



# Parenting Challenges in Families of Children with a Diagnosis of Autism Spectrum Disorder: A Qualitative Research Study in Istanbul

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## Abstract

**Introduction** This qualitative research study examines problems experienced by families with children who have received a diagnosis of autism spectrum disorder (ASD) living in Turkey.

**Background** In recent years, Turkey has moved to expand services to children who have received a diagnosis of ASD and their families. However, families still experience hidden issues that are crucial to consider while developing appropriate policies.

**Method** In this study, we interviewed 10 families whose children attended special education schools in the Bağcılar and Bahçelievler districts of Istanbul. We used semistructured interviews conducted via phone, WhatsApp video chat, and Zoom and a phenomenological approach to gain an in-depth understanding of the caregivers' experience. Themes were obtained by utilizing descriptive analysis.

**Results** Parents expressed a variety of concerns including financial burden, intrafamilial conflict, mental health problems, and community-related issues.

**Conclusions** Moving forward, the emerging social work profession should assist children who have been given a diagnosis of ASD and their parents in accessing mental and behavioral health and community-level resources, especially mothers, as they often bear the most responsibilities in Turkey.

**Keywords** Autism · Opinions of parents · Family · Social work

## Introduction

Once a child has been given a diagnosis of autism spectrum disorder (ASD), families find they must allocate time and resources to effectively support their child (Gray, 2002b). Oftentimes, lack of knowledge regarding ASD further negatively affects a child's development, increasing the need for additional support. Families can struggle with treatments prescribed for autistic children,<sup>1</sup> which can marginalize the

children and their parents (Salgado, 2020). Lack of support for an autistic child impacts family dynamics in several ways such as deteriorating family relations, increasing financial problems, and increasing negative psychological effects (Kudaibergenova, 2018; Yassıbaş, 2015). Our study was carried out to understand the family dynamic between parents and an autistic child, identify existing problems, improve the search for solutions, and emphasize the role of social workers in helping autistic children and their families.

## Conceptual Background

### Autism and Spectrum Concept

Autism is considered a neurodevelopmental disorder, commonly identified around the age of 3. Through advances in ASD diagnostic tools, recent data from the Turkish Ministry

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<sup>1</sup> Throughout this article, we use identity-first language ("autistic person") rather than person-first language ("person with autism"), except in phrasing related to diagnoses ("child with a diagnosis of ASD").

of Education indicate that 1 in every 80 children in Turkey has a diagnosis of ASD (Karal & Riccomini, 2016). Autistic children may have comprehension difficulties, limited verbal and nonverbal communication (Karacasu, 2019; Özdereli, 2019; Pektaş, 2016; Rustioğlu et al., 2018), or sensory processing disorders. When social demands surpass an autistic individual's capacity, they may engage coping mechanisms (Main, 2004; Monk et al., 2022), among which the most common is stimming (limited and repetitive behavioral movements; Bottema-Beutel et al., 2021; Möhrle et al., 2020). Autistic children, who have greater support needs but receive appropriate services such as strength-based programs, develop the abilities needed to live independently, access gainful employment, and have successful adult lives (Lee et al., 2020).

ASD has replaced the term *autism* in studies conducted in Turkey, though both terms are used interchangeably in the literature (Karacasu, 2019; Pektaş, 2016; Yassıbaş & Çolak, 2019). Defining autism as a spectrum reflects the variety of behaviors seen among autistic people and reduces the generalizability of certain traits (American Psychiatric Association, 2013). Autistics have shown underlying patterns of brain functions in regions that mediate repetitive behaviors, interaction, and communication, such as the hippocampus, amygdala, neocortex, and basal ganglia (Kim et al., 2016). The fifth edition of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-5; American Psychiatric Association, 2013) combined various subdiagnoses presented in the DSM-4 into ASD and refined the requirements for this diagnosis. According to Duvekot et al. (2017), the ratio of male-to-female diagnoses was 2.6:1, indicating a higher diagnostic prevalence of autism in males compared to females. However, it is important to stress that even the current diagnostic tools fail to capture female-specific manifestations of autism (Mandy & Lai, 2017).

