems, however, the impact of this stigmatization on parents declined.

Similar findings were found by Fitzgerald, Birkbeck and Matthews (2002) who reported that parents of older children with autistic disorder have better maternal mental health and less caregiving burden than parents of younger children with autistic disorder. However, some studies reported different findings. Mothers of toddlers (n= 153) and mothers of adolescents (n= 201) with autism spectrum disorders (ASD) were compared on the impact of autism symptoms, coping strategies and well-being to see age-related differences. The results of the study showed that both groups had signs of significant distress. Mothers of adolescents reported higher levels of anger and behavioral disengagement in comparison to mothers of toddlers (Smith, Seltzer, Tager- Flusberg, Greenberg & Carter, 2007).

Montes and Halterman (2007) conducted a population-based study of psychological functioning in mothers of children with autistic disorder. They used The National Survey of Children's Health (NSCH) 2003 results. Mothers were asked on the telephone "has a doctor or health professional ever told you your child has autism?". From 61.772 school-aged children (4 to 17 years) there were 364 children

with autistic disorder. Mothers with or without a child with autisistic disorder rated their own overall health as poor or fair. However, mothers of autistic children rated their mental and emotional health as poor or fair compared to other mothers. As expected, mothers of children with autistic disorder also reported higher maternal stress than normally developing children's mothers. Another significant difference between these mothers was about the parent-child relationship domain. Mothers of autistic children do not talk about important things with their children mostly because of the child's communication and social problems. They also reported that their children were bothering them more. But again there were no significant differences in these mothers' relationships with their children and level of anger toward their children. Mothers were also not distinguishable on their coping, support and disagreement styles (Montes & Halterman, 2007).

Stressors Unique to Parents of Children with Autistic Disorder

Marcus, Kunce and Schopler (1997) stated that there are stressors unique to families with autistic children. Diagnostic confusion is one of them. It is difficult and sometimes a long process to diagnose a child with autistic disorder. Because autistic disorder is invisible, which means that the physical appearances of children with autistic disorder are normal, parents mostly expect normal social and communicative behaviors. When these expectations are unmet however, stress among family members may arise. Also, this invisibility of the condition make, parents encounter more difficulties in their social lives, as stated by one parent; "if he were physically handicapped people would understand and would be kind. Because he looks like a

normal child, people don't see the autism and don't understand." (Midence & O'Neill, 1999, p. 280).

Late diagnosis is another source of stress for families (Quine & Pahl, 1987, cited in Hutton & Carron, 2005). Parents describe the waiting period to have a diagnosis as frustrating and sometimes as a sense of powerlessness. One mother describes her powerlessness during this period "When we didn't know what was wrong, I just felt like I couldn't do anything. I knew that if they told me something then I could research it, or find out how to handle it. But as long as there was no diagnosis, there was nothing I could do but wait" (Schall, 2000, p. 411).

Behavioral problems of children with autistic disorder embarrass parents in public. Challenging behaviors like aggression, self – injury, depression, screaming or biting can be seen with autistic disorder (Hare et al., 2004). These characteristics can make the daily lives of families harder. A child's behavioral problems can be seen as the most common source of stress for parents (Sharpley, Bitsika & Efremidis, 1997).

According to Sharpley, Bitsika and Efremidis (1997) the permanency of the disorder, lack of acceptance of autistic disorder by society and family members and low levels of support for parents are the three most stressful factors for parents of children with autistic disorder. One mother states that " She experiences anxiety, awkwardness, and behavior challenges. She can be very uncooperative. These are the things that cause other mothers to look, whisper and even comment, offering unsolicited advice" (Perryman, 2007, p. 230).

Because of these negative factors parents experience exhaustion (Benderix, Nordström & Sivberg, 2007). A mother explains her exhaustion like this " It's been so difficult with him. I sometimes wonder what he really feels. He wakes up at night

and screams. The only thing that helps is my sitting and holding him. I feel so tired, so tired all the time. He wakes up at five or six in the morning. I'm so tired I just cry" (Benderix, Nordström & Sivberg, 2007, p. 634). Another mother also says "… I am exhausted. Exhausted from the constant judgments from family and strangers. She looks so normal. They just don't get it. 'give me one day with that child, and I'll take care of her problem!' they say. Exhausted from explaining it isn't a discipline issue" (O'Neil, 2007, p. 114). While making interviews with parents of autistic children Schall (2000) described her observations about their exhaustion, and said "I could see, feel, and hear their exhaustion" (p. 416). In her study one mother said "I think that the worst thing is that I felt like a prisoner for a whole bunch of years" (p. 416). Another mother also stated her exhaustion "I just think it was totally exhausting. I just don't think that anyone knows how you have to fight battles constantly…an excruciating daily grind" (p. 416).

Furthermore, there is no cure for autistic disorder. Unproven therapies are another stressor for parents. These popular therapies make parents susceptible and make them spend their time and money (Marcus, Kunce & Schopler, 1997). Treatments may reduce some of the behavioral problems but families know that this is a life - long disability (Gray & Holden, 1992).

Bristol (1984) explained the factors that increase stress and family crisis in families of autistic children. The ambiguity of the child's condition is one of them. According to Bristol, parents of children with mild autistic disorder face more stress and risk for family crisis because of the uncertainty of the condition. The severity and duration of the child's autism are other factors that affect family negatively. Life – long disabilities like autistic disorder are very stressful for any family to cope with.

The severity of the child's deficits adds another hardiness to that stressful event. Lastly, Bristol (1984) pointed to another important factor which is lack of community understanding and support. This often makes parents feel rejected and isolated.

Needs of Parents of Children with Autistic Disorder

Every family is unique and different, so are their needs. Needs of parents may change according to their priorities in life. For instance, one mother may be concerned about her child's medical needs and another may be concerned about educational needs. Professionals and support services must search for these needs and preferences of support that parents receive. There are few studies that have examined the needs parents with autistic children have and whether these needs are being met.

Freedman and Boyer (2000) examined the types of needs parents felt that were not being met. In this exploratory research, data was collected through group interviewing and discussion. In these discussions, parents of children with developmental disabilities identified many areas of unmet needs like more and consistent therapies, mental health counseling for families, social and recreational opportunities for their children, coordination of services and support and public education.

Bromley, Hare, Davison, and Emerson (2004) interviewed sixty-eight mothers of children with autism spectrum disorders to explore their needs, sources of support and mental health status. In this study, help with care during holidays, doing things parents enjoy, getting advice on best ways to help child and break from caring

for child were the most common unmet needs of mothers. In other words, mothers mostly reported unmet needs for practical support and respite care.

In another study, twenty-six families of adults with autism spectrum disorders were asked to rate their current and previous needs. The main unmet needs identified by parents were break from caring for the person, help planning for the person's future and help getting care for the person in the future (Hare et al., 2004). So, it seems that whether a child is a toddler or an adult, the needs of parents still exist.

Parents have lots of concerns about their children's future. Like all parents, parents of children with autism spectrum disorders also have expectations about their child. Ivey (2004) investigated the expectations of twenty-five parents (twenty-one mothers) of children with autistic disorder. When it comes to achieving future outcomes, parents' expectations differed on the likelihood and importance of the outcomes. They believed that "the importance of the outcomes was greater than the likelihood of those outcomes" (p. 30). For parents "attending school" and "their child's safety" were highly important. Also the likelihood mean of attending school was high. However, the likelihood of being safe from physical harm was low. The lowest means for likelihood and importance were for "take care of parent in old age."

Educational needs of parents for their children is another important issue. Dymond, Gilson and Myran (2007) made a survey with 783 parents of children with autistic disorder and asked their recommendations and needs for improving services in Virginia. The most selected types of services needed by parents were applied behavior analysis (ABA), speech therapy, respite care and social skills training.

Family Support

Children with autistic disorder need a lot of support but so do their families. Having a child with a disorder is very hard and stressful for family members but having no support from other family members, friends or school makes the situation even more stressful.

According to Sharpley et al. (1997 cited in Boyd, 2002) concern about the permanency of the disorder, poor acceptance of autistic disorder by society and family members and low levels of social support are the three most stressful factors for parents of children with autistic disorder.

Family support includes both formal and informal support systems. Friends, extended family members or other parents who have children with autistic disorder can be sources of informal support. On the other hand, school and other professionals are sources of formal support. Informal support is sometimes not very helpful and sufficient. Especially if the child has severe autistic disorder the family may need more formal support (Hecimovic, Powell & Christensen, 1999). However, parents need to have both of these support systems to strengthen their functioning and to be more effective in their child's development. Also, support for the family should include not only the mother and the father but also the siblings or the grandparents.

Studies have shown that for successful adaptation, an informal support system is very important (Bristol, 1984). Especially support from spouses effect mothers positively. Such mothers had lower levels of stress, fewer depressive symptoms and happier marriages. As stated by Bristol (1984) formal support is another fundamental resource for successful adaptation. Previous studies of Bristol found favorable

differences in stress levels for mothers who have more availability of activities and services.

Boyd (2002) reviewed the literature about the relationship between social support and stress for mothers of children with autistic disorder. He found that informal support (support from spouses, the mother's relatives, other parents) is more important and leads to lower stress levels than formal support. Bristol (1984, cited in Weiss, 2002) found that mothers of children with autistic disorder who experienced the least stress were receiving the greatest support from their spouses or relatives. Furthermore, according to the results of several studies, mothers who perceived lower levels of support were the ones who had higher depression and anxiety scores (Boyd, 2002). The impact of informal support on reducing parenting stress was supported in a study with 68 parents (60 mothers and 8 fathers) of children with autism spectrum disorders (ASD) (Benson, 2006). Informal support was perceived more by parents of children with less severe symptoms. Also, while informal support was found to play an important role in reducing stress proliferation and depression in parents, formal support was not found to be a significant factor on these problems (Benson, 2006).

As previously stated, social support reduces family stress and encourages family members to function positively and cope well (Seligman & Benjamin - Darling, 1997). Studies showed that there is a strong association between low levels of support and psychological distress (Bromley et al., 2004; Hare et al., 2004). Cobb (1976, cited in Siklos & Kerns, 2006) defined social support as "information leading the person to believe that he is cared for and loved, valued and esteemed and is important in a network of mutual obligation and communication." Support from

one's spouse, family, friends, availability of leisure time, community programs, professional help and availability of services and programs can be examples of support (Siklos & Kerns, 2006).

Effects of social support and hardiness on the stress levels of mothers of 60 children with autistic disorder were assessed by Gill and Harris (1991). There were significant differences between mothers who perceived more support and those who did not. Stress-related somatic problems and depressive symptoms were fewer in mothers who received more social support. Hardiness was also found as a significant factor in adaptation to stressors. According to Gill and Harris (1991) if parents of autistic children can find philosophically comforting views, feel more efficient in parenting and view events as opportunities, the stressors they face can be lessened.

Extended family, especially grandparents, play a major role in the family's adaptation and can be a source of practical help and emotional support (Seligman & Benjamin - Darling, 1997). In his study with 165 mothers, Görgü (2005) stated that mothers who look after their child alone perceive less social support than mothers who look after their child with a spouse, with grandparents or with a babysitter. Although many families see relatives or friends as very supportive sometimes parents do not want to have informal support. In some cases this is done not to upset grandparents, in others, due to the fear of others' denial of the problem or rejection of the child (Seligman & Benjamin – Darling, 1997).

According to another survey of 219 parents of children with autistic disorder, parents who have access to other family members (grandparents, aunts, uncles and siblings etc.) for child care, have lower scores on depression, anxiety and daily level of stress than parents who do not have access to other family members (Sharpley,

Bitsika & Efremidis, 1997). Furthermore, if family members have a clear understanding of the child's condition and needs then parents are less anxious, depressed and have higher levels of confidence to handle the child's problems (Sharpley, Bitsika & Efremidis, 1997). In other words, when grandparents do not understand or accept the condition of the child, they become another source of stress and burden for the family (Seligman & Benjamin – Darling, 1997).

Dunst (1995, cited in Hecimovic, Powell & Christensen, 1999, p. 281) stated six major areas that family support programs should include. These are; enhancing a sense of community, mobilizing resources and supports, sharing responsibility and collaboration, protecting family integrity, strengthening family functioning and adopting proactive program practices. Hecimovic, Dowell and Christensen (1999) also mention family support services which are beneficial for parents. Financial assistance, parent education, respite care and transition planning are some of these effective programs for parents. Other variables can also have an effect on the perceived social support of mothers. For example, Görgü (2005) found that mothers who have high income levels perceive more social support than mothers who have lower income levels.

As cited by Preece and Jordan (2007) short breaks (respite care) services for children with autism spectrum disorders (ASD) have a positive impact on their parents. Parents who have limited informal support are suggested to use more short breaks than parents who have support from their families or friends. However, sometimes parents wait for years to receive those services and sometimes when they access services, because of behavioral problems, children are excluded from them. Preece and Jordan (2007) studied 256 families by using a postal survey to identify

why some families use these services and others do not. They hypothesized that non-users of short breaks had more support than users but this was not supported. Both groups were receiving little informal support. Their second hypothesis was that children of users were more dependent and this was supported. They also stated the differences between those groups. According to Preece and Jordan (2007) parents who do not have a social worker, whose child's age is under 11, in a mainstream educational setting and a diagnosis of autistic spectrum are less likely to receive such support.

Elçi (2004) examined ways of coping, social support and perceived stress levels in predicting burnout and posttraumatic growth levels of parents who have a child with autistic disorder. He found that both social support, coping styles and stress levels are important factors in burnout as well as posttraumatic growth of the parents. Only the stress level does not predict posttraumatic growth. So, it is important to help parents find themselves effective ways of coping and to direct them to social support groups or programs. All of these will help them to reduce their burnout (Elçi, 2004). "These groups provide a forum for catharsis, education, mutual aid and advocacy" (Seligman & Benjamin – Darling, 1997, p. 24).

Connecting with other parents experiencing similar problems via the internet is another support unit. Online connections are easier than face to face interactions and one may reach many parents from various reigions. Recently, e-mail groups or chat rooms have become very popular in Türkiye as well as in other parts of the world. Parents use these groups mostly "to gather information" and "share practical tips" (Wiseman, 2006). According to Seligman and Benjamin – Darling (1997),

support groups are a source of practical information and an opportunity to see others who are coping very well.

Parenthood Experiences

All mothers and fathers have dreams for their children even before they are born. With an unexpected and shocking condition like autistic disorder, those dreams may go upside down. Adapting to this new situation takes time and energy for the whole family. Sometimes this adaptation can never be achieved.

Hutton and Carron (2005) interviewed twenty-one parents (nineteen mothers and two fathers) about their children with autistic disorder. Experiences of parents were examined under three categories which were a) recognition and diagnosis, b) intervention services, and c) the impact of having a child with autism on their family. They found that most of the parents (twenty) had accepted the diagnosis of autistic disorder. However, the first reaction that they gave to the diagnosis was mostly "relief". Grief and loss, shock or surprise and self-blame came next. Siklos and Kerns (2007) assessed the diagnostic experiences of fifty-six parents of children with autism spectrum disorders. Although parents were aware of some of the problems of their children and sought help at the average age of two years four months, the formal diagnosis was obtained at the average of five years. This was also later for the girls which was six years old. Eighty two percent of parents found this process stressful and fifty one percent of parents were not satisfied with the diagnostic process (Siklos & Kerns, 2007).

