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Expectations of Families with Mentally Disabled Children[1]

Zihinsel Engelli Çocuğu Bulunan Ailelerin Beklentileri

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ABSTRACT

Having a child with a mental disability causes significant social, cultural, and economic problems in the lives of families, which in turn generates significant expectations for the solution of these problems. In this context, the aim of this research is to determine the social, cultural and economic expectations of parents who have mentally disabled children at home from different units and groups of people. The research consists of interviews conducted with 39 mothers and 1 father who have mentally disabled children at home in 3 different rehabilitation centers in Kemalpaşa district of İzmir. Therefore, in order to determine the different expectations of families in a more in-depth and accurate way, the semi-structured interview technique, which is one of the interview methods of the qualitative research approach, was preferred. The analysis of the research findings was carried out with the content analysis method. The results indicate that the most important expectations of families with children with mental disabilities are related to education and health services, and increased awareness in social relationships.

Keywords: Expectations, Parents with Mentally Disabled Children, Education, Disability Care Salary, Awareness

ÖZ

Zihinsel engelli bir çocuğa sahip olmak ailelerin hayatında önemli sosyal, kültürel ve ekonomik sorunlara neden olurken, bu durum sorunların çözümüne yönelik önemli beklentiler oluşturmaktadır. Bu bağlamda bu araştırmanın amacı, evlerinde zihinsel engelli çocuğu olan ebeveynlerin farklı birim ve kişi gruplarından sosyal, kültürel ve ekonomik yöndeki beklentilerini tespit etmektir. Araştırma, İzmir'in Kemalpaşa ilçesinde 3 farklı rehabilitasyon merkezinde, evlerinde zihinsel engelli çocuğu olan 39 anne ve 1 baba ile yapılan mülakatlardan oluşmuştur. Bu nedenle, ailelerin farklı beklentilerinin daha derinlemesine ve doğru bir şekilde belirlenebilmesi amacıyla nitel araştırma yaklaşımının görüşme yöntemlerinden biri olan yarı yapılandırılmış görüşme tekniği tercih edilmiştir. Araştırma bulgularının analizi içerik analizi yöntemiyle gerçekleşmiştir. Sonuç olarak, evlerinde zihinsel engelli çocuğu bulunan ailelerin en önemli beklentilerinin eğitim ve sağlık hizmeti olduğu, ilişkiler açısından da farkındalığın arttırılmasını beklediği tespit edilmiştir.

Anahtar kelimeler: *Beklentiler, Zihinsel Engelli Çocuğa Sahip Ebeveynler, Eğitim, Engelli Bakım Maaşı, Farkındalık*

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INTRODUCTION

According to TUIK 2021 data, there are 5,841,180 disabled people living in Turkey, including 3,337,922 women and 2,503,258 men (Confederation of Disabled People, 2022). Although this is a significant number, the number increases even more when disabled individuals who immigrate as well as unidentified and unregistered people are included. A significant majority of these disabled individuals are mentally disabled individuals.Having a mentally disabled child can create many psycho-social and economic problems for families. Having a child that is different from what is thought and expected, not being able to accept the child, problems between spouses, dependence on the family, lifelong care, what will happen to the child after the death of the parents and economic concerns can cause various problems for the individuals in these families (Işıkhan, 2006, p. 28).In addition to the difficulties that parents of mentally disabled children have regarding the child, family and society, this situation becomes serious due to the parents' adaptation process to these difficulties and the pressure and anxiety created by their feelings about the future. Therefore, parents of disabled children face significant and challenging experiences stemming from psychological, emotional, social, economic, and physical difficulties (Sherbini et al., 2016, p. 35).The family experiences psychological difficulties when they learn that they will have a disabled child, and the economic burden of caring for the child after the child is born also poses another challenge. On the other hand, the negativities brought about by social relationships and interactions also have a negative impact on this difficult process that families go through. Human differences can lead to marginalization and exclusion when they are perceived as a threat. Othering is the negative perception of those outside of "I" and "we" (Özensel, 2020, p. 369). For this reasons, while the traumatic exclusions experienced by disabled individuals cause greater awareness of the disability, it can also cause exclusion from social life (Özil, 2023, p. 188-189). Individuals with disabilities are exposed to exclusion in the context of education, social participation, access and social relations, as well as in basic areas such as economy (Kaldık, 2024: 393).As a matter of fact, in sociology, Goffman's biggest concern is to contribute to the examination of human relations that are forgotten, ignored and ignored in social events (Çetin Dagdelen, 2020: 240). In this context, according to Goffman, disadvantaged groups may face the problem of stigmatization within their social relations. According to Goffman (2014: 29), when there is a belief that a stranger in front of us has a quality that is different from others and is not considered important, he/she can be categorized as a bad, dangerous or weak group. In this case, this person may cease to be a normal and healthy ordinary person in our minds and be reduced to a tainted, disabled and disregarded person. Such an attribute is a stigma with a particularly high discrediting effect. Sometimes this can be called failure, inadequacy or obstacle. To put it briefly, stigma includes devaluation and its consequences (Okumuşoğlu, 2019:118). Disabled people face various social difficulties, exclusions and obstacles. And these are mostly related to environmental factors. There is a need for educational support activities that will help disabled people improve their skills and the creation of social environments that enable them to establish relationships with their peers for their social development. For this