### Factors Causing Autism

While factors that contribute to the development of ASD are under investigation, ASD is thought to be caused by both genetic and environmental factors (Gardener et al., 2011). The mother's exposure to high amounts of radiation, vomiting more than normal, abnormal increase in weight, and diabetes during pregnancy correlate with increased likelihood of children being autistic (Koca, 2019; Kurt, 2018). Recent studies show a positive correlation between parental age and the likelihood of children being autistic (Karimi et al., 2017).

### Problems Experienced by Families of Autistic Children in Turkey

Common problems experienced by families with autistic children can be categorized into four main groups:

psychological problems experienced by parents, problems in family relationships, economic problems, and community-related issues.

#### Psychological Problems Experienced by Parents

When children receive an ASD diagnosis, they may need therapy sessions, educational assistance, and support through major transitions, which may stress the parents and overall family dynamic (Firat, 2016). A systematic meta-analysis of 31 studies (total sample size 9208) revealed a prevalence of psychological disorders such as depression, anxiety, and obsessive-compulsive disorder among the parents of individuals with a diagnosis of ASD (Schnabel et al., 2020). Mothers of children with a diagnosis of ASD have a higher frequency of depression, fragility, exhaustion, and hopelessness. In contrast, fathers tend to distance themselves from the family and, as a result, from these needs (Aydın & Saraç, 2014; Üstüner-Top, 2009). An ASD diagnosis can result in self-blame and arguments between the parents, which sometimes leads to divorce. Most families misunderstand ASD as a disease (Akbulut, 2019) and report stress surrounding their children's future (Nuri et al., 2018) and chronic sadness from "loss" of a "typical" child (Lutz et al., 2012). However, coping mechanisms differ between families; some grow resilient and more connected after learning of their child's neurocognitive identity.

#### Problems Experienced in Family Relationships

When a Turkish child is diagnosed as autistic, they may require additional supervision that one of the parents, typically the mother, fulfills, often at the expense of her own self-care. Allistic siblings could experience abandonment as the mother spends more time with her autistic child (McConkey et al., 2008) and may also experience stress or shame in social situations from assisting their autistic siblings (Critchley et al., 2021). These transformations may lead to an unhealthy family profile (Yassıbaş, 2015). This situation is even more challenging for families with low socioeconomic status who struggle financially to provide resources such as education, therapy (speech, occupational, and related therapies), and social activities (Kudaibergenova, 2018).

#### Economic Problems

Diagnosed autistic children are often prescribed special therapy and educational activities, assistive technologies, and other support, which can prove costly for families of low socioeconomic status (Aylaz et al., 2012; Kudaibergenova, 2018; Lavelle et al., 2014; Yassıbaş, 2015). Families of children with a diagnosis of ASD need up to 3 times more financial support than families with only allistic children (Nuri

et al., 2018). Akkuş et al. (2020) found that parents must make difficult decisions, such as taking a leave of absence from work to care for their autistic children. According to Mengi (2017), government assistance in Turkey is insufficient, and diagnosis often triggers new costs related to education, health, and community participation. These added costs often put the family in a vulnerable situation.

### Community-Related Issues

In Turkey, parents of children with an ASD diagnosis are more likely to experience exclusion, belittlement, and discrimination when they take their children into the community. According to Üstüner-Top (2009), families of autistic children expressed that community members in Turkey are not tolerant of autistic children's behaviors. To avoid discrimination, parents often conceal their children's diagnosis or remain isolated (Kudaibergenova, 2018; Plumb, 2011). In a self-fulfilling cycle, families of children with an ASD diagnosis may think their relationships with people around them will deteriorate and preemptively distance themselves (Gray, 2002a; Kudaibergenova, 2018). Consequently, families who do not receive support from their social environment may become isolated and experience more vulnerability.