Harrington, Patrick, Edwards and Brand (2006) stated the time between the parents' recognition of their child's problems and the diagnosis as nine months and

the age of the child's diagnosis as two years and three months. Young, Brewer and Pattison (2003) found similar results in their research. They stated that the recognition of abnormal developmental signs by 153 parents of children with autism spectrum disorders (ASD) was found as 15.1 months and the mean age of the diagnosis was found as 41.82 months. Delayed language, no attention to caregiver, poor socialization and tantrums/crying were found to be the most common unusual behaviors by parents of children with ASD respectively (Young, Brewer & Pattison, 2003).

In 1999, Midence and O'Neill conducted a pilot study with four parents about their experiences of having children with autistic disorder. Six categories were identified to explore these experiences: "behavior development," "confusion," "incorrect diagnosis," "autism," "support" and "acceptance/adaptation." In this study, all four parents were aware that there was something different in their child's development. They were not able to understand their children's behaviors and this confusion made them feel guilty, led them to blame themselves, led to problems within family or isolation from social life. During this pre-diagnosis stage all parents had told incorrect diagnoses like Fragile X syndrome or deafness. After that, the diagnosis of autistic disorder made all of them feel relieved. One parent said that "Well I think it was a relief for both of us to know he had autism. Once the diagnosis was made it did help. We felt better, I know that this is a horrible thing to say but if there is a label on the child, you know where to go for help. You have a new start, it was like he was born again." (Midence & O'Neill, 1999, p. 280). All parents in this pilot study accepted their child's condition and their positive hopes for the child's future never declined (Midence & O'Neill, 1999).

For parents it is very hard and sad to hear from a professional that their child has autistic disorder but they also feel relieved because they finally know their child's problem, why he or she acts like that. One mother said that "Once they told us it was autism, I knew what to do. I knew that I had to go to the library and read and find other people like us who had the same thing" (Schall, 2000, p. 415). Another mother of a child with autistic disorder also stated similar experiences in her book: "Although we were overwhelmed with grief, a part of me was relieved that at least we knew what was going on. He wasn't acting the way he did because I was a bad mother. R. couldn't help it; he had autism. We finally had our answer" (Hamilton, 2000, p. 26). Schall (2000) explains three parental experiences both within the family and outside world in detail. According to him for these parents having a diagnosis was an opportunity to learn about the disorder, search for answers and help.

Autistic disorder effects every member of the family deeply. The mother of an autistic child explains the effect of her child on their family as "It was really hard, it was extremely hard…on all of us" (Schall, 2000, p. 414). Caring for a special child requires 24 hours and 7 days supervision (Schall, 2000).

Too much social isolation is experienced by parents because of their child's behavioral problems, care burden or educational burden. Most parents' social life changes dramatically after the diagnosis. A mother of an autistic child states that "Our life is totally different now. Before (he was born) I had many friends and liked to socialize a lot and invite people to the house. But now it's not easy at all, and we haven't visited others to any extent either. Since if we do there's likely to be a battle

after half an hour so, it's just not possible" (Benderix, Nordström & Sivberg, 2007, p. 634).

Reading others' stories or successes can help the people in crisis. Sometimes people prefer to use the Internet to share their experiences. Fleischmann (2005) examined thirty – three websites prepared by parents of children with autistic disorder to share their experiences with an autistic child. Writing experiences on the Internet can be seen as a form of catharsis or a way of assisting others. The readers of those stories can save themselves from isolation by seeing other parents with similar experiences and lives (Fleischmann, 2005). "No one would wish autism on a person; no one would be pleased at the diagnosis. But when you come across someone else who is affected by the condition, you welcome the sense of relief that, after all, you are not alone. Someone else is going through what you're going through, and there is comfort in that shared experience" (Feeny, 2007, p. 206-207) says another mother of a child with autistic disorder.

There are also books in the literature written by mothers of children with autism spectrum disorders. To share their experiences with other people they told their stories in these books. Sometimes they just write about their child's developmental process and sometimes they give strategies or examples of activities that may help other parents at difficult times. A mother of an autistic son explains her stressful days while waiting for a diagnosis in her book with these words: " I am not me anymore. I lost six to seven kg. in a month… Most of the day, I have coffee and a cigarette in my hands… At nights I research or I cry. My husband is calmer because he does not believe that Ö. has autism…" (Kahraman – Küçükaras, 2005, p. 36). Another mother of an autistic boy describes the moment she heard the word autism

as a “shocking moment.” She continues with these words: “… after the shock we began to get informed. The first thing that I learned was there was no cure for autism, it was life-long. In other words R. will be a grown- up autistic someday. We felt that we lost him in those moments… we felt that our thoughts about him, our plans with him will never come true” (Penny-Benal, 2005, p. 7).

Maybe the most important problem for parents is the child’s “future.” Every parent who has a child with a disability experiences this anxiety. Parents of autistic children also worry about their children’s future life. Eren (1994) found that 59.3% of mothers and 83.3% of fathers stated that future anxiety is the most important problem for them.

Having a child with autistic disorder is not always negative. Parenting a child with special needs may also have positive effects on parents’ life. Sometimes they grow with them and have a new perspective on life (Schall, 2000). One mother said that “I think that you learn a lot as a human being by having a child with disabilities. You mature as a person and you get a totally new perspective on life” (Benderix, Nordström & Sivberg, 2007, p. 634). Another mother also said “…this child was given to us. Without this child I thought that I would have never noticed some of the idiosyncrasies of people that I noticed, and I think now are just character traits that are extremely interesting to me. I wouldn’t have noticed them at all” (Schall, 2000, p. 420).

Summary of Literature

Autistic disorder is a developmental disorder that mainly affects the social and communication skills of an individual. It can be seen in every culture, social

class or ethnicity. It is seen four times more in boys. The prevalence ranges between 4 to 5 in 1000. The probable causes of autistic disorder are still not known. However, neurological and genetic factors are found to be stronger reasons than environmental factors. There is no cure for autistic disorder, however, early identification and education can help children develop faster.

Autistic disorder is a life-long disability that affects every family member. Mothers are the ones who are most affected by this condition. They spend more time with their children and the heavy careburden of the child is on their shoulders. Studies have shown that stress among mothers of children with autistic disorder is very high. Mothers of children with autistic disorder also have higher depression scores than fathers of children with autistic disorder and mothers of children with other developmental disabilities like Down syndrome or intellectul disability.

Under these circumstances, the needs of mothers have to be taken seriously. If they are provided with support, mothers might be more likely to raise children in a less stressful way. This study does not only attempt to understand the experiences but also the needs, difficulties, support systems of mothers and the impact of their children on them as well as on their family, along with the future expectations for their children.

Research Questions

The study attempts to answer the following questions. In answering all these questions an attempt is made to understand whether mothers' experiences, stress levels and support systems relate to the symptom severity of the children.

A. Diagnosis:

1. When and how do mothers of children with autistic disorder first realize their children's difference?
2. When and by whom were their children diagnosed as having autistic disorder?
3. What were the feelings of mothers when their children were diagnosed by a professional?
4. What are the feelings of mothers now in regards to the diagnosis?

B. Mothering Role:

5. How do mothers whose children are diagnosed as having autistic disorder describe their mothering role?
6. How do mothers describe their mothering role for their children without disabilities?

C. Resources / Support:

7. What kind of support (emotional, informational, caregiving, intimate relations and financial) do mothers of children with autistic disorder utilize?

8. Does the support mothers feel change according to child and family (symptom severity, sibling number, school attendance, mothers' work status, mothers' educational levels) characteristics?
9. What kind of help (education, medication, alternative therapies etc.) do children with autistic disorder receive?
10. What do mothers do in coping with the difficulties of having children with autistic disorder?

D. Difficulties & Needs:

11. What are the unique difficulties mothers face in dealing with their children with autistic disorder?
12. What are the sources of stress (functional incapacitation, pessimism, and parent and family problems) that mothers of children with autistic disorder experience?
13. Do the stress levels of mothers change according to symptom severity, sibling number, school attendance, mothers' work status and mothers' educational levels?
14. What kind of support, resources and educational activities do mothers need in dealing with their children with autistic disorder?

E. Impact on Family:

15. What is the impact of having a child with autistic disorder on the mother?
16. According to the mother, what is the impact of having a family member with autistic disorder on the rest of the family?

F. Future Perspectives:

17. What are the expectations of mothers whose children were diagnosed as having autistic disorder for their children's future?

18. What are the messages of mothers whose children were diagnosed with autistic disorder for the society?

CHAPTER III

METHOD

In this section, the design of the study, sample, instruments, procedures and the analyses of the data are explained in detail.

Design

This research follows a descriptive design. Both qualitative and quantitative methods of data collection are used. Qualitative information is obtained through semi-structured interviews. Mothers are interviewed individually and their interviews are audio-taped with their permission. Quantitative information is collected by the Family Information Form for mothers (FIF), the Turkish short form of the Questionnaire on Resources and Stress (QRS-FT), the Family Support Scale (FSS) and the Childhood Autism Rating Scale (CARS).

Sample

Because mothers are the primary caregivers of their children, participants of this study are the mothers of children with autistic disorder. Thirty mothers whose children were diagnosed with autistic disorder and were aged between three to eight are our sample. Mothers with children around these ages tend to need more help and have more problems because the situation is relatively new for them.

Participants are drawn from the mothers who applied to receive special education for their children. Mothers were chosen on the basis of the availability and willingness to participate. All the mothers who were asked to participate accepted to

be part of the study. They were selected from five educational services in Istanbul which were; Özel Çocuk Educational and Psychological Counseling Center (n= 7), Ekim Educational and Psychological Counseling Center (n= 2), 8. Gün Special Education and Rehabilitation Center (n= 9), TODEV (Türkiye Otistiklere Destek ve Eğitim Vakfı) (n= 6) and TOHUM (Türkiye Otizm Erken Tanı ve Eğitim Vakfı) (n= 6). The two of them (TODEV and TOHUM) are the only foundations about autistic disorder in Istanbul. Other centers were chosen because we were able to establish collaboration with the professionals who work at these centers. To be included in the study, mothers had to have a child who had a formal diagnosis of autistic disorder and was between the ages of three and eight. Two children were excluded from the study because according to the results of CARS they were in the "not autistic" range. During the interview it was understood that the children had no other disorders, so there was not a comorbidity problem in the sample.

The mean age of mothers was 35.4 years and children's mean age was 5.4 years. Table 2 shows other demographic information about the sample. According to the results of Childhood Autism Rating Scale (CARS), children who scored less than 30 (which means non – autistic) were not included in this study. Sixty percent of children (n= 18) were in the mild to moderate form of autistic disorder and forty percent of children (n= 12) were severe. Boys (n= 23) were more than girls (n= 7) as expected. Only thirty percent of children (n= 9) were attending school. Thirty three point three percent of mothers (n= 10) had graduated from primary school, thirty percent of mothers (n= 9) had graduated from university and twenty three point three percent of mothers (n= 7) had graduated from lycee. One of them had completed her doctorate and two of them had graduated from secondary school. Only one mother

had received no education. From those mothers forty percent were not working, forty three point three percent had worked before. Only five mothers were currently working. All parents were married except one mother who was divorced. Half of the children (n= 15) did not have a sibling, thirty six point seven percent (n= 11) had only one sibling and thirteen point three percent (n= 4) had more than two siblings. Fifty percent of children were the only child, ten percent (n= 3) were the first child, twenty three point three percent (n= 7) were the second child and thirteen point three percent (n= 4) were the third child.

The economic status of parents was also rated by mothers from 1 (low) to 10 (very high). More than half of the mothers rated their economic status as middle and nearly 27% of mothers rated their economic status as high middle. Thirteen point three percent of mothers (n= 4) stated that there is someone at home living with them, these people were mostly grandparents. According to twenty percent of mothers there is someone in the family who has similar problems, but no mother stated any other autistic person in their families.

Table 2: *Demographic characteristics of the sample*

	f	%
Symptom severity		
Mild-moderate	18	60.0
Severe	12	40.0
Gender		
Girl	7	23,3
Boy	23	76,7
School attendance		
No	21	70
Yes	9	30
Mother's education		
No education	1	3,3
Primary	10	33,3
Secondary	2	6,7
Lycee	7	23,3
University	9	30
Doctorate	1	3,3
Mother's Work Status		
Not working	12	40
Working	5	16,7
Worked Before	13	43,3
Marital Status		
Married	29	96,7
Divorced	1	3,3
Sibling		
No sibling	15	50
1 sibling	11	36,7
2 siblings	4	13,3
Birth Order		
Only	15	50
First	3	10
Second	7	23.3
Third	4	13.3
Economical Status		
Low (3-4)	3	10
Middle (5-6)	19	63,3
High (7-8)	8	26,7
Other people living with the family		
No one	26	86,7
Someone	4	13,3
Similar problems in the family		
No	24	80
Yes	6	20

Instruments

The Family Information Form (FIF), the Childhood Autism Rating Scale (CARS), Semi – Structured Interview (SSI), the Questionnaire on Resources and Stress – F (QRS-FT) and Family Support Scale (FSS) are used in the study.

Family Information Form (FIF)

The Family Information Form (Appendix B, see also English version in Appendix C) was developed by the researcher to obtain basic descriptive information about the sample. Family information data includes questions concerning the mother's age, marital status, education, occupation, number of siblings and family income. Additional questions concern the child's age and sex, people who live in the same house and other people having similar problems. Family information received from the FIF is summarized in the sample section.

Childhood Autism Rating Scale (CARS)

In 1971, Reichler and Schopler developed the Childhood Psychosis Rating Scale (CPRS) to classify autistic children. They used the term "psychosis" rather than "autism" to reflect a broader conceptualization than Kanner's classic definition. Then, in 1980, after the definition of autistic disorder expanded, they changed the name into "Childhood Autism Rating Scale" (CARS) (Appendix D, see also English version in Appendix E) (Schopler, Reichler, DeVellis and Daly, 1980).

CARS includes both the definitions of Rutter and Ritvo & Freeman of autistic disorder (1978, cited in Schopler, Reichler, DeVellis & Daly, 1980). It consists of

fifteen scales, namely; impairment in human relations, imitation, inappropriate affect, bizarre use of body movement and persistence of stereotypes, pecularities in relating to nonhuman objects, resistance to environmental change, pecularities of visual responsiveness, pecularities of auditory responsiveness, near receptor responsiveness, anxiety reaction, verbal communication, nonverbal communication, activity level, intellectual functioning and general impressions.

Based on the clinician's observations or parent report the child is rated on each subscale (Ventola, Kleinman, Pandey, Barton, Allen, Green, Robins & Fein, 2006). Each scale is scored from normal (1) to severely abnormal (4). One point means that the child's behaviour is normal. Two points mean mildly abnormal, three points mean moderately abnormal and four points mean severely abnormal. The total score ranges from 15 to 60, where a child whose total score is less than 30 is not autistic, a score between 30- 36 is mild to moderate, and if a child's score is more than 36, is severely autistic (Schopler et. al., 1980).

The reliability coefficient alpha of CARS was .94 which is highly reliable. Also .71 interrater reliability was obtained. For the validity of CARS, total scores were compared to clinical ratings. The correlation was $r=.84$, $p<.001$. Also total scores were correlated with independent clinical assessments made by a child psychiatrist and a child psychologist. These correlations were $r=.80$, $p<.001$ which indicates that CARS is a valid instrument (Schopler et. al., 1980).