reason, families with mentally disabled children have needs and expectations to be supported emotionally, psycho-socially, economically and from different aspects, to be informed and to be able to plan the future (Demirbilek, 2013: 58). In addition, expectations of families with mentally disabled children have emerged for their children and themselves, such as public awareness, emotional and psychological support, and independence (Washington-Nortey and Serpell 2021, Sunay 2022). As a matter of fact, according to Irawati, Suyasa and Heng (2023), families with mentally disabled children emphasized that their expectations in this regard are important due to the bullying their children are exposed to in the community and the difficulties of providing socially and culturally suitable schools for their children. In this respect, what is important and needs to be considered is to integrate disabled individuals into society. Because disabled individuals, who constitute an important part of the society in terms of population, will show positive improvements in terms of the mental health of both themselves and their families who care for them, if they are integrated into society (Cihan, 2021, p. 1) In this context, in the context of examining the problems of families with mentally disabled children, it is considered important to determine the social, economic and cultural needs and expectations of these families from the state, local governments, rehabilitation center and the people and communities they are associated with, in order to reduce or eliminate their problems. On the other hand, the limited number of studies investigating and revealing the expectations of families with mentally disabled children makes this research important. Because while there are studies on disability in both national and international literature, it is seen that these studies focus on issues such as exclusion, social policy, and women's disability. However, it seems that there are few studies that address the expectations of families with mentally disabled children in the context of their problems, specifically for mentally disabled parents and from a sociological perspective.

Purpose of the Research

Parents of mentally disabled children face social, cultural and economic problems in their lives. While parents try to cope with these problems, they also develop wishes and expectations to overcome these problems. Therefore, the aim of this research is to determine the social, cultural and economic expectations of parents who have mentally disabled children in their families in the context of the state, local governments, rehabilitation center and the people and communities they are associated with.

METHODS

Qualitative research can be defined as research in which qualitative data collection methods such as observation, interview and document review are used, and a qualitative process is followed to reveal events and perceptions in a real and holistic way in their natural environment (Yıldırım and Şimşek, 2013, p. 135). Although qualitative study is about emotions, ideas and experiences, it is also preferred to obtain new perspectives. Interview, one of the qualitative research data collection methods, is applied in unstructured or semi-structured (Ugwu and Eze, 2023, p. 20). Therefore, in

this study, qualitative research method was preferred in order to obtain a more comprehensive and rich understanding of what parents' expectations from people and institutions are socially, culturally and economically, in the context of their social relations. In addition, for the field research of this study, ethics committee permission was obtained from Bolu Abant İzzet Baysal University Human Research in Social Sciences Ethics Committee with the number 2021/272.

Sample Selection and Data Collection Process

While layered, systematic and random sampling techniques are preferred among the sampling techniques that will provide the most appropriate representation of the research population in quantitative research, a purposeful approach is used in qualitative analysis (Burcu, 2018, p. 121). Purposeful practice techniques, different from probability-based practice methods within the scope of good research, qualitative research tradition emerged (Yıldırım and Şimşek, 2013, p. 135). The goal of research programming is to uncover thoughtful details and uncover rich and detailed information. Methods aimed in this way are useful in taking and revealing statements about facts and events from various perspectives (Tarhan, 2015, p. 653). In this research, mothers and fathers who have mentally disabled children at home were interviewed in detail and in order to reveal their knowledge.

While determining the interviewees who participated in the research, field qualities made it necessary to choose more than one of the qualitative research sample types. Before the main researchers were determined, it was thought that a pilot study would be important in terms of the clarity and answerability of the questions, and a pilot study was conducted with 3 participants. The three participants in question were reached through easy-to-access sampling and known people (Yıldırım and Şimşek, 2013: 141-142). The participants of this pilot study were reached through the vice president of a disabled association in the research area. As a result of the pilot studies, some questions were changed, parts that were not understood were corrected, and the questionnaire was finalized before proceeding with the main interviews. In addition, during the pilot interviews, the main participants of the research were tried to be determined through the interviewees who participated in the pilot study. Initially, it was planned to reach these interviewees using the snowball sampling technique, one of the qualitative research sampling types. In other words, after interviewing the parent with a mentally disabled child, the aim was to reach the interviewers by asking whether they knew anyone with a mentally disabled child (Merriam, 2018: 77). However, when it was realized that this plan would not work properly during the pilot study, it was decided to follow a different method to reach the interviewees. Among the people in whom the pilot study was conducted, 2 families reached through snowball sampling gave a negative response to participate in the interview. Therefore, in order to access appropriate information in line with the purpose and problem of the research, an application was made to the District Directorate of National Education in the research area as a different channel.

After the District Directorate of National Education provided information to the Rehabilitation center, which is the largest in the research area and has the most students, the relevant educational institution was visited and an introduction was made. Interviews started at a place and time deemed appropriate by the rehabilitation center. In order to reach the second Rehabilitation Center, communication was made through an acquaintance who knew the founder of the relevant Rehabilitation Center, and interviews were held at the place and time deemed appropriate by the Rehabilitation Center manager and officials. In reaching the third and last Rehabilitation center, we acted individually and met with the relevant authorities, provided information about the research, and interviews were held in a place deemed appropriate by the institution officials. The interviews, which were held in a total of 3 different rehabilitation centers, were held on the day and class hours when parents brought their children to the Rehabilitation center, in suitable empty classrooms and places. On the other hand, individual communication and the institution officials informing the families and making suggestions beforehand have emerged as persuasive qualities in persuading the families to meet. Disabled children from the Kemalpaşa district and its villages receive education in these 3 centres. The students receiving