### Theoretical Framework: Bioecological Systems Theory, Parental Experience, and Autistic Children

We used the bioecological systems theory of development to understand the unique lived experience of caregivers of children with ASD diagnoses in Turkey. This theory looks at points of interaction between humans and their environment, emphasizing the microsystem (family, peers, and related social environments), mesosystem (interactions between microsystem elements), exosystem (external forces affecting larger systems: health, education, community engagement, etc.), macrosystem (social aspects like cultural beliefs and socioeconomic status), and chronosystem (events that influence individual development: starting school, death in the family) (Bronfenbrenner & Morris, 2007). For autistic individuals and their families, the microsystem could be the most influential through direct contact, but all systems interact together and with external forces. For example, when the education system provides a positive environment for autistic children, that influences how allistic children interact with their autistic peers, classmates, and friends. Together, these systems form the unique experiences and the developmental outcomes of parents and their children regarding acceptance, access, health, and inclusion.

### The Purpose and Importance of the Research

With advances in diagnosis, there is a need to understand the challenges of families with autistic children (Yılmaz Altuntas & Öney Doğanığiğit, 2021), and social workers have a crucial role in assisting families and their autistic children (Dababnah et al., 2011). We examined the difficulties experienced by families of children with a diagnosis of ASD in Turkey by thoroughly examining the challenges that parents encounter while caring for an autistic child. The study concludes by providing suggestions for policymakers and the social work profession on how to improve the lives of families of autistic children.

### Method

#### Research Design and Model

This research was conducted using a qualitative phenomenological approach to examine problems experienced by families of children with a diagnosis of ASD (Creswell & Poth, 2016; Guest et al., 2011). After collecting data through semi-structured interviews (Patton, 2014), we reread the excerpts several times, looking for trends and themes. After completing the codes, the entire team identified common themes. The data were entered into a Microsoft Excel spreadsheet, and descriptive analysis was conducted.

#### Research Group

The study included 10 caregivers between the ages of 35–49 who were recruited on a voluntary basis from the families of students (7–11 years old) who had been given a diagnosis of ASD at special education schools in Bağcılar and Bahçelievler districts in Istanbul, Turkey. These districts are migration destinations chosen for their economically, ethnically, linguistically, and politically diverse population. Convenience sampling was used due to COVID restrictions in Turkey. Parents were recruited through poster advertisements. The only inclusion criterion was that caregivers had a diagnosed autistic child attending one of these schools. We evaluated our base sample size after completing seven interviews (Guest et al., 2020). We decided to recruit three more participants to weigh against the information already collected, after which we saw redundancy and decided to end recruitment.

#### Data Collection

Before starting the study, we developed interview questions using bioecological theory, as well as consulting experts and community members. Data were collected

from 50- to 60-min semistructured interviews consisting of 12 questions (Table 1) between December 7, 2020, and January 8, 2021. Participants' oral consent and interviews were recorded via voice recorder, phone, WhatsApp video chat, and Zoom. Parents' background details were recorded (Table 2). Parental details were kept confidential to protect participant identities. In the "Results" section, age and caregiver role were used to identify participants.

## Data Analysis

To analyze parents' experiences (Elliott & Timulak, 2005), this study used descriptive, interpretative analysis following Ritchie and Spencer's (1994) five-step framework: including familiarization, identification of the thematic framework, indexing, charting, and mapping and interpretation. Familiarization occurred by transcribing the recordings with initial notes, after which each team member was assigned a script for reanalysis (including removal of incidental phrases). Identification of the thematic framework was conducted in this reanalysis, and the scripts were classified into themes and subthemes, revealing higher-level categories. During indexing, we systematically applied the framework to better organize the data and assigned each script under the correct theme. Charting involved further regrouping and ordering of the themes under four headings: problems experienced by families with autistic children, psychological problems experienced by these families, parental problems, and economic and community-related issues. All of these steps were done manually using paper, pen, and Microsoft Word. The findings were mapped and interpreted by identifying patterns, defining concepts, finding associations and common issues experienced by parents, and developing explanations. For validity and triangulation purposes, we consulted providers and community members about the findings and constantly referred to the bioecological systems theory (Bronfenbrenner & Morris, 2007; Thurmond, 2001). The materials were completed in Turkish then translated into English.