The Turkish translation, reliability and validity studies of CARS have been done by Sucuoglu et al. in 1996 (cited in Motavalli Mukaddes, Kılınçaslan, Küçükyazıcı, Sevketoğlu & Tuncer, 2007). Twenty three autistic children aged between 5 to 15 years were the sample. Reliability studies for internal consistency

revealed that the cronbach's alpha was .86. ıtem-total correlations were between .60 and .91 except item 14. Discriminant validity studies showed that $p<0.05$ for 11 items and $p<0.05$ for 3 items (Motavalli Mukaddes et. al., 2007).

This instrument requires clinician's observations or parents' reports. In this study, observation of the child was made in waiting rooms of settings before the child's therapy session began. Then the researcher asked mothers the questions of CARS. The results of the CARS were shared with the child's psychologist or educator. There was no disagreement between the researcher and the psychologist or the educator of any of the children.

Semi-Structured Interview (SSI)

A Semi-structured interview (Appendix F, see also English version in Appendix G) was developed by the researcher to be used with mothers. Detailed information about their children, mothers' needs, experiences, expectations for their children's future, coping strategies and messages for the society were asked in these interviews.

Before implementing the interviews, three special education specialists were consulted about the questions. It was pilot tested with three mothers to confirm that the questions were clearly understood by them. It took fifteen to thirty minutes to complete the interview. Mothers, in face-to-face interaction, were given information about the aim of the study and how long the interview would take. Also an information letter (Appendix A) which explains the purpose of the study, the interview questions, the way the data would be collected was given to mothers.

Responses were audiotaped with the permission of the mothers to be analyzed later by the researcher.

Questionnaire on Resources and Stress – F (QRS-FT)

The Questionnaire on Resources and Stress (QRS) was developed by Holroyd in 1974 to investigate the perceived familial stress of those who have disabled children (Appendix H, we were unable to obtain the original English version of this measure). It consisted of 285 items and 15 subscales. Then in 1987, Holroyd developed a shorter form of QRS which had 66 items. Friedrich and his colleagues (cited in Kaner, 2002) developed another shorter form of QRS in 1983 which had more powerful psychometric properties and called it QRS-F. The QRS-F had 52 items and 4 factors.

In Türkiye, Akkök (cited in Kaner, 2002) translated and adopted the QRS into Turkish in 1989. However, the reliability and validity studies of QRS were done by Küçüker (cited in Kaner, 2002) in 1999 with 190 parents who had disabled children aged between 0-5. After factor analysis, 49 items and 4 factors were found.

Kaner (2002) conducted the reliability and validity studies of QRS-F with a wide age range and with various kinds of disabilities with 622 parents. After factor analysis, Kaner found that QRS-F had 39 items and 3 factors which were conceptualized as functional incapacitation (item numbers: 1, 6, 13, 15, 17, 20, 22, 26, 28, 29, 30, 31, 32, 36, 37, 39), pessimism (item numbers: 3, 4, 5, 8, 9, 19, 21, 23, 24, 25, 27, 33, 34, 35, 38), and parent and family problems (item numbers: 2, 7, 10, 11, 12, 14, 16, 18). She named the Turkish form of QRS-F as QRS-FT. The reliability of QRS-FT was measured by KR-20, Cronbach alpha and Spearman-Brown techniques. Total reliabilities of QRS-FT were .92, .91 and .89 respectively.

High scores in QRS-FT indicate more stress. True answers get point (1) and wrong answers get no (0) point. Items (6, 11, 13, 14, 15, 19, 20, 23, 26, 28, 30, 31, 32, 36, 39) are graded inversely.

Family Support Scale (FSS)

The Family Support Scale (FSS) was developed by Kaner (2003) to investigate the perceived social support of parents' with disabled children (Appendix I). There are 34 questions in the scale. For each item, choices are grouped in three categories: "Always" (3), "sometimes" (2) and "never" (1). One may get a maximum of 93, a minimum of 31 points from the scale. The last three questions give qualitative information about the support systems of parents and are not included in the scoring. Getting a high score from FSS means that parents have the support systems that they need. On the other hand, getting a low score means that they do not have these support systems.

After factor analysis, 5 factors were found which were named as "emotional support" (item numbers: 1, 2, 3, 4, 5, 6, 7, 8, 9), "informational support" (item numbers: 11, 24, 25, 26, 27, 28, 29, 30) "caregiving support" (item numbers: 10, 12, 18, 22, 31), "intimate relations support" (item numbers: 13, 14, 16, 19, 20, 21) and "financial support" (item numbers: 15, 17, 23).

The results of reliability studies showed that the internal consistency and test-retest reliabilities of both total and subscale scores were quite high. For the total test Cronbach alfa was .95, also test-retest correlation coefficients ranged from .95 - .99. The time intervals were not stated in the study.

Procedures

Participants of the study were reached through the professionals who work with them. Initial contacts with mothers were made face to face when they came to the educational center. They were given information about the aim of the study, how long the interview would take and under what conditions. There was no mother who did not want to participate. Mothers who agreed to take part in the study were interviewed and given the questionnaire packages with a brief covering letter explaining the rationale of the study. The package included measures to assess support, stress levels as well as a family information sheet. After the interview mothers completed these questionnaires. Only in one educational center the professional wanted to inform parents before the researcher met them face to face.

Mother and children names were not included in the study, an id number was assigned to each interviewee.

Data Analyses

Interviews were audiotaped with the permission of participants. Responses to interview questions were first transcribed and then read by the researcher to be grouped into categories according to their thematic similarity. So the analyses of the qualitative data were done by conceptual analysis.

For the quantitative data (questions 7, 8, 12 and 13) results were examined through descriptive statistics (means, standard deviations and frequencies) and non-parametric group comparisons (Mann Whitney U test and Kruskal Wallis test). The quantitative data was analyzed using the SPSS 16.0 statistical package, and $p < 0.05$ was considered to be statistically significant.

CHAPTER IV

RESULTS

This section is organized in the order of the research questions. It covers the responses of mothers to the interview questions and the results of the questionnaires.

Diagnosis

Research Question 1: When and how do mothers of children with autistic disorder first realize their children's difference?

Interview question 1: "When and how was it first understood that your child was different?

Mothers mostly said that they realized their children's difference between one to three and a half years of age. They mostly suspected because of their children's communication problems and when their children did not respond to their names. Not being interested in other people, not having eye contact, prefering to be alone, watching too much television, stereotypes or obsessions and not playing with toys or playing with them inappropriately were mentioned as the problem behaviors of children. Also, being hyperactive, having sleep problems, crying too much, lack of imitative play, tiptoe walking, losing words while having some and not signing objects were other things they realized in their children. Having another child was helpful in realizing that something was different in their children because mothers had an opportunity to compare their children's development with others.

> We understood it when he was two and a half years of age. He was turning around himself, walking on tiptoe and he was not talking. He had no communication, so we understood he was different. (Id no: 11)

> She was one and a half years old and she had obsessions. She walked around with an object in her hand. She was not playing with toys. (Id no: 19)

Research Question 2: When and by whom were their children diagnosed as having autistic disorder?

Interview question 2: "When and by whom was your child diagnosed as autistic?"

Nearly half of the mothers took their child to a child neurologist or psychiatrist at least 6 months and at most two and a half years after their first recognition of a problem. They claimed that waiting this long could be due to not accepting the problem and other people's belief that "boys talk later" and it is natural that they have delayed speech.

Sometimes parents waited until their child became 3 years of age because when the child is little it is sometimes impossible to give a diagnosis. Professionals prefer to wait to give an exact diagnosis until that age but all propose starting special education without waiting. Late diagnosis does not only result from parents' late application to a professional but also from the misdirection of some doctors like, "he will talk, wait" or "nothing is wrong with him, my daughter talked at age 4, too" due to their insufficient information about autistic disorder.

Research Question 3: What were the feelings of mothers when their children were diagnosed by a professional?

Interview question 3: "What did the diagnosis make you feel? What were your feelings?"

Mothers stated that after diagnosis they felt very sad and bad. Some of them had not known what autistic disorder was so they began searching for information or thought of it as a disorder that would soon pass. Disappointment, fear, shock and

collapse were the other feelings they had in the beginning. One mother after two years still uses antidepressant to feel better.

> … after the diagnosis you feel very sad, the worst stories that you see from your environment or movies come into your mind. You feel anxious about your child's future. For a second you visualize his future. He is only two years old but you begin to think his 20s, 40s and 60s. But then acceptance takes place… (Id no: 9)

> At the beginning I thought that she would be okay after six months of intervention or I just convinced myself so. But now we're in an endless marathon. When we saw her agemates we felt very disappointed but we love her so much. We do whatever we can do for her to be better. (Id no: 15)

Research Question 4: What are the feelings of mothers now in regards to the diagnosis?

Interview question 3: "What are your feelings now in regards to diagnosis?"

Some mothers said that they are still sad but some said that they got used to it and accepted their child. Mothers have mood changes, they feel better sometimes and worse at other times. When they see differences or development in their children they feel better.

> I did not know what autism was. So I did not understand anything. I thought it was a disorder that would be cured with medication. But after I read and understood I felt very sad. I am now used to it but I still do not accept it. (Id no: 6)

> When we first heard of it of course we felt very bad. It took years to get used to it. Now we have overcome it, we struggle and try to learn. We try to be helpful to him but at first it was really bad. (Id no: 11)

Mothering Role

Research Question 5: How do mothers whose children are diagnosed as having autistic disorder describe their mothering role?

Interview question 11: "How does it feel to be the mother of (child's name)? Could you describe?"

Mothers also described their feelings about their children who have autistic disorder. Most of them described it as a nice, wonderful and special experience.

M is the most beautiful girl in the world. I'm very sad for her but I will never abandon her. She is my silent princess. (Id no: 15)

Very hard. I love my son, he is my everything. I'm very proud of being his mother, but it is also very hard to be his mother. (Id no: 8)

For some mothers there was no difference between being the mother of a normal child or a special child. Nearly two thirds of mothers found it very hard to be the mother of a special child. One mother said that she did not want to be the mother of a special child.

Research Question 6: How do mothers describe their mothering role for their children without disabilities?

Interview question 10: "How does it feel to be the mother of (sibling's name)? Could you describe?"

We asked this question only to mothers who had other children. Nearly half of the children (n=14) had siblings. All of these mothers who have other children described their mothering role as very nice, wonderful. They felt proud of their children without any disabilities or found themselves very lucky. One mother said that because of her autistic daughter she could not show her other children any love.

Resources or Support

Research Question 7: What kind of support (emotional, informational, caregiving, intimate relations and financial) do mothers of children with autistic disorder utilize?

Interview question 4: "Who has the responsibility of the child in your family? Are these responsibilities shared? If so, how?"

The responsibility of the child was mostly on mothers. More than half of the mothers agreed on this. Others share it with fathers, grandparents and babysitters or relatives like aunts. This is the result of working fathers, as mostly stated by mothers. Because fathers go to work in the morning and come home at night very tired, mothers have all the careburden of their child.

Usually it is on me. His father comes home late because he is working. He is tired so he cannot spend lots of time with him, if he can, it is only an hour. (Id no: 1)

It is only on me. There is no shared responsibility. (Id no: 11)

We share it with my husband. We also have two very good helpers. Furthermore with my mother's unbelievable support we share M's responsibilities. I make the organisation. One of us for her special education and another of us for her cleaning. One of us wait her at nights if she does not sleep. (Id no: 15)

Interview question 6: "If there are people or organizations that support you, who are they, what are they?"

More than half of the mothers said that there is nobody to help them. For other mothers, grandparents and educators were very helpful. Few mothers said their child's foundation which gave a scholarship was very helpful. The government in Turkiye gives 6 hours of free individual therapy and 4 hours of group therapy monthly for children who have a diagnosis of autistic disorder (Rehberlik Araştırma Merkezleri, 2007). But, if the child goes to school, then his or her therapy sessions decrease to only 6 hours of individual therapy. Although the number of sessions are very few and not enough for those children, parents with financial problems still use these services.

(Family support scale)

The Family Support Scale (FSS) was used to investigate mothers' support systems in their lives. As Table 3 shows the mean score of mothers from total FSS was M= 72. 96 which means that mothers perceive some support but not much (one may get minimum 31 and maximum 93 points from FSS). Mothers perceive emotional support the most (M= 2.49). Next was intimate relations support (M= 2.43) and the third one was informational support (M= 2.30). According to mothers, financial support (M= 2.27) and careburden support (M= 2.12) were perceived the least.

Table 3: *The means and standard deviations of the mothers from Family Support Scale*

Mean Scores	M (SD)
Emotional support	2,49 (0,44)
Intimaterelations support	2,43 (0,50)
Informational support	2,3 (0,51)
Financial support	2,27 (0,66)
Caregiving support	2,12 (0,59)
Total	72,96 (13,2)

Note: Ranges were 1 to 3.

Research Question 8: Does the support mothers feel change according to child and family (symptom severity, sibling number, schooling, mothers' work status, mothers' educational levels) characteristics?

Mothers of children with severe autistic disorder tended to have slightly higher mean rank (M= 15.92) than mothers of children with mild to moderate autistic disorder (M= 14.88) (Table 4). However, this was not statistically significant.

Table 4: *Mann Whitney mean rank differences in Family Support Scale scores of mothers by children's symptom severity*

	Severity	N	Mean rank	z	U	p
FSS	Mild-moderate	18	15,92	-.318	100,5	.751
	Severe	12	14,88			

As shown in Table 5 it was found statistically significant that mothers who have one other child have the highest mean rank (M= 17.59) from FSS. Also mothers who have no other child have higher mean rank (M= 16.73) than mothers who have two other children. Mothers who have two other normally developing children have the least mean rank (M= 5.12) from FSS.

Table 5: *Kruskal Wallis mean rank differences in Family Support Scale scores of mothers by siblings*

		N	Mean rank	Chi-square	p
FSS	no sibling	15	16,73	6,48	.039
	have one sibling	11	17,59		
	have two siblings	4	5,12		

Whether a mother is working or not has been found to be statistically significant for the total score of support systems (Table 6). Working mothers had the highest mean rank from FSS (M= 23.50) where non-working mothers had the lowest mean rank (M= 10.46). Mothers who had worked before (M= 17.08) were between these two groups in terms of their perceived support systems.

Table 6: *Kruskal Wallis mean rank differences in Family Support Scale scores of mothers by working status of mothers*

	Work status	N	Mean rank	Chi-square	p
FSS	Not working	12	11.46	8.49	.014
	Working	5	23.50		
	Worked before	13	17.08		

Mothers of children who go to school tended to perceive more support (M= 17.06) as shown in Table 7 than mothers of children who do not go to school (M= 14.83). However, this tendency was not statistically significant.

Table 7: *Mann Whitney mean rank differences in Family Support Scale scores of mothers by schooling*

	School	N	Mean rank	z	U	p
FSS	no	21	14.83	-.63	80.50	.52
	yes	9	10.00			

Mothers who had higher levels of education (lycee, university and doctorate) tended to have higher mean rank of support (M= 18.21) than mothers who had lower levels of education (no education, primary and secondary school) (M= 11.96) (Table 8). Again, this tendency was not statistically significant.

Table 8: *Mann Whitney mean rank differences in Family Support Scale scores of mothers by education levels of mothers*

	Education level	N	Mean rank	U	p
FSS	Lower	13	11.96	64.50	.054
	Higher	17	18.21		

Research Question 9: What kind of help (education, medication, alternative therapies etc.) do children with autistic disorder receive?

Interview question 5: "What kind of help (education, medication, alternative therapies etc.) has your child received so far? What were the benefits of each?"