## Findings

### Psychological Problems of Families

**Parents' Initial Emotions Following Child's ASD Diagnosis** Most parents did not know about ASD, as reflected by their strong emotional responses when their initial feelings about their child's diagnosis were evaluated.

I didn't know what autism was, and I had never heard of it before. Well, what can I do? I cried a lot on the first night. I said, what can I do? (Mother, 37)

At first, I didn't know what it was. I thought autism was a disease and thought it would heal like this. I learned the situation from the first doctor... we were so scared, and I became miserable when there was no treatment later on. (Father, 38)

Our evaluation of the participants' opinions revealed parents discovered their child's ASD coincidentally, and most regarded it as a disease.

My child with autism had a deep burn on his finger, and my friend said how he does not hurt, and how does he not cry... then my friend asked if she had autism like in her brother-in-law's child. After things like my daughter not speaking, not being sensitive to her name, and not feeling a burn on her finger, we talked to my husband, and made a research on the internet, and understood that my child was autistic. (Mother, 41)

We went to visit our relatives, and the children were playing. The relative's child hit our child, and then our kid hit his head. The blood started to flow, but the reaction of the child was zero. My child did not cry, nor was he talking ... We learned from the neurologist by chance that the child has autism ... I thought the disease would pass, but whatever we did, they did not work. (Father, 49)

Some participants stated that they initially met the diagnosis with deep sadness.

At the age of 3, signs of autism were found ... there the doctor said. Of course, I was very sad when I first heard about it [autism]. It was said that he would not be able to walk [and] that he would be spastically disabled. Thank God none of them happened. Of course, I am very sorry that he has autism. (Mother, 35)

### Psychological State After Understanding the Child's Diagnosis

Participants revealed that emotional processing varied.

I said, what can I do for my child... I asked myself how I could overcome it... I thought a lot about how I could fix it... I was still very sad... I talk to my daughter a lot, I think she understands me, and I have tried to comfort myself for years. I mean, I consoled myself like this because I wanted her to understand me, maybe because I wanted her to be normal. I always thought, feeling as if she understood me and understood. (Mother, 35)

Some of the participants stated that the process was prolonged due to concerns about their children's future.

Since my brother's son also has severe autism, I was terrified. How do we cope? How will it be? Anxiety and boredom got a knife in my heart. So those who do not have these troubles cannot understand me. (Mother, 44)

## Problems Experienced in the Family

**Problems Experienced in the Home** Some participants stated that they had problems because their children did not allow them to move around the house or move things within the house.

I have not been going anywhere from home for 10 years, and I am always at home... the child is uncomfortable in other houses and does not want to go. I cannot move something at home; my child never allows it. These are tough things, and you can't buy anything new for the house. (Mother, 42)

Some participants stated their home lives changed to accommodate the child's emotional states.

Everything changed according to my child, including our sitting up. We live according to my child, whatever we live from breakfast to bedtime. I do not know whether he will be angry, anxious, afraid, where he will do what and how to tell... we live everything according to our child... Even mealtime can change according to my child. We live without knowing when and what will come. You cannot arrange anything in order. (Mother, 44)

**Problems Experienced by the Parents as a Couple** Family conflict due to the needs of an autistic child was examined. We found that fathers generally distanced themselves from the care of the child, and responsibilities were left to the mothers, which added extra burdens on them.

I am at home, so I cannot spend time with my husband. I forgot what a holiday after the child means. I really forgot what it was like to have a holiday with my husband... sometimes I say how far it will go at home like this? Will I never be able to leave the house? You know the bird on the street is happier than me. I missed being free so much. May my Lord not test anyone with a child. (Mother, 42)

Some participants stated that after diagnosis, their spouse did not accept the child and tended to distance themselves

from their spouse through verbal aggression, accusations, and divorce.

My husband got so cold from me; he insulted me a lot. I couldn't prevent it, and he didn't understand me. He always held me responsible; he told me you were the reason, and I cried for days. I barely took my husband to the hospital because the child did not stop there. He mostly upset me, he always quarreled with the doctor for the child, and he said, "How is this disease not cured? How are you a doctor?" When the doctor kept telling us that medicine is love, my husband told me, "What do you mean?" and "You're talking about unnecessary things." Husbands have more difficulty accepting this situation than mothers. (Mother, 35)

We were very good with my husband before the child. We dreamed everything would be beautiful. When my husband learned that we would have a son, he was pleased... then everything changed when the child was autistic. He didn't want the boy and me. He wanted to get divorced, got divorced, and left home. He did not come home for a while, then he had to come.... When the second child also became autistic, we were more devastated. Of course, we are not like a spouse anymore; we are like friends. (Mother, 40)

Some participants stated that there were discussions between the spouses about the child's condition during pregnancy.

We had a lot of quarrels at first. I blamed my wife because she was smoking during pregnancy, and I said it was because of her. The child did not sit comfortably in the womb. Then my wife got angry with me because my family has genetic diseases. We had many quarrels, but we said there was nothing to do; we had to accept it. (Father, 49)

I had a very stressful pregnancy. I could not eat so well. During pregnancy, the doctor gave me vitamins. My husband said that our child was autistic because I drank the chemicals. My husband was very angry with me that those vitamins had side effects. We had a lot of quarrels because of that. (Mother, 45)

## Economic Problems

**Economic Problems Regarding the Needs of the Child** Participants cited economic problems in purchasing diapers, the provision of materials for the child's education, and providing for therapies, diets, and health needs of the child.

I use a diaper for my child. For example, our state also provides diapers, but three packages every 2 months are not enough. I am having difficulties with my child

because of it... Teachers say buy this game for the development of the child; I cannot buy it. There were paid classes, and some mothers take their children to those classes. (Mother, 37)

There are lots of expenses, private lessons, language therapy, swimming, sports, etc.... I took my child to special sessions for sensory development for 4 years. We went to individual and group classes. My child took lessons for 4 hours a day, and then we gave my child to special education from morning to evening. I hired a language therapist and a private tutor at home. (Mother, 44)

**Economic Problems Arising from Family's Working Life** Mothers of children with a diagnosis of ASD often had to stop working, and those who quit their jobs during pregnancy often could not return to their careers. While there was a change in the working life of fathers who partially assumed responsibility for the care demands of their child, no change was observed in the working lives of fathers who attributed full care responsibility to the mother.

I was working before... I cannot leave the house anymore, and I cannot go anywhere. I cannot take my child anywhere. There is no problem in my husband's business life. He leaves the child to me, and he is not interested at all. (Mother, 37)

I cannot work when the child is autistic because my child is challenging. Both are hard, though, but they are more difficult when they are younger... My husband was fired from his workplace and is unemployed. Due to our child's issues, my husband could find another job for 4-5 months. Because in this situation, it was difficult for my husband to get permission from his workplace. Sometimes we need to take the child to the doctor. How can I go alone? There is no way. (Mother, 40)

I was working, but after the fifth month of pregnancy, I had problems. I quit my job because of that. But I would like to work. I think a career is an important process for women, but it isn't easy, so it is not possible for me anymore... if I am tired as a mother and I can say "offffff" [sic] while looking after my child, I do not believe that anyone can take care of my child. (Mother, 41)

**Economic Problems Arising from Child's Behavior at Home** Participants stated that oftentimes their furniture was damaged or lost due to the child's behavior, creating significant additional economic problems.

My child breaks furniture and pours many things all the time. Even the heater does not have a top panel.

In other words, glasses, bowls break very often, fork, knife, and spoon always disappear, always disappear... I need diapers, and we buy them too. I only buy 33-34 diapers in a week. These are the only things that I can remember. (Mother, 40)

My daughter was always throwing the glasses in the kitchen to the floor, too many to count how many broke. The trinkets in my house were shattered... I almost run out of ornaments in my house. Here are those paintings or something, glass vases, in short, I put everything on the top shelf in my life. (Mother, 35)

## Community-Related Issues

Families of children with a diagnosis of ASD experienced problems with their communities due to judgment, not being understood, and not being able to participate fully in society due to their child's behaviors.