As mothers said, after diagnosis all children began to take special education. Some children took individual therapy once a week and some of them took two, three or more. After special education mothers stated other intervention methods, like sensory integration therapy and speech therapy. Alternative methods like the gluten-casein diet was used by few mothers and vitamins, acupuncture, physiotherapy and pony riding by some others. For behavioral problems, hyperactivity or attention problems medications were used by nearly half of the children. Mothers found every therapy method that they used helpful for their children especially special education.

Research Question 10: What do mothers do in coping with the difficulties of having children with autistic disorder?

Interview question 9: "Are you able to do things to feel better, to relax? If yes, what? If no, what would you have liked to do?"

More than half of the mothers did not have any time for themselves. All those mothers stated that they just wanted to go walking alone, to rest at home, be with friends and sleep. Some of those mothers who did not have any opportunity to relax did not want to have any time for themselves. This may be because they feel guilty when they have some extra time without their children.

Mothers who have an opportunity to relax are the ones whose children go to school, or who can leave their children to others like babysitters or grandparents.

They prefer to be with friends, go shopping, listen to music, watch tv, do sports, start a masters degree and take walks.

I always have question marks in my head. If I'm alone, he is always on my mind. I always compare him with other kids. I don't want that free time. I think of him more than I think of myself. (Id no: 6)

No, I don't have free time, I would like to relax without thinking about anything. (Id no: 12)

My husband helps me a lot so I can relax. Sometimes our friends visit us or we go out to dinner with them. But of course this happens less than before. Or sometimes I go shopping. (Id no: 17)

Difficulties and Needs

Research Question 11: What are the unique difficulties mothers face in dealing with their children with autistic disorder?

Interview question 7: "As the mother of (child's name) which issues/situations do you struggle the most with?"

Raising a child with autistic disorder effects mothers' lives from many perspectives. According to them their children's communication problems effect them the most. If the child is not talking it is very hard for them to understand his or her needs and problems. Second, they have problems outside the home because of the child's behavioral problems like aggression, hyperactivity or obsessions. Others' reactions and questions about the child's behaviors also make them feel sad. Because of the invisibility of autistic disorder some people do not understand the child's seemingly odd behaviors.

Communication problem… sometimes we cannot understand what she wants or what she needs. You cannot know if she has any trouble. (Id no: 26)

When we go somewhere like home visiting he reacts too much, he doesn't want to go and cries. Then it becomes a torture to me. (Id no: 7)

Sleep problems, fears, passivity, eating problems and toilet training were other difficulties that mothers face. Also, two mothers stated the need for a school for their children. They cannot find preschools or primary schools that accept their children.

Research Question 12: What are the sources of stress (functional incapacitation, pessimism, and parent and family problems) that mothers of children with autistic disorder experience?

(Questionnaire on resources and stress)

The Questionnaire on Resources and Stress (QRS-FT) was used to see the stress sources of mothers of autistic children. The questionnaire included three factors which were; pessimisim, functional incapacitation and parent and family problems.

As Table 9 shows the mean total score of mothers from QRS-FT was M= 20 which means mothers of children with autistic disorder perceive middle levels of stress (one may get minimum 1 and maximum 39 points from QRS-FT). Among the three factors, the highest mean score of mothers was from the pessimisim factor (M= .61). The functional incapacitation factor (M= .46) came next. Mothers perceived parent and family problems (M= .42) as the least stress factor among all of them.

Table 9: *The means and standard deviations of the mothers from Questionnaire on Resources and Stress*

Mean Scores	M (SD)
Pessimisim	.61 (.22)
Functional Incapacitation	.46 (.19)
Parent & Family Problems	.42 (.25)
Total	20 (7)

Note: Ranges were 0 to 1.

Research Question 13: Do the stress levels of mothers change by symptom severity, sibling number, schooling, mothers' work status and mothers' educational levels?

A comparison of the total scores of mothers from QRS-FT with children's severity of symptoms were not found to be statistically significant (Table 10). However, mothers of children with mild to moderate autistic disorder tended to have lower mean ranks (M= 13.17) than mothers of children with severe autistic disorder (M= 19.00).

Table 10: *Mann Whitney mean rank differences in Questionnaire on Resources and Stress scores of mothers by severity of child's symptom*

	Severity	N	Mean rank	z	U	P
QRS-FT	Mild-moderate	18	13.17	-1.78	66.00	.075
	Severe	12	19.00			

As shown in Table 11 it is found statistically significant that mothers who have two other children who are developing normally have higher levels of stress (M= 24.00) than mothers who have one other normally developing child (M= 17.59) and mothers who do not have any other children than their children with autistic disorder (M= 11.70).

Table 11: *Kruskal-Wallis mean rank differences in Questionnaire on Resources and Stress scores of mothers by sibling*

	Sibling	N	Mean rank	Chi-square	p
QRS-FT	No sibling	15	11.70	7.18	.02
	One sibling	11	17.59		
	Two siblings	4	24.00		

It is also found statistically significant that mothers of children with autistic disorder who go to school have lower levels of stress (M= 10.00) than mothers of children who do not go to school (M= 17.86) (Table 12).

Table 12: *Mann Whitney mean rank differences in Questionnaire on Resources and Stress scores of mothers by school attendance*

	School	N	Mean rank	z	U	p
	no	21	17.86	-2.24	45.00	.025
QRS-FT	yes	9	10.00			

Mothers who do not work have higher mean ranks for their total score of stress (M= 19.88) than mothers who had worked before (M= 13.38) and mothers who still work (M= 10.50) (Table 13). But this finding between mean ranks was not found to be statistically significant.

Table 13: *Kruskal Wallis mean rank differences in Questionnaire on Resources and Stress scores of mothers by working status of mothers*

	Work status	N	Mean rank	Chi-square	p
	Not working	12	19.88	5.35	.069
QRS-FT	Working	5	10.50		
	Had worked	13	13.38		

Mothers' education levels' total scores from QRS-FT were analyzed through the Kruskal Wallis test. As shown in Table 14, mothers who have lower levels of education (no education, primary and secondary education) tended to have higher mean rank scores (M= 18.96) than mothers who have higher levels of education

(lycee, university and doctorate) (M= 12.85). But these tendencies were not statistically significant.

Table 14: *Mann Whitney mean rank differences in Questionnaire on Resources and Stress scores of mothers by mothers' education levels*

	Education level	N	Mean rank	U	p
QRS-FT	Lower	13	18.96	65.50	.059
	Higher	17	12.85		

Research Question 14: What kind of support, resources and educational activities do mothers need in dealing with their children with autistic disorder?

Interview question 8: "What kinds of support, resources, help or education would you have liked to receive to better contribute to your child? What are your needs?"

The needs of mothers vary according to their child. Mothers mostly need more education for their child. Because of economic difficulties, mothers do not have the opportunity for more therapy sessions. They also need education for themselves. They want to be more educated about autistic disorder. One mother stated the need for psychological counseling. The others mostly stated the need for an appropriate preschool or primary school that accepts these children. Home teacher, speech therapist and early identification of autistic children were also stated as needs by mothers. Furthermore, two mothers wanted a map for their long roads because at the beginning they did not know what to do, whom to apply to or whom to ask.

I would like to take him to a speech therapist and increase his individual therapy sessions. (Id no: 6)

I need psychological counseling too but I do not have time for this. I would like to talk more with someone. I would like to learn from professionals how I should

treat him. This must be done systematically. He takes education three times a week, during those times we could have education as well. (Id no: 14)

Some mothers did not state any need. Those were the ones who have an opportunity to do research about autistic disorder from books and via the internet.

Impact on Family

Research Question 15: What is the impact of having a child with autistic disorder on the mother? *Interview question 12: "How did becoming the mother of (child's name) influence you and your life in positive or negative ways?"*

Mothers mostly stated the negative aspects because these were present more than the positive aspects. Most mothers stated that their social life had changed dramatically. Few of them said that they became autistic too. They had no social lives any more. They spent all their time with their children. They could not go outside, spend time with friends or with their husbands. One mother left her work though she had originally planned to return after birth. And one mother changed her position at work and started a new position which has more flexible times and less work burden.

I have no life anymore. I must always be with him. It is very hard to go somewhere with him. You do not have any social life. (Id no: 19)

Before we had a social life. I woke up happily. Now I don't have any social life. I do not remember the last time I went to the cinema. However, I have learned not to be sad for simple things. Maybe it has made us tough. (Id no: 12)

Research Question 16: According to the mother, what is the impact of having a family member with autistic disorder on the rest of the family?

Interview question 13: "What is the impact of (child's name) on your family?"

According to most mothers, other than themselves all member of the family including their husbands are influenced by their child's autistic disorder negatively. However, some mothers also stated that no one was affected by the situation. Those mothers who spent their whole time with their children were the most affected. Sometimes because fathers did not accept their children's disorder they rejected the situation but they were helpful to mothers. Fathers who went to work in the morning and came home late were not helpful because of their limited time. One mother said that because of their child she and her husband did not have any time to share alone.

Furthermore, mothers sometimes prefer not to tell grandparents or relatives about their children's disorder in order not to upset them or because they think that those people cannot understand the condition and it would be hard to explain to them.

Future Perspectives

Research Question 17: What are the expectations of mothers whose children were diagnosed as having autistic disorder for their children's future?

Interview question 14: "What are your expectations for your child's future?"

Like all mothers, mothers of children with autistic disorder have expectations for their children. Unlike mothers of normally developing children, mothers of children with special needs firstly and mostly want their children to live independently by themselves, go to a store alone, live alone and protect themselves from harm.

They also want their children to be normal, to go to school, to talk, to have jobs and be healthy and happy persons. One mother said that she did not make any

plans for the future, this may be the result of being afraid of disappointment. (Id no: 20)

(mother cries) In three years, I want him to be indistinguishable from his agemates at first sight. (Id no: 10)

I want him to live independently, have a healthy and happy life. (Id no: 26)

I only want him to be healthy, live alone without being dependent on others, what else can I say… (Id no: 30)

Research Question 18: What are the messages of mothers whose children were diagnosed with autistic disorder for the society?

Interview question 15: "If you had the chance, what would you like to say to everyone as the mother of (child's name) regarding your experiences? (Let's assume the public is listening to you, what would you tell them? Would you like to say something to people about your expectations from them?) What?"

While having lots of problems in their lives mothers also face problems in the outside world. When we asked what they would want from other people they mostly said that they wanted them to be more understanding, supportive and empathic. They also added that it might happen to them, as well. Mothers were mostly disturbed by the way other people looked. They wanted them to be aware of autistic disorder and accept those children.

One mother told other mothers to raise conscientious children who would not discriminate people on differences. Another mother also wanted others not to label those children. According to her because of labeling, people do not give opportunities to those children. Two mothers also warned other mothers for early identification of autistic disorder and the positive effect of education on those children.

People must be supportive instead of judgmental. As a society we all have to learn to be empathic. (Id no: 26)

I would say it will happen to you too. (Id no: 3)

When we get on a bus if my child cries or shouts people around us look at us strangely. I want them to be more understanding. It can happen to anyone. (Id no: 19)

Summary of Results

The results of this study showed that there is a significant amount of time between mothers' first recognition of something different or problematic in their children and their application to a professional. Most mothers felt very sad when they heard the diagnosis and some still feel the same. Mothers did not describe any difference in their mothering roles to their children with autistic disorder and their normally developing children. However, some of them found being the mother of an autistic child very hard.

The responsibility of children was mostly on the mothers. There was not much support from an institution or people around them. Because of these mothers did not have any free time to relax. Children's communication and behavioral problems were the most commonly stated difficulty that they had to cope with. All children were receiving special education while some others were also undergoing other therapies like speech or sensory integration therapy. The needs of mothers were about their children like more therapy sessions, school and other educational services.

Being the mother of a child with autistic disorder effected all mothers and other family members negatively. Especially mothers' social lives changed dramatically. Mothers expect their children to live independently and to be healthy.

Also they expect other people to be more understanding, empathic and aware of autistic disorder.

Mothers perceived middle levels of stress and support. Mothers whose children go to school had lower levels of stress than mothers whose children do not go to school. Also, mothers who had more children perceived more stress. But, mothers who had two children perceved more support than mothers who had only one child or three children. Furthermore, working mothers perceved more support than mothers who had worked before and who were currently not working.

CHAPTER V

DISCUSSION

There are some studies in Türkiye on mothers of children with autistic disorder, Down syndrome or other childhood disorders. However, none of these studies have given mothers an opportunity to tell their stories in terms of the needs, experiences and difficulties of raising a child with special needs. Thus, the aim of this study was to understand mothers of children with autistic disorder, to explore their needs, experiences, difficulties, stress levels and supports.

Our interview analyses showed that mothers recognized something different or problematic in their children between one to three and a half years of age due to their lack of communication, or behavioral and social problems. Communication problems were the most often stated problem behavior of their children. This finding shows us the priorities of our society in the development of children. Not talking, not having eye contact, stereotypical behaviors, prefering to be alone and tiptoe walking were stated by mothers as the different or problematic behaviors of their children.

Nearly half of the mothers applied to a professional between six months and two and a half years later. This finding of time lag was consistent with the previous studies (Harrington, Patrick, Edwards & Brand, 2006; Siklos & Kerns, 2007; Young, Brewer & Pattison, 2003). The delay could be due to several reasons, including denial of the problem, ignorance about disabilities, social beliefs like “boys talk late” and misdirections of pediatricians. Pediatricians who serve all parents should have adequate educational preparation to recognize disorders. They may use M-CHAT (Modified Checklist for Autism in Toddlers) or observe the key features of autistic disorder in children or ask parents questions not only about children’s physical

development but also about their social and communication development (Korkmaz, personal communication). In my own experiences with parents of children with autistic disorder, I notice that because of ignorance, even parents who are pediatricians or teachers apply to professionals very late. Furthermore, the invisibility of the condition and children's surprising abilities leave parents to face the dilemma of accepting or denying the problem.

Like every mother of a child with special needs, mothers of children with autistic disorder felt very sad when they heard the word "autism" from a professional. Some of them stated their feelings with the words "shock," "collapse" and "crashing a wall." In contrast to the findings of Midence & O' Neill (1999), Schall (2000) and Hutton and Carron (2005), mothers in our study did not state any feeling of "relief" after hearing the diagnosis, which means there was denial and wishful thinking that all would get better and problems would disappear. "Time will heal everything" does not describing every mothers' emotions. Some mothers were still feeling like the first day, while others were used to it.

Most mothers described their mothering roles for their normally developing children and their children with autistic disorder as very nice and special. They added that there was no difference in terms of loving, caring and supporting them. This finding can be due to "social desirability." Maybe saying something like "it is very difficult and stressful" or "I wish I was not his or her mother" can make mothers feel guilty. However, some mothers found being the mother of a child with autistic disorder hard and stressful. Only one mother stated that she did not want to be the mother of her child with autistic disorder.