I will go to Adiyaman; my child does not stay in the car. Everyone says, shut up, your child, our head is swollen, I say the child does not understand. How can I shut my child up? He does not understand. Therefore, I go to a village every 4 years because I miss my family. I cannot take my child to the Market because he throws everything aside. (Mother, 37)

I have had a lot of trouble, so even people showing compassion sometimes annoy me. Sometimes I take the bus, and they call me to shut up that kid, saying we got swollen heads.<sup>2</sup> You may not know how I feel when the women sitting behind me say I have no children like that. (Mother, 35)

We moved away from many families. They did not call us, no matter how close we are, it does not happen as relatives, so commuting each other decreases. For example, if you go to a visit, they look at the child strangely. If the guests come, they look at the child strangely. (Father, 39)

Some participants expressed that they preferred to isolate themselves to avoid possible problems and repeating past situations.

I ended my relationships with most of [my friends] because their perspective towards my child changed... my relatives and neighbors were not welcome because they did not know what autism was. People were also not able to understand what I was experiencing because they did not know about autism. (Mother, 41)

<sup>2</sup> "Swollen head" (word in Turkish) is equivalent to the English idiom "made my head explode."

I kept a distance from all of them. The people where I go do not understand me. (Mother, 42)

## Discussion

Our findings revealed that families with autistic children experience challenges in relationship conflicts, psychological issues, community-related problems, and economic hardships. While parents of diagnosed autistic children living in Turkey experience barriers and challenges similar to those living in developed nations (Lavelle et al., 2014), our findings revealed that a lack of awareness about ASD in Turkish society exacerbates families' socioeconomic and intrafamilial conflict, can lead to delayed or avoidant diagnosis, and forces families into isolation, consistent with the findings of previous studies (Aylaz et al., 2012; Üstüner-Top, 2009; Yilmaz Altuntas & Öney Doğanyığıt, 2021). An early diagnosis of ASD helps families provide adequate resources for the child and helps ensure the child's success in education, employment, and building social support (Plumb, 2011).

Bioecological theory suggests that people's immediate environment affects behavior directly (Bronfenbrenner & Morris, 2007). Lacking parental education about ASD diagnosis can result in family conflict and negatively impact the development of autistic children (Bronfenbrenner & Morris, 2007). This study indicated that families who received training and education on ASD showed reduced familial conflict and were more successful in supporting the child's education, development, and improvement of self-care skills. Families with low educational levels of ASD have low expectations of their autistic children (Softa, 2013). Another study showed that the need for social support increased inversely to the education level of families of children with disabilities (Ayyıldız et al., 2013). These studies align with our call for a holistic approach to assisting families, to benefit autistic children in the short and long term.

In Turkish communities, mothers assume most of the child-care responsibilities. It has been demonstrated that mothers were more depressed and anxious than fathers (Olsson & Hwang, 2001) and that unemployed mothers of autistic children experienced more stress, burnout, and anxiety than working mothers (Çengelci, 2009). Özsoy et al. (2006) found that more than half of the families in their study felt that they did not receive support from their community, that 54.5% of the families were worried about the future, and that 48.2% were worried about the potential for various accidents happening to their children. Our study highlights the importance of ASD educational programs, psychological support, and financial support for caregivers with low-income status.

Our study showed that to meet the needs of their children, some working parents had to quit their job or make significant changes in employment, which typically worsened the

economic stability of the family, affecting families' ability to afford the various needs of their autistic child. In developed nations, such as the USA, Gnanasekaran et al. (2016) found that small adjustments in the employment environment (unpaid leave, telecommunication, flexible work hours) empowered parents to support their children while remaining employed. Participants in our study indicated a need for such adjustments to help families maintain their employment.