In Türkiye, the responsibility of children is mostly on mothers, this is the same for both normally developing children and children with special needs. Our study supported this statement as well. Most mothers stated that they had all the responsibility of their children and added that there was no caregiving support for them. This can be the result of both fathers' work burden and financial problems. Sharing the responsibility of the child is very helpful and important for all members of the family. This lessens the careburden of the child so no one gets tired, exhausted or depressed. As it is shown by many studies, mothers who have more support systems have lower levels of stress (Benson, 2006; Boyd, 2002; Bristol, 1984; Sharpley, Bitsika & Efremidis, 1997). Most mothers did not state any support from people or organizations which means that in Türkiye mothers of children with autistic disorder do not perceive social support. As stated by Gill and Harris (1991) and Seligman and Benjamin – Darling (1997), social support reduces family stress and encourages family functioning in a positive way. Mothers in other countries mostly use the internet, blogs and e-groups to share information and experiences. Although there are e-groups (ABA-Turkce@yahoogroups.com, asperger-turk@yahoogroups.com) in Türkiye as well, no one in our study even educated mothers, stated this kind of support from other parents via the internet.

According to the results of the Family Support Scale (FSS), mothers perceived middle levels of support (M= 73). Emotional (M= 2.49) and intimate relations (M= 2.43) sources of support were perceived more by mothers of children with autistic disorder. This can be due to Turkish people's close relationships where we share our feelings and daily life events with others. Informational support (M= 2.30) was perceived as the next support unit because children in our study were

having individual or group therapies from psychologists or special education experts. So all mothers had an opportunity to have information from these professionals. The least perceived supports were financial support (M= 2.27) and caregiving support (M= 2.12). Bromley, Hare, Davison and Emerson (2004) and Hare et al. (2004) both reported caregiving support as the most unmet need of mothers in their studies as well.

According to our findings, mothers who work or worked before perceived more support than mothers who do not work. The results of FSS also supported this finding. It was statistically significant that working mothers perceived more support than mothers who were currently not working but had worked before. Görgü (2005) found similar results in his study, working mothers perceived more social support than mothers who did not work. This could be due to the help of other people like babysitters or grandparents, who take care of the child when the mother is at work.

It was surprising that mothers who had two children (one with autistic disorder and one normally developing) perceived more support than mothers who did not have any other children or who had two other normally developing children. This finding was statistically significant. It could be that normally developing children are supportive for mothers in terms of mothers' psychological well-being. Raising a child who does not have any problems, who can talk and show his or her love to others can make mothers feel better.

Furthermore, the support mothers feel does not seem to differ by children's symptom severity, school attendance and mothers' educational levels. However, the educational levels of mothers affected our interviews because we had longer interviews with mothers who had a higher level of education than mothers who had

lower educational levels. They shared their experiences and feelings with more words. Although they had both economic and personal opportunities like hiring baby sitters, they said more needs and difficulties.

Most mothers had no free time to feel relieved. Mothers who could have some time for themselves were the ones who worked and had higher income levels because those mothers had an opportunity to have babysitters or support personnel who helped them at home. Furthermore, as children go to school their mothers get some free time.

Mothers face difficulties while raising children with autistic disorder. In our study, the communication problems of their children affected mothers the most. The second difficulty was children's behavioral problems like agression, hyperactivity, stereotypes and obsessions. All these challenging behaviors effect mothers negatively. Sharpley, Bitsika & Efremidis (1997) stated behavioral problems as the most common source of stress for parents.

In this study we also tried to find out the sources of stress for mothers. The Questionnaire on Resources and Stress (QRS-FT) was used for this purpose. Mothers of children with autistic disorder perceived middle levels of stress (M= 20). Studies in the literature (Esenler, 2001; Fırat, Diler, Avcı & Seydaoğlu, 2002; Gray & Holden, 1992; Moes, Koegel, Schreibman & Loos, 1992; Olsson & Hwang, 2001) generally compare the stress levels of mothers of children with autistic disorder with mothers of children with other disabilities or with fathers' stress levels. Also, the studies of Bristol (1979, as cited in Bebko, Konstantareas & Springer, 1987) and DeMyer and Goldberg (1983, as cited in Bebko, Konstantareas & Springer, 1987) show that mothers of older children with autistic disorder find the situation more

stressful than mothers of younger children with autistic disorder. In our study we did not have any comparison group and children were between three to eight years old, so mothers' middle levels of stress can be seen as meaningful.

Because autistic disorder is a life-long disorder and there is no cure for it, mothers had the highest mean score from the pessimism factor (M= .61). Functional incapacitation (M= .46) was perceived as the second stress factor by mothers and parent and family problems (M= .42) was perceived as the least source of stress by mothers. Here, the child's severity of symptoms or behavioral problems can play a role. Mothers of children with milder autistic disorder do not experience the same difficulties as mothers of children with severe autistic disorder. As it was stated by Bebko, Konstantareas & Springer (1987) the more severe the symptoms are, the more stressful it is for parents. This was not the case in our study, but mean ranks of mothers' were in the expected direction. Mothers of children with severe autistic disorder tended to have higher levels of stress than mothers of children with mild to moderate forms of autistic disorder. A child who is seven years old and still not talking can make a mother more pessimistic and stressful. On the other hand, a child like my niece, who learned to talk at age two and a half and learned to read and write at age three and began primary school with her normally developing agemates can make a mother less stressful and hopeful like my sister.

As expected, the number of children had an effect on mothers' stress levels. Mothers who had three children (one with autistic disorder and others normally developing) had the highest mean scores from QRS-FT compared to mothers who had two children (one with autistic disorder and one normally developing) and

mothers who had only one child with autistic disorder. The number of children increases careburden so this can result in higher levels of stress for mothers.

Whether a child goes to school or not was found to be statistically significant with mothers' stress levels. As it was stated before this can be due to the free time mothers have when the child is at school. Also it may show that the child has mild to moderate autistic disorder which results in lower levels of stress in mothers. Because generally children with severe autistic disorder are not accepted into schools.

Although working mothers tended to have smaller mean scores from total QRS-FT than mothers who do not work or had worked before, this was not statistically significant as found by Eren (1994). Mothers' stress levels also seemed to differ by educational levels but this was not statistically significant either. Mothers who do not have any education, who graduated from primary or secondary school tended to have higher scores from QRS-FT than mothers who graduated from lycee, university or doctorate.

Mothers mostly stated needs concerning their children like individual therapies, speech therapy, schools that would accept their children and home teacher. This finding was similar to Freedman and Boyer's (2000) study. In their interviews with mothers, mothers mostly stated needs of more and consistent therapies, public education and recreational opportunities for their children. Educational needs of parents for their children were also stated by Dymond, Gilson and Myran (2007). And as it was stated by one of our mothers, mental health counseling for families was among the needs. However, inconsistent with Hare et al. (2004) and Bromley, Hare, Davison and Emerson's (2004) findings, mothers in our study never mentioned practical support and respite care needs for themselves. Living in Türkiye where

limited public health services exist, they probably were not even aware that these services are actually provided in the health care systems of other countries.

After having a child with autistic disorder, the social lives of mothers changed dramatically. As stated by some mothers, in a way they became autistics themselves. This overidentification with the child is the basic and most important problem of mothers. Therapeutic help might be needed by mothers in dealing with guilt feelings, if they do not over-protect and identify with their child. Parents must have to learn that being a good mother or father does not mean spending their whole time with the child. In other words, those parents, especially mothers, must be encouraged to have "their own lives" as well. This way they can still experience life outside of being the mother of a child with autistic disorder.

Benderix, Nordström and Sivberg (2007) pointed to social isolation in their research as well. Same as our study findings, after diagnosis parents reported social changes in their lives. As a sister of a mother with a child who is in this spectrum, I saw this unsocialization in my sister as well. There were times when she wanted to return to her career but felt anxious "my time is valuable, I can do lots of things with my daughter in these times. Maybe my working life can affect her negatively." Some mothers in our study shared similar experiences with my sister. One of them changed her position at work and some others changed their plans for returning to their careers after birth. Social isolation not only resulted from children's problematic behaviors or careburden but also from mothers' preferences. Mothers might prefer not to spend time with others for different reasons. One is to avoid feelings of guilt that they are not good mothers. Another is protecting themselves from questions or comments about their children.

Like mothers, other family members (fathers, siblings or grandparents) were also effected negatively. But some mothers said that no one in their family was as strongly affected as they were. Fathers in our society do not state negative feelings like mothers do because they tend to be more defensive. Men are socialized not to accept feelings of weakness, thus may not express their frustration. But we would expect that especially fathers of boys with autistic disorder may feel responsible for not having a young man who will keep their family name and blood to pass on to the generations to come. From my own experiences with parents of children with autistic disorder, fathers were mostly asocial (distant, even aloof) and mothers were mostly obsessive. Another reason for fathers' to remain relatively and seemingly unaffected might be to maintain balance or to compensate for a stressed out mother.

The condition of their children also destroyed parents' future expectations for their children. Most mothers began to cry at this question in our interview. They do not have dreams that are possible for normally developing children, like graduating from university, establishing a career and forming a family. They only expect their children to have healthier, reasonable lives. The biggest question mark that occurs in the minds of mothers about their children's life after their death was: "What will happen to him or her." This question made them feel anxious for the future. The future anxiety of mothers and fathers of children with autistic disorder was found in Eren's (1994) study as well. In Türkiye there is no institution to care for children or adults with autistic disorder. Sometimes, mothers choose to have another child for this reason, that is, to leave their children to the care of his or her sibling after their death. This was not stated by any mother in our study probably because their children were relatively young. Because of these, all mothers wanted their children to live

independently. They expected their children to go to a school, to protect themselves from harm or to have a job and live like other people.

Mothers also wanted other people to be more understanding, supportive, empathic and aware of autistic disorder. As stated by Midence and O'Neill (1999), the invisibility of the condition makes parents face difficulties in their social lives. Likewise, the behavioral problems or stereotypical behaviors of children make other people look at them and those looks disturb mothers.

Most mothers reminded other people that this disorder was unexpected for them and it might happen to anyone as well. When we look at this societal problem from an adult's point of view who is in this spectrum we can see it more clearly "It is not only the autistic child who needs, and has a right to, some form of education. It is also the larger population, which I hope can come to the advanced conclusion that it isn't terrible to be different, even vastly different" (O'Neill, 1998, p. 203).

Parents do not have much opportunity to tell their stories, with this study we wanted to open the closed curtains to allow in some air. Most of the mothers stated their happiness and relaxation during the interviews. Having an opportunity to share their experiences and feelings sometimes led to tears but also allowed some sense of relief to mothers.

Conclusions

This study aimed to understand mothers of children with autistic disorder in terms of their experiences, needs, difficulties, stress levels and supports. The results of this study showed that social isolation is the most important problem of those mothers. As stated by some mothers, they became autistic as well. Another important

finding was about their needs. Mothers of children with autistic disorder need educational services for their children but also respite care services to lessen their care burden and anxieties. Lastly, the society must be educated about autistic disorder. Social pressure on mothers make them more isolated. With all the information that we have gathered in this study, useful and purposeful programs or intervention strategies could be developed for mothers of children with autistic disorder.

Limitations

Although we know that autistic disorder is a rare disorder and therefore a small sample like ours is acceptable, it is still important to recognize that this sample represents a small number of mothers of children with autistic disorder. In addition, the sampling was convenient. The sample of mothers of children with autistic disorder was reached through educational centers and foundations about autistic disorder in Istanbul, Türkiye, therefore it is not possible to generalize the findings as it would be if we had used a random sample of mothers. We also need to keep in mind that there are mothers of children with autistic disorder who do not have any opportunity to have these services. For example, a sample from the rural areas of Türkiye can give very different results, because the sample of our study consisted of parents who had the opportunity to educate their children. They also had middle or high socio-economic status. So, a larger and representative sample would improve the statistical power of the quantitative results. Another limitation of our study was that information was only gathered from mothers. Qualitative reports could be

supported by interviews with other members of the family, fathers and siblings in particular, and this would broaden our understanding of mothers.

Suggestions for Future Research

In this study we have only focused on mothers of children who have autistic disorder. However, autistic disorder is a disorder that effects every member in the family, and further research addressing other members in the family like fathers, siblings and even grandparents would provide a more comprehensive picture of the conditions involving this disorder.

While trying to understand mothers' experiences we also looked at mothers' support systems and stressors. To understand mothers more deeply, future research may point to other factors including personality and mental health status. Additional information will help us to understand mothers better.

We asked a wide range of questions in our semi-structured interviews but these interviews were not in-depth. However, every research question asked here is worth an in-depth analysis. Therefore future research is needed to deepen our understanding of mothers whose children are diagnosed as having autistic disorder.

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APPENDIX A
INFORMATION LETTER

01 Kasım 2007

Sayın İlgili,

Boğaziçi Üniversitesi, Eğitim Fakültesi, Eğitim Bilimleri Bölümü, Rehberlik ve Psikolojik Danışmanlık Yüksek Lisans Programı'nda "Otizm Tanısı Almış Çocuğu Olan Anneleri Anlamak: Deneyimler ve Gereksinimler" başlıklı bir tez araştırması yürütmekteyiz.

Çalışmanın amacı, otizm tanısı almış 3-7 yaşları arasında çocuğu olan annelerin deneyimlerini ve gereksinimlerini anlamaktır. Betimleyici desenle yürütülecek olan çalışmada niteliksel ve niceliksel yöntemler birlikte kullanılacaktır. Annelere doldurulması yaklaşık olarak 15 dakika süren 3 anket verilecek ve tamamlanması 45 dakika süren yüz yüze bir görüşme yapılacaktır. Annelerin deneyimlerini doğru olarak yansıtabilmek için görüşmeler teybe alınacak, yanıtlar daha sonra yazıya dökülecektir.

Aile Bilgi Formu annelerin demografik özelliklerini (yaş, medeni durum, eğitim, meslek, kardeş sayısı, aile geliri vs.), Aile Stresini Değerlendirme Ölçeği stres kaynaklarını (işlev yetersizliği, karamsarlık, anababa ve aile sorunları), Aile Destek Ölçeği ise gördükleri destek türünü (duygusal destek, bilgi desteği, bakım desteği, yakın ilişki desteği ve maddi destek) ortaya koymak üzere hazırlanmıştır. Çocukluk Otizmi Derecelendirme Ölçeği otizmin derecesini belirlemek amacı ile uygulanacaktır. Yarı yapılandırılmış bireysel görüşmeler ise, özel gereksinimi olan çocuğa sahip olmanın anne için olan anlamını, çocuklarının tanı sürecinde yaşadıklarını, sorunlarını, destek kaynaklarını, gereksinimlerini, çocuklarının geleceğine yönelik beklentilerini ve toplumsal beklentileri irdelemek üzere geliştirilmiştir.

Dökümde ailenin kimliğine ilişkin toplanan tüm bilgiler gizli tutulacak, sonuçlar grup halinde değerlendirilecektir. Konuyla ilgili sorularınız için lütfen bizimle iletişime geçin. Katılımınız için teşekkür ediyoruz.

Saygılarımızla,

Akşın Ceylan Köktürk
Yüksek Lisans Tez Öğrencisi

Doç. Dr. Deniz Albayrak-Kaymak
Tez Danışmanı

APPENDIX B
FAMILY INFORMATION FORM
(Turkish)

AİLE BİLGİ FORMU

Tarih:
ID No:

Çocuğun

Adı – Soyadı:

Doğum Tarihi (Gün, Ay, Yıl):

Cinsiyeti: [ ] Kız [ ] Erkek

Kaçıncı Çocuğunuz: …….

Okulu:

Annenin

Adı – Soyadı:

Doğum Tarihi (Gün, Ay, Yıl):

Eğitim Derecesi:

Mesleği:

Şu anda çalışıyor mu? [ ] Evet [ ] Hayır

Önceden Çalışıyor muydu? [ ] Evet [ ] Hayır

Çalışıyorsa; [ ] Tam Zamanlı [ ] Yarı Zamanlı

- Anne ve Baba: [ ] Birlikteler [ ] Boşandılar [ ] Ayrı Yaşıyorlar [ ] Baba öldü

- Kardeş: [ ] Var [ ] Yok

Varsa; Kardeş(ler)in Adı:…… Yaşı:……. Cinsiyeti:…

……. ……. ….

Varsa; Evde Yaşayan Diğerleri: Adı Yaşı

1.

2.

3.

- Sizin dışınızda çocuğunuzun ilişki kurduğu diğer kişiler: ……..

- Ailede bu ve/veya benzeri problemi olanlar var mı? Varsa kimler?

- Ailenizin ekonomik durumunu nasıl değerlendirirsiniz?

0__1__2__3__4__5__6__7__8__9__10__

Çok Kötü Orta Çok iyi

Teşekkür Ederiz.

APPENDIX C
FAMILY INFORMATION FORM
(English)

FAMILY INFORMATION FORM

Date:
ID No:

Child's

Name – Surname:

Birth of Date (day, month, year):

Sex: [ ] Girl [ ] Boy

Birth Order: ……

School:

Mother's

Name – Surname:

Birth of Date (day, month, year):

Education Level:

Job:

Is she working now? [ ] Yes [ ] No

Had she worked before? [ ] Yes [ ] No

If she is working; [ ] Full time [ ] Part time

- Mother and Father: [ ] Together [ ] Divorced [ ] Living Apart [ ] Father is dead

- Sibling: [ ] Yes [ ] No

If there is; sibling Name: …… Age: ……. Sex: …….

…… ……. ……..…

If other people live with them: Name Age

1.

2.

3.

- Other than the mother with whom the child has a relationship: ……

- Other people in the family with similar problems: ……

- How would you rate your family's economical status?

0_ 1_ 2_ 3_ 4_ 5_ 6_ 7_ 8_ 9_ 10

Very Bad Average Very Good

Thank you.

APPENDIX D
CHILDHOOD AUTISM RATING SCALE (CARS)
(Turkish)

Ç • O • D • Ö

ÇOCUKLUK OTIZMI DEGERLENDIRME ÖLÇEGI

Adı, Soyadı :_____ Cinsiyet:_____

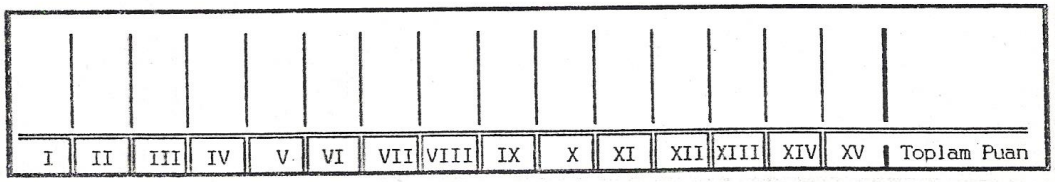
Test Tarihi : Yıl:_____ Ay:_____ Gün:_____

Doğum Tarihi : Yıl:_____ Ay:_____ Gün:_____

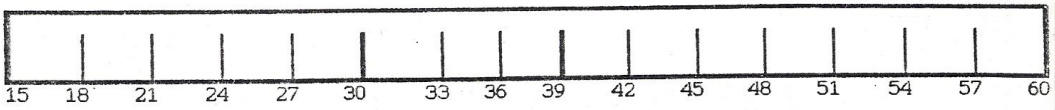
Takvim Yası : Yıl:_____ Ay:_____

Değerlendiren:_____

Kategorileri Dereceleme Puanları



Toplam Puan



Otistik Değil | Hafif Otistik | Ağır Derecede Otistik

• Ç O D D Değerlendirme Ölçeği •

Yönerge: Herbir kategori için, herbir ölçeğin altında bırakılan yeri kullanınız. Çocuğu gözlemlemeyi bitirdikten sonra, ölçeğin maddeleriyle ilgili davranışları değerlendiriniz. Her madde için çocuğu en iyi biçimde tanımlayan ifadenin numarasını daire içine alınız. İki ifade arasında değerlendirmeniz gerekiyorsa 1.5, 2.5 ya da 3.5 değerlerinden birini kullanabilirsiniz. Her ölçek için kısaltılmış değerlendirme ölçütü gösterilmiştir. Maddelerin yrıntılı açıklamaları için El Kitabı'nın ikinci bölümüne bakınız.

I. İNSANLARLA İLİŞKİ

1 — İnsanlarla ilişki kurmada bir anormallik ya da zorluk belirtisi yok • Çocuğun davranışı yaşına uygun. Bir şey yapması istendiğinde utangaçlık, rahatsızlık ya da rahatsızlık belirtileri gözlenebilir, ancak bunlar atipik derecede değildir.

1.5

2 — Hafif derecede anormal ilişki • Çocuk yetişkinin gözüne bakmaktan kaçınabilir, yetişkinden kaçınabilir ya da etkileşime zorlandığı zaman huysuzlanabilir, çok utangaç olabilir, yetişkine tipik tepkiler vermeyebilir ya da yaşıtlarından biraz daha fazla anne-babaya yapışabilir.

2.5

3 — Orta derecede anormal ilişki • Çocuk zaman zaman çevreden kopmuş (yetişkinin farkında değilmiş) gibi görünür. Çocuğun dikkatini çekebilmek için zaman zaman ısrarlı ve zorlayıcı girişimler gerekir. Çok az ilişki çocuk tarafından başlatılır.

3.5

4 — Ağır derecede anormal ilişki • Çocuk sürekli bir şekilde çevreden kopuktur ya da yetişkinin ne yaptığının farkında değildir. Hemen hemen hiç bir zaman yetişkine tepki vermez ya da yetişkinle ilişki başlatmaz. Çocuğun dikkatini çekmek için ancak çok ısrarlı girişimlerin bir etkisi olabilir.

Gözlemler:

II. TAKLİT

1 — Uygun taklit • Çocuk, beceri düzeyine uygun ses, kelime ve hareketleri taklit edebilir.

1.5

2 — Hafif derecede anormal taklit • Çocuk çoğu zaman el çırpma, tek ses çıkartma gibi basit davranışları taklit eder; bazen sadece zorlandıktan sonra ya da gecikmeli olarak taklit eder.

2.5

3 — Orta derecede anormal taklit • Çocuk, arasıra ve ancak yetişkinin yoğun yardım ve ısrarı ile taklit eder; taklit çoğunlukla gecikmeli olarak ortaya çıkar.

3.5

4 — Ağır derecede anormal taklit • Çocuk, yetişkinin ısrar ve yardımına rağmen sesleri, kelimeleri, hareketleri çok seyrek taklit eder ya da hiç etmez.

Gözlemler:

III. DUYGUSAL TEPKİLER

1 — Yaş ve duruma uygun duygusal tepkiler • Çocuk, duygusal tepkilerini, uygun tarz ve derecede, yüz ifadesi duruş ve davranış değişikliği ile gösterir.

1.5

2 — Hafif derecede anormal duygusal tepkiler • Arasıra çocuk, kısmen uygun olmayan tarz ve derecede duygusal tepkiler gösterir. Tepkiler bazen, çevredeki nesneler ve olaylarla ilişkili değildir.

2.5

3 — Orta derecede anormal duygusal tepkiler • Çocuk belirgin olarak uygun olmayan tarz ve derecede duygusal tepkiler gösterir. Tepkiler azalmış ya da abartılı ya da durumla bağıntısız olabilir; duygu uyandıran belirgin olaylar ve nesneler olmasa bile "grimace", gülme, ya da kaskatı kesilme görülebilir.

3.5

4 — Ağır derecede anormal duygusal tepkiler • Tepkiler nadiren duruma uygundur; çocuk belirli bir duygu durumunda iken bu durumu değiştirmek çok zordur. Buna karşın çocuk, hiçbir şey değişmediği halde aşırı duygu değişiklikleri gösterebilir.

Gözlemler:

IV. BEDENİN KULLANIMI

1 — Bedenin yaşa uygun kullanımı • Çocuk normal yaşıtları ile aynı rahatlık, çeviklik ve koordinasyonla hareket eder.

1.5

2 — Bedenin hafif derecede anormal kullanımı • Hantallık, yineleyici hareketler, koordinasyon zayıflığı gibi küçük, kendine özgü tuhaflıklar olabilir ya da seyrek olarak alışılmadık beden hareketlerine rastlanabilir.

2.5

3 — Bedenin orta derecede anormal kullanımı • Bu yaştaki bir çocuk için alışılmadık ya da belirgin derecede garip olan parmak hareketleri, tuhaf parmak ve vücut duruşu, bedenin bir parçasına takılıp kalma ya da çimdikleme, kendine yönelik saldırganlık, sallanma, dönme, parmak oynatma, ayak uçlarında yürüme gibi davranışlar görülebilir.

3.5

4 — Bedenin ağır derecede anormal kullanımı • Yukarıda sıralanan hareketlerin sık ya da yoğun görülmesi, bedenin ağır derecede anormal kullanımının belirtileridir. Bu davranışlar, bunları engelleme ya da çocuğu başka etkinlikler içine sokma girişimlerine karşın ısrarlı bir devamlılık gösterebilir.

Gözlemler:

V. NESNE KULLANIMI

1 — Oyuncak ve diğer nesnelere uygun ilgi ve kullanım ▪ Çocuk, kendi beceri düzeyine uygun oyuncaklara ve diğer nesnelere normal ilgi gösterir ve bu oyuncakları normal şekilde kullanır.

1.5

2 — Oyuncak ve diğer nesnelere hafif derecede uygun olmayan ilgi ve kullanım ▪ Çocuk bir oyuncağa atipik bir ilgi gösterebilir ya da onunla uygun olmayan bebeksi biçimde oynar (oyuncağa vurma, emme gibi).

2.5

3 — Oyuncak ve nesnelere orta derecede uygun olmayan ilgi ve kullanım ▪ Çocuk oyuncaklara ve diğer nesnelere çok az ilgi gösterebilir ya da bir oyuncak ya da nesneyi tuhaf bir şekilde kullanmaya kendini kaptırmış olabilir. Oyuncağın önemsiz bir parçasına odaklaşabilir, nesnenin yansıttığı ışıktan çok hoşlanabilir. Yineleyici bir biçimde oyuncağın bazı kısımlarını hareket ettirebilir ya da yalnızca bir nesne ile yoğun bir şekilde oynar.

3.5

4 — Oyuncak ve nesnelere ağır derecede uygun olmayan ilgi ve kullanım ▪ Çocuk yukarıdaki davranışları daha sık ve yoğun olarak gösterebilir. Bu uygun olmayan etkinliklere kendini kaptırdığında, çocuğun dikkatini bir başka tarafa çekmek zordur.

Gözlemler:

VI. DEĞİŞİKLİĞE UYUM

1 — Değişikliğe yaşa uygun uyum ▪ Çocuk, alıştığı düzendeki değişiklikleri fark etse ya da bunları (sözel olarak) belirtse de yersiz rahatsızlık göstermeden bu değişiklikleri kabul eder.

1.5

2 — Değişikliğe hafif derecede anormal uyum ▪ Yetişkin yapılan etkinliği değiştirmeye kalktığı zaman çocuk aynı etkinliğe ya da aynı araç-gereci kullanmaya devam eder.

2.5

3 — Değişikliğe orta derecede anormal uyum ▪ Çocuk alıştığı düzendeki değişikliklere ciddi biçimde direnir, eski etkinliğe devam etmeye çalışır, dikkatini başka tarafa çekmek çok zordur. Düzen değiştirildiği zaman mutsuz ve öfkeli olabilir.

3.5

4 — Değişikliklere ağır derecede anormal uyum ▪ Çocuk değişikliğe ağır tepkiler verir. Eğer değişikliğe zorlanırsa çok fazla kızabilir ya da işbirliği yapmaz ve öfke nöbetleriyle tepki verebilir

Gözlemler:

VII. GÖRSEL TEPKİ

1 — Yaşa uygun görsel tepki ▪ Çocuğun görsel davranışları normaldir ve yaşına uygundur. Görme, yeni bir nesneyi keşfetmek için diğer duyularla birlikte kullanılır.

1.5

2 — Hafif derecede anormal görsel tepki ▪ Çocuğa zaman zaman nesnelere bakması hatırlatılmalıdır. Arkadaşları yerine ışığa ya da aynaya bakmakla daha çok ilgilenebilir, arasıra boşluğa gözünü dikip bakabilir ya da insanların gözlerine bakmaktan da kaçınabilir.

2.5

3 — Orta derecede anormal görsel tepki ▪ Çocuğa sık sık yaptığına bakması hatırlatılmalıdır. Boşluğa gözünü dikip bakabilir, insanların gözüne bakmaktan kaçınabilir, nesnelere alışılmadık bir açıdan bakabilir, nesneleri gözlerine çok yakın tutabilir.

3.5

4 — Ağır derecede anormal görsel tepki ▪ Çocuk ısrarlı bir şekilde insanlara ya da belirli nesnelere bakmaktan kaçınır ve yukarıda tanımlanan diğer görsel tepkilerin aşırı biçimlerini sergiler.

Gözlemler:

VIII. DİNLEME TEPKİSİ

1 — Yaşa uygun dinleme tepkisi ▪ Çocuğun dinleme davranışı normal ve yaşına uygundur. Dinleme diğer duyularla birlikte kullanılır.

1.5

2 — Hafif derecede anormal dinleme tepkisi ▪ Belirli seslere karşı hafif tepkisizlik gösterebilir ya da hafif derecede fazla tepki verebilir. Seslere tepkiler geçikebilir, çocuğun dikkatini çekebilmek için sesin tekrar edilmesi gerekebilir. Çocuğun dikkati yabancı (dıştan gelen) seslerle dağılabilir.

2.5

3 — Orta derecede anormal dinleme tepkisi ▪ Çocuğun seslere tepkileri değişkenlik gösterir, ilk birkaç defada sesi duymazlıktan gelebilir, bazı günlük sesleri işittiği zaman ürkebilir ya da kulaklarını kapatabilir.

3.5

4 — Ağır derecede anormal dinleme tepkisi ▪ Çocuk, sesin türünden bağımsız olarak, seslere karşı aşırı derecede tepkisel ya da tepkisiz davranabilir.

Gözlemler:

IX. TATMA, KOKLAMA, DOKUNMA TEPKİSİ VE KULLANIMI

1 — Tatma, koklama ve dokunmaya normal tepki ve kullanım ▪ Çocuk yeni nesneleri yaşına uygun şekilde, genellikle bakarak ve hissederek keşfeder. Tatma ve koklama duyularını gerektiğinde kullanabilir. Küçük, can yakıcı veren durumlar karşısında çocuk rahatsızlığını belirtir, ancak aşırı tepki göstermez.

1.5

2 — Tatma, koklama ve dokunmaya hafif derecede anormal tepki ve kullanım ▪ Çocuk nesneleri ısrarlı bir şekilde ağzına koyabilir, yenmeyen nesneleri koklayabilir, tadabilir, normal çocukların rahatsızlık ifade ettikleri orta şiddetli ağrıları fark etmiyor gibi davranabilir ya da aşırı tepki verebilir.

2.5

3 — Tatma, koklama ve dokunmaya orta derecede anormal tepki ve kullanım ▪ Çocuk insanlara ya da nesnelere dokunma, koklama ve tatmaya yönelik orta derecede bir eğilim gösterebilir, çok az ya da çok fazla tepki verebilir.