## Limitations and Future Research

In Turkey, families with children with an ASD diagnosis are generally difficult to reach, which was exacerbated by the COVID-19 pandemic. Some families rejected our requests for a meeting because they had not accepted the child's diagnosis: "My child has no problem, does not create any problem, etc." Cultural barriers also discouraged families from participating in research due to fears of intrafamilial conflict. While the interviews were conducted virtually, meeting with participants in person could have increased the depth of the work. A longitudinal study is needed to further examine economic, psychological, and intrafamilial issues. This study was conducted in Istanbul, Turkey, which has more services and resources than other cities in Turkey. We suggest that future research to investigate these issues in other cities that have higher poverty rates.

## Conclusions and Implications

Parents of autistic children experience a range of challenges in Turkey, including mental health issues, familial disputes, economic problems, and social discrimination. Although it is difficult to generalize from this study, we have observed severe consequences of exclusion, criticism, and labeling of families in their social environment, which have pushed them away from their communities. The economic and mental health burdens parents face require extra attention from policymakers as well as social workers and health providers. The government, alongside social workers, should allocate more resources for these parents to alleviate their struggles.

Many challenges are ahead to increase public awareness of ASD in Turkey. Yildiz et al. (2019) argued that public record-keeping related to autism prevalence is underdeveloped, making it difficult to recommend targeted services and policies. They also found that the online platform needed to be improved for parents to share experiences, manage isolation, and raise public awareness. To increase public awareness, Yilmaz Altuntas and Öney Doğanyığıt (2021) recommended mainstream media that represent autistic people accurately to bring awareness of their needs and strengths. Additionally, to empower families, we call upon the Ministry of Family,

Labor, and Social Services to increase social programs targeting the needs of families of autistic children. At this time, home-based payments for each autistic child are insufficient to cover the child's necessities. Support for autistic children should be covered by state programs to empower parents to reclaim their status and rejoin the labor market.

Turkey lacks social service providers, which limits its ability to provide adequate services for autistic people and their families (Bulut, 2003), but in recent years, the number of social workers has rapidly increased, and they have taken important service roles (Bolgün & Şahin, 2019). A major step taken by the Turkish government is the declaration of the Autism Action Plan of 2016–2019, but no advancement has been made on this initiative (“Otizm Spektrum

Bozuklug”, 2016). We suggest that social workers in Turkey lead the effort to advocate for resources for children and their families as they are uniquely situated to effectively assist families of autistic children at the micro-, meso-, and macrolevels. To advocate for resources, social workers could develop more educational materials related to ASD and family challenges to better equip incoming providers. Finally, given their role in ASD screening, diagnosis, and early intervention (Dababnah et al., 2011), it is crucial that social workers provide needed support both for children and their caregivers.

## Appendix

**Table 1** The interview guide

- 1) How did you learn your child has autism, and how did you meet this situation?
- 2) What did you feel when you found out that your child has autism?
- 3) What has changed in your life after your child was born?
- 4) How does living with a child with autism affect your life?
- 5) How did having a child with autism affect your relationships with your spouse?
- 6) Has having autistic children changed your relationships with society?
- 7) What has living with a child with autism changed financially?
- 8) Has your working life changed after you found out that your child has autism?
- 9) Could you tell us about your child's health-related needs?

**Table 2** Participant demographic and background information

Role	Age	Education	Marital status	Children <i>n</i>	Autistic child <i>n</i>	Autistic rate
Mother	37	Not given	Married	4	1	90
Mother	35	High school	Married	1	1	90
Father	38	Elementary	Married	3	1	90
Mother	40	Elementary	Married	2	2	80
Mother	42	High school	Married	2	1	95
Father	39	Not given	Married	1	1	82
Mother	44	University	Married	2	1	95
Mother	41	University	Married	2	1	60
Father	49	Elementary	Married	1	1	95
Mother	45	Elementary	Married	3	1	95



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**Data Availability** The datasets generated during and/or analysed during the current study are available from the corresponding author on reasonable request.

## Declarations

**Informed Consent** Informed consent was obtained from all subjects involved in the study.

**Conflict of Interest** The authors declare no competing interests.

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