3.5

4 — Tatma, koklama ve dokunmaya ağır derecede anormal tepki ve kullanım ▪ Çocuk normal kullanım ve keşfetme yerine, sadece duyumsama amacıyla nesneleri koklar, tadar ya da onlara dokunur. Çocuk ağrıyı (acıyı) tümüyle algılamaz görünür ya da hafif derecede rahatsızlık veren durumlara çok aşırı tepki verir.

Gözlemler:

X. KORKU YA DA SINIRLILIK

1 — Normal korku ya da sinirlilik ▪ Çocuğun davranışları hem yaşına hem de durumuna uygundur.

1.5

2 — Hafif derecede anormal korku ya da sinirlilik ▪ Çocuk, aynı yaş ve benzer durumdaki çocuğun tepkileriyle karşılaştırıldığında, arasıra çok az ya da çok fazla korku ve sinirlilik gösterir.

2.5

3 — Orta derecede anormal korku ya da sinirlilik ▪ Çocuk, benzer durumdaki daha küçük bir çocuk için bile tipik olandan biraz daha az ya da biraz daha fazla korku gösterir.

3.5

4 — Ağır derecede anormal korku ya da sinirlilik ▪ Zararsız olaylar ve nesnelere ilişkin yinelenen deneyimlerden sonra bile korku sürer. Çocuğu sakinleştirmek ya da rahatlatmak çok zordur. Buna karşın, çocuk aynı yastaki diğer çocukların kaçındığı tehlikelere karşı uygun davranışı göstermekte başarısızdır.

Gözlemler:

XI. SÖZEL İLETİŞİM

1 **Yaşa ve duruma uygun normal sözel iletişim.**

1.5

2 **Hafif derecede anormal sözel iletişim :** Konuşma genel olarak gerilik gösterir. Konuşmanın çoğu anlamlıdır; ancak ekolali ve kişi zamirlerinin ters kullanımı görülebilir. Bazı özel sözcükler ve jargon kullanılabilir.

2.5

3 **Orta derecede anormal sözel iletişim :** Konuşma olmayabilir. Konuşma olsa da sözel iletişim, 'anlamlı konuşma' ile 'jargon, ekolali, zamir değiştirme gibi kendine özgü konuşma' karışımından oluşabilir. Anlamlı konuşmada yoğun soru sorma ve belirli konular üzerinde ısrarla durma gibi özellikler görülebilir.

3.5

4 **Ağır derecede anormal sözel iletişim :** Anlamlı konuşma kullanılmaz. Çocuk bebeksi sesler, tuhaf ya da hayvan seslerine benzer sesler, konuşmaya yakın karmaşık sesler çıkarabilir ya da tanıdık kelimeler ve cümlelerin tuhaf kullanımı görülebilir.

Gözlemler:

XII. SÖZEL OLMAYAN İLETİŞİM

1 **Sözel olmayan iletişimin yaşa ve duruma uygun normal kullanımı.**

1.5

2 **Sözel olmayan iletişimin hafif derecede anormal kullanımı:** Olgunlaşmamış sözel iletişim; yaşıtlarının istediklerini daha belirgin işaret ettikleri ya da gösterdikleri durumlarda çocuk belirsizce işaret edebilir ya da istediğine uzanabilir.

2.5

3 **Sözel olmayan iletişimin orta derecede anormal kullanımı :** Çocuk genellikle isteklerini ya da gereksinimlerini sözel olmayan şekilde ifade edemez ve diğerlerinin sözel olmayan iletişimini anlayamaz.

3.5

4 **Sözel olmayan iletişimin ağır derecede anormal kullanımı :** Çocuk sadece belirgin bir anlamı olmayan garip ya da özel jestler kullanır ve diğerlerinin yüz ifadelerinin ya da jestlerinin farkında değildir.

Gözlemler:

XIII. ETKİNLİK DÜZEYİ

1 **Yaşa ve koşullara uygun normal etkinlik düzeyi :** Çocuk benzer duru normal bir yaşıtından ne daha fazla ne de daha az hareketlidir.

1.5

2 **Hafif derecede anormal etkinlik düzeyi :** Çocuk hafif derecede huzursuzdur ya da biraz "tembelce" ve yavaş hareket edebilir. Çoc etkinlik düzeyi performansını hafif biçimde etkiler.

2.5

3 **Orta derecede anormal etkinlik düzeyi :** Çocuk oldukça aktiftir ve zaptetmek zordur. Sınırsız enerjisi olabilir ve uykuya dalmakta gü çeker. Buna karşın, oldukça hareketsiz olabilir ve harekete geçirebilmek için çok fazla çaba gerekebilir.

3.5

4 **Ağır derecede anormal etkinlik düzeyi :** Çocuk hareketlilik ya da hareketsizliğin en uç noktalarındadır ve bir aşırı uçtan diğerine geçebilir.

Gözlemler:

XIV. ZİHİNSEL TEPKİLERİN DÜZEYİ VE TUTARLILIĞI

1 **Normal ve pek çok alanda uygun tutarlılık gösteren zeka :** Çocuk ay yaştaki tipik çocuklar kadar zekidir ve olağandışı zihinsel beceri ya da problemleri yoktur.

1.5

2 **Hafif derecede anormal zihinsel işlevsellik :** Çocuk aynı yaştaki t bir çocuk kadar zeki değildir, yaklaşık tüm alanlarda beceriler ay düzeyde çerilik gösterir.

2.5

3 **Orta derecede anormal zihinsel işlevsellik :** Çocuk genel olarak ay yaştaki tipik bir çocuk kadar zeki değildir ancak bir ya da daha f alanda normale yakın işlevsellik gösterebilir.

3.5

4 **Ağır derecede anormal zihinsel işlevsellik :** Çocuk aynı yaştaki ti bir çocuk kadar zeki değilken, zihinsel gelişimin bir ya da daha f alanında normal bir çocuktan bile daha iyi işlev gösterebilir.

Gözlemler:

XV. GENEL İZLENİMLER

1 **Otizm yok :** Çocuk otizme özgü belirtilerin hiçbirini göstermez.

1.5

2 **Hafif otizm :** Çocuk yalnızca az sayıda ya da yalnızca hafif derecede otizm belirtileri gösterir.

2.5

3 **Orta dereca otizm :** Çocuk belirli sayıda ya da orta derecede otizm belirtileri gösterir.

3.5

4 **Ağır otizm :** Çocuk otizm belirtilerinden çoğunu ya da ağır derecede otizm gösterir.

Gözlemler:

APPENDIX E
CHILDHOOD AUTISM RATING SCALE (CARS)
(English)

C·A·R·S

The Childhood Autism Rating Scale

Eric Schopler, Ph.D., Robert J. Reichler, M.D.,
and Barbara Rochen Renner, Ph.D.

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12031 Wilshire Boulevard
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Name: _____ Sex: _____

ID Number: _____

Test Date: Year _____ Month _____ Day _____

Birth Date: Year _____ Month _____ Day _____

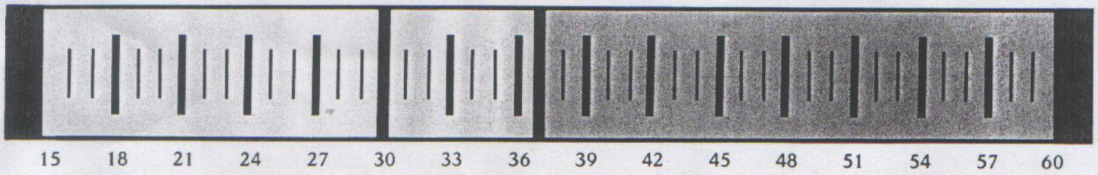
Chronological Age: Years _____ Months _____

Rater: _____

Category Rating Scores

I	II	III	IV	V	VI	VII	VIII	IX	X	XI	XII	XIII	XIV	XV	Total Score

Total Score



W-231A

CARS Rating Sheet

Directions: For each category, use the space provided below each scale for taking notes concerning the behaviors relevant to each scale. After you have finished observing the child, rate the behaviors relevant to each item of the scale. For each item, circle the number which corresponds to the statement that best describes the child. You may indicate the child is between two descriptions by using ratings of 1.5, 2.5, or 3.5. Abbreviated rating criteria are presented for each scale. See chapter 2 of the Manual for detailed rating criteria.

I. RELATING TO PEOPLE

No evidence of difficulty or abnormality in relating to people • The child's behavior is appropriate for his or her age. Some shyness, fussiness, or annoyance at being told what to do may be observed, but not to an atypical degree.

Mildly abnormal relationships • The child may avoid looking the adult in the eye, avoid the adult or become fussy if interaction is forced, be excessively shy, not be as responsive to the adult as is typical, or cling to parents somewhat more than most children of the same age.

Moderately abnormal relationships • The child shows aloofness (seems unaware of adult) at times. Persistent and forceful attempts are necessary to get the child's attention at times. Minimal contact is initiated by the child.

Severely abnormal relationships • The child is consistently aloof or unaware of what the adult is doing. He or she almost never responds or initiates contact with the adult. Only the most persistent attempts to get the child's attention have any effect.

Observations:

II. IMITATION

Appropriate imitation • The child can imitate sounds, words, and movements which are appropriate for his or her skill level.

Mildly abnormal imitation • The child imitates simple behaviors such as clapping or single verbal sounds most of the time; occasionally, imitates only after prodding or after a delay.

Moderately abnormal imitation • The child imitates only part of the time and requires a great deal of persistence and help from the adult; frequently imitates only after a delay.

Severely abnormal imitation • The child rarely or never imitates sounds, words, or movements even with prodding and assistance from the adult.

Observations:

III. EMOTIONAL RESPONSE

1 **Age-appropriate and situation-appropriate emotional responses** • The child shows the appropriate type and degree of emotional response as indicated by a chang in facial expression, posture, and manner.

1.5

2 **Mildly abnormal emotional responses** • The child occasionally displays a somewhat inappropriate type or degree of emotional reactions. Reactions are sometimes unrelated to the objects or events surrounding them.

2.5

3 **Moderately abnormal emotional responses** • The child shows definite signs of inappropriate type and/or degree of emotional response. Reactions may be quite inhibited or excessive and unrelated to the situation; may grimace, laugh, or become rigid even though no apparent emotion producing objects or events are present.

3.5

4 **Severely abnormal emotional responses** • Responses are seldom appropriate to the situation; once the child gets in a certain mood, it is very difficult to change the mood. Conversely, the child may show wildly different emotions when nothing has changed.

Observations:

IV. BODY USE

1 **Age appropriate body use** • The child moves with the same ease, agility, and coordination of a normal child of the same age.

1.5

2 **Mildly abnormal body use** • Some minor peculiarities may be present, such as clumsiness, repetitive movements, poor coordination, or the rare appearance of more unusual movements.

2.5

3 **Moderately abnormal body use** • Behaviors that are clearly strange or unusual fo a child of this age may include strange finger movements, peculiar finger or body posturing, staring or picking at the body, self-directed aggression, rocking, spinning, finge wiggling, or toe-walking.

3.5

4 **Severely abnormal body use** • Intense or frequent movements of the type listed above are signs of severely abnormal body use. These behaviors may persist despite attempts to discourage them or involve the child in other activities.

Observations:

V. OBJECT USE

Appropriate use of, and interest in, toys and other objects • The child shows normal interest in toys and other objects appropriate for his or her skill level and uses these toys in an appropriate manner.

Mildly inappropriate interest in, or use of, toys and other objects • The child may show atypical interest in a toy or play with it in an inappropriately childish way (e.g., banging or sucking on the toy).

Moderately inappropriate interest in, or use of, toys and other objects • The child may show little interest in toys or other objects, or may be preoccupied with using an object or toy in some strange way. He or she may focus on some insignificant part of a toy, become fascinated with light reflecting off the object, repetitively move some part of the object, or play with one object exclusively.

Severely inappropriate interest in, or use of, toys or other objects • The child may engage in the same behaviors as above, with greater frequency and intensity. The child is difficult to distract when engaged in these inappropriate activities.

Observations:

VI. ADAPTATION TO CHANGE

Age appropriate response to change • While the child may notice or comment on changes in routine, he or she accepts these changes without undue distress.

Mildly abnormal adaptation to change • When an adult tries to change tasks the child may continue the same activity or use the same materials.

Moderately abnormal adaptation to change • The child actively resists changes in routine, tries to continue the old activity, and is difficult to distract. He or she may become angry and unhappy when an established routine is altered.

Severely abnormal adaptation to change • The child shows severe reactions to change. If a change is forced, he or she may become extremely angry or uncooperative and respond with tantrums.

Observations:

VII. VISUAL RESPONSE

Age appropriate visual response • The child's visual behavior is normal and appropriate for that age. Vision is used together with other senses as a way to explore a new object.

Mildly abnormal visual response • The child must be occasionally reminded to look at objects. The child may be more interested in looking at mirrors or lighting than peers, may occasionally stare off into space, or may also avoid looking people in the eye.

Moderately abnormal visual response • The child must be reminded frequently to look at what he or she is doing. He or she may stare into space, avoid looking people in the eye, look at objects from an unusual angle, or hold objects very close to the eyes.

Severely abnormal visual response • The child consistently avoids looking at people or certain objects and may show extreme forms of other visual peculiarities described above.

Observations:

VIII. LISTENING RESPONSE

1 — **Age appropriate listening response** • The child's listening behavior is normal and appropriate for age. Listening is used together with other senses.

1.5

2 — **Mildly abnormal listening response** • There may be some lack of response, or mild overreaction to certain sounds. Responses to sounds may be delayed, and sounds may need repetition to catch the child's attention. The child may be distracted by extraneous sounds.

2.5

3 — **Moderately abnormal listening response** • The child's responses to sounds vary; often ignores a sound the first few times it is made; may be startled or cover ears when hearing some everyday sounds.

3.5

4 — **Severely abnormal listening response** • The child overreacts and/or underreacts to sounds to an extremely marked degree, regardless of the type of sound.

Observations:

IX. TASTE, SMELL, AND TOUCH RESPONSE AND USE

1 — **Normal use of, and response to, taste, smell, and touch** • The child explores new objects in an age appropriate manner, generally by feeling and looking. Taste or smell may be used when appropriate. When reacting to minor, everyday pain, the child expresses discomfort but does not overreact.

1.5

2 — **Mildly abnormal use of, and response to, taste, smell, and touch** • The child may persist in putting objects in his or her mouth; may smell or taste inedible objects; may ignore or overreact to mild pain that a normal child would express as discomfort.

2.5

3 — **Moderately abnormal use of, and response to, taste, smell, and touch** • The child may be moderately preoccupied with touching, smelling, or tasting objects or people. The child may either react too much or too little.

3.5

4 — **Severely abnormal use of, and response to, taste, smell, and touch** • The child is preoccupied with smelling, tasting, or feeling objects more for the sensation than for normal exploration or use of the objects. The child may completely ignore pain or react very strongly to slight discomfort.

Observations:

X. FEAR OR NERVOUSNESS

1 — **Normal fear or nervousness** • The child's behavior is appropriate both to the situation and to his or her age.

1.5

2 — **Midly abnormal fear or nervousness** • The child occasionally shows too much or too little fear or nervousness compared to the reaction of a normal child of the same age in a similar situation.

2.5

3 — **Moderately abnormal fear or nervousness** • The child shows either quite a bit more or quite a bit less fear than is typical even for a younger child in a similar situation.

3.5

4 — **Serverely abnormal fear or nervousness** • Fears persist even after repeated experience with harmless events or objects. It is extremely difficult to calm or comfort the child. The child may, conversely, fail to show appropriate regard for hazards which other children of the same age avoid.

Observations:

XI. VERBAL COMMUNICATION

1 **Normal verbal communication, age and situation appropriate.**

.5

2 **Mildly abnormal verbal communication** • Speech shows overall retardation. Most speech is meaningful; however, some echolalia or pronoun reversal may occur. Some peculiar words or jargon may be used occasionally.

.5

3 **Moderately abnormal verbal communication** • Speech may be absent. When present, verbal communication may be a mixture of some meaningful speech and some peculiar speech such as jargon, echolalia, or pronoun reversal. Peculiarities in meaningful speech include excessive questioning or preoccupation with particular topics.

.5

4 **Severely abnormal verbal communication** • Meaningful speech is not used. The child may make infantile squeals, weird or animal-like sounds, complex noises approximating speech, or may show persistent, bizarre use of some recognizable words or phrases.

Observations:

XII. NONVERBAL COMMUNICATION

1 **Normal use of nonverbal communication, age and situation appropriate.**

.5

2 **Mildly abnormal use of nonverbal communication** • Immature use of nonverbal communication; may only point vaguely, or reach for what he or she wants, in situations where same age child may point or gesture more specifically to indicate what he or she wants.

.5

3 **Moderately abnormal use of nonverbal communication** • The child is generally unable to express needs or desires nonverbally, and cannot understand the nonverbal communication of others.

.5

4 **Severely abnormal use of nonverbal communication** • The child only uses bizarre or peculiar gestures which have no apparent meaning, and shows no awareness of the meanings associated with the gestures or facial expressions of others.

Observations:

XIII. ACTIVITY LEVEL

1 **Normal activity level for age and circumstances** • The child is neither more active nor less active than a normal child of the same age in a similar situation.

1.5

2 **Mildly abnormal activity level** • The child may either be mildly restless or somewhat "lazy" and slow moving at times. The child's activity level interferes only slightly with his or her performance.

2.5

3 **Moderately abnormal activity level** • The child may be quite active and difficult to restrain. He or she may have boundless energy and may not go to sleep readily at night. Conversely, the child may be quite lethargic, and need a great deal of prodding to get him or her to move about.

3.5

4 **Severely abnormal activity level** • The child exhibits extremes of activity or inactivity and may even shift from one extreme to the other.

Observations:

XIV. LEVEL AND CONSISTENCY OF INTELLECTUAL RESPONSE

1 **Intelligence is normal and reasonably consistent across various areas** • The child is as intelligent as typical children of the same age and does not have any unusual intellectual skills or problems.

1.5

2 **Mildly abnormal intellectual functioning** • The child is not as smart as typical children of the same age; skills appear fairly evenly retarded across all areas.

2.5

3 **Moderately abnormal intellectual functioning** • In general, the child is not as smart as typical children of the same age; however, the child may function nearly normally in one or more intellectual areas.

3.5

4 **Severely abnormal intellectual functioning** • While the child generally is not as smart as the typical child of his age, he or she may function even better than the normal child of the same age in one or more areas.

Observations:

XV. GENERAL IMPRESSIONS

1 **No autism** • The child shows none of the symptoms characteristic of autism.

1.5

2 **Mild autism** • The child shows only a few symptoms or only a mild degree of autism.

2.5

3 **Moderate autism** • The child shows a number of symptoms or a moderate degree of autism.

3.5

4 **Severe autism** • The child shows many symptoms or an extreme degree of autism.

Observations:

APPENDIX F
INTERVIEW FORM
(Turkish)

ÖZEL GEREKSİNİMİ OLAN ÇOCUKLARIN ANNELERİYLE GÖRÜŞME FORMU[•]

Tarih: ID No:

Çocuğun Adı – Soyadı:

1. Çocuğunuzun farklı olduğu ilk ne zaman ve nasıl anlaşıldı?

2. Çocuğunuza otizm tanısı ne zaman ve kimin tarafından kondu?

3. Çocuğunuza konan tanı size neler hissettirdi? Bu konudaki duygularınız neler oldu? Şimdiki duygularınız neler?

4. Çocuğun sorumluluğu ailede kim(ler)de? Bu konuda bir paylaşım var mı? Varsa nasıl?

5. Çocuğunuz şimdiye kadar ne gibi (eğitim, ilaç, alternatif tedavi, vb.) yardım(lar) aldı? Bunların her birinin yararı ne oldu?

6. Çocuğunuzla ilgili size destek olan kişi ya da kurumlar varsa bunlar kimler ve neler?

7. (Çocuğun adı)'nın annesi olarak en çok hangi konularda/durumlarda güçlük çekiyorsunuz?

8. Çocuğunuza daha iyi katkıda bulunabilmek için hangi konularda destek, kaynak, yardım ya da eğitim almak isterdiniz? Ne gibi gereksinimleriniz var?

[•] Bu görüşme formu tez araştırması amacıyla Boğaziçi Üniversitesi Rehberlik ve Psikolojik Danışmanlık Yüksek Lisans Programı öğrencisi Akşın Ceylan Köktürk tarafından, tez danışmanı Doç. Dr. Deniz Albayrak-Kaymak gözetiminde, Mayıs 2007 tarihinde geliştirilmiştir. Doğrudan izinleri olmaksızın başkaları tarafından kullanılamaz.

9. Kendinizi daha iyi hissetmek ya da rahatlatmak için bir şeyler yapabiliyor musunuz? Evet ise, neler? Hayır ise, neler yapabilmek isterdiniz?

10. (Kardeşin adı)'nın annesi olmak nasıl bir şey? Tanımlayabilir misiniz?

11.(Çocuğun adı)'nın annesi olmak nasıl bir şey? Tanımlayabilir misiniz?

12. (Çocuğun adı)'nın annesi olmak sizi ve yaşamınızı olumlu ya da olumsuz anlamda değiştirdi mi? Nasıl?

13. (Çocuğun adı)'nın varlığının ailenizin üzerindeki etkisi nedir?

14. Çocuğunuz için gelecekteki beklentileriniz neler?

15. Eğer fırsatınız olsaydı, (çocuğun adı) annesi olarak yaşantınız ile ilgili herkesin duyması için neler söylemek isterdiniz? (Diyelim ki toplum sizi dinliyor, onlara ne derdiniz, onlardan beklentilerinizle ilgili insanlara bir şeyler söylemek ister misiniz?) Neler?

Teşekkür Ederim.

APPENDIX G
INTERVIEW FORM
(English)

INTERVIEW FORM FOR MOTHERS OF CHILDREN WITH SPECIAL NEEDS

ID No:

Date:

Child's Name – Last Name:

1. When and how was it first understood that your child was different?

2. When and by whom was your child diagnosed as autistic?

3. What did the diagnosis make you feel? What were your feelings? What are your feelings now in regards to diagnosis?

4. Who has the responsibility of the child in your family? Are these responsibilities shared? If so, how?

5. What kind of help (education, medication, alternative therapies etc.) has your child received so far? What were the benefits of each?

6. If there are people or organizations that support you, who are they, what are they?

7. As the mother of (child's name) which issues/situations do you struggle the most with?

8. What kinds of support, resources, help or education would you have liked to receive to better contribute to your child? What are your needs?

9. Are you able to do things to feel better, to relax? If yes, what? If no, what would you have liked to do?

10. How does it feel to be the mother of (sibling's name)? Could you describe?

11. How does it feel to be the mother of (child's name)? Could you describe?

12. How did becoming the mother of (child's name) influence you and your life in positive or negative ways?

13. What is the impact of (child's name) on your family?

14. What are your expectations for your child's future?

15. If you had the chance, what would you like to say to everyone as the mother of (child's name) regarding your experiences? (Let's assume the public is listening to you, what would you tell them? Would you like to say something to people about your expectations from them?) What?

Thank you.

APPENDIX H
The Questionnaire on Resources and Stress – F
(Turkish)

Tarih:
ID No:

Lütfen aşağıdaki cümleleri dikkatlice okuyunuz ve size uygun olduğunu düşündüğünüz seçeneğe (X) işareti koyunuz.

Aile Stresini Değerlendirme Ölçeği	Evet	Hayır
1. ……., yaşıtlarıyla iletişim kuramaz.		
2. Ailemizin diğer bireyleri …….'ın yüzünden bir şeylerden vazgeçmek zorunda kalıyorlar.		
3. Ona bakamayacak duruma geldiğimde ……..'a ne olacağı konusunda endişeliyim.		
4. ……'a bakmak için gereken sürekli ilgi yüzünden ailemizin diğer bireylerinin gelişimi sınırlanmaktadır.		
5. …….'ın hayatını kazanmak için yapabileceği işler sınırlıdır.		
6. ……. kendi kendine yemek yiyebilir.		
7. Bazen ……'ı dışarıya çıkarmaktan çekiniyorum.		
8. Artan sorumluluklar ve parasal sıkıntılar, ileride ailemizin sosyal yaşamını etkileyecek.		
9. …….'ın hep böyle kalacağı düşüncesi beni çok rahatsız ediyor.		
10. ……'ı dışarı çıkardığım zamanlar rahatsızlık duyuyorum		
11. İstediğim zaman arkadaşlarımla dışarı çıkabilirim.		
12. ……..'ı seyahate götürmek bütün ailenin keyfini kaçırıyor.		
13. …….. evimizin adresini bilir.		
14. Ailesi olarak, eskiden yaptığımız her şeyi yapıyoruz.		
15. ……. kim olduğunu bilir.		
16. Bazen, ……..'ın yüzünden çok utanırım.		
17. Kendine söylenenleri anlamakta çok zorlandığı için …… ile iletişim kurmak çok güçtür.		
18. ……. aşırı korunuyor.		
19. ……. bizimle beraberken ailece zevk alabileceğimiz birçok şey vardır.		
20. …… oyunlara ve sportif etkinliklere katılabilir.		
21. …….'ın normal bir yaşam süremeyeceği düşüncesi beni hayal		

kırıklığına uğratıyor.		
22. …… boş zamanlarında ne yapacağını bilemez.		

23. Kendimi kolayca rahatlatabilirim		
24. …….'ın büyüdüğü zaman ne olacağını düşünmek beni endişelendiriyor.		
25. Yaşamdan zevk alamıyorum.		
26. ……..'ın en hoşnut olduğum yönlerinden biri, kendine olan güvenidir.		
27. Ailemizde öfke ve kızgınlık duyguları çok yaşanır.		
28. …….. tuvalete kendi başına gidebilir.		
29. ……. bir dakika önce söylediğini, bir dakika sonra hatırlamaz.		
30. ……. otobüse binebilir.		
31. ……. ile iletişim kurmak kolaydır.		
32. ……. kendini bir birey olarak kabul eder.		
33. Ne zaman …..'ı düşünsem kendimi üzgün hissederim.		
34. ……'a artık bakamayacağım zaman, ona ne olacağı konusunda sık sık endişelenirim.		
35. …….. bizim için her zaman sorun olacak		
36. ……. kendi duygularını başkalarına ifade edebilir.		
37. ……. bez kullanmak zorundadır.		
38. Çoğu zaman endişeliyim.		
39. …… yardımsız yürüyebilir.		

APPENDIX I
FAMILY SUPPORT SCALE

Tarih:
ID No:

Lütfen aşağıdaki cümleleri dikkatlice okuyunuz ve size uygun olduğunu düşündüğünüz seçeneğe (X) işareti koyunuz.

Aile Destek Ölçeği	**Her zaman**	**Bazen**	**Hiçbir zaman**
1. Konuşmak ihtiyacı duyduğumda beni gerçekten dinleyeceğine inandığım birileri var.			
2. Güç durumda olduğumda, bana gerçekten yardım edeceğine inandığım birileri var.			
3. Birlikte olduğumuzda, kendimi gerçekten rahat hissettiğim birileri var.			
4. Bana bir birey, bir insan olarak değer verdiğini hissettiğim birileri var.			
5. Çok üzgün olduğumda beni teselli edeceğine inandığım birileri var.			
6. Yardıma ihtiyaç duyduğumda, bana yardımcı olacağına güvendiğim birileri var.			
7. Önemli bir karar vereceğim zaman ya da bir sorunumu çözeceğim zaman, bana tavsiyelerde bulunacak birileri var.			
8. Kişisel sıkıntılarım, üzüntülerim, beklentilerim, umutlarım, sevinçlerim ve bu gibi duygularımla ilgili konuşacağım birileri var.			
9. Kişisel sorunlarımı tartışıp, tavsiyeler alabileceğim birileri var.			
10. Çocuğumun bakımında bana yardımcı olacak birileri var.			
11. Çocuğumun özellikleri hakkında bana bilgi verecek birileri var.			
12. Kısa süreli de olsa sorumluluklarımı bırakabileceğim birileri var.			
13. Yaşamımdaki en önemli kararlarımı paylaşabileceğim birileri var.			
14. Duygusal olarak güçlü bir şekilde bağlı olduğumu hissettiğim birileri var.			
15. Param olmadığı zaman, çocuğumun bir ihtiyacını almak zorunda kalsam, bana borç para verecek birileri var.			
16. Uzun ve yorucu bir günün sonunda, kendimi bitmiş, tükenmiş ya da sıkıntılı hissettiğimde, beni rahatlatacak birileri var.			
17. Yardıma ihtiyaç duyduğumda, hiç düşünmeden rahatlıkla başvurabileceğim birileri var.			
18. Acil bir işim çıktığında, çocuğuma göz kulak olacak birileri var.			
19. Sırlarımı rahatsızlık duymadan açabileceğim			

birileri var.			
20. Neyin nasıl yapılacağı konusunda bana yararlı tavsiyelerde bulunacak birileri var.			
21. Beni gerçekten sevdiğini hissettiğim birileri var.			

22. Gece dışarı çıkmam gerektiğinde, çocuğumu bırakabileceğim birileri var.			
23. Parasal açıdan sıkıntıda olduğumda, bana yardım edecek birileri var.			
24. Çocuğumun eğitimi hakkında bana bilgi verecek birileri var.			
25. Benim çocuğum gibi çocuğu olup görüşüp, konuşabileceğim birileri var.			
26. İhtiyacım olduğunda, öğretmen, danışman, yönetici gibi bana yardımcı olacak birileri var.			
27. Çocuğumun nasıl gelişip, büyüyeceği hakkında beni bilgilendirecek, tavsiyelerde bulunacak birileri var.			
28. Çocuğuma nasıl davranmam gerektiği konusunda bana yol gösterecek birileri var.			
29. Çocuğuma nasıl beceri öğreteceğimi bana gösteren, öğreten birileri var.			
30. Çocuğumun yararlanacağı okul, merkez, klinik, spor salonu, iş okulu, yaz kampları, kurslar ve bu gibi yerler var.			
31. Hoşlandığım şeyleri yapmak için kendime zaman ayırmamı sağlayan birileri var.			
32. En yakın akrabalarınız, arkadaşlarınız, komşularınız ve bu gibi kişilerle yüz yüze ve telefonla görüşme sıklığınız nedir?			
33. Geçtiğimiz ay akrabalarınız, arkadaşlarınız, komşularınız, yakınlarınız evinize kaç kez geldiler?			
34. Yakınlarınızı ziyaret etmek, gezmek, sinemaya gitmek, alışverişe gitmek gibi, kendiniz için kaç kez dışarı çıkabiliyorsunuz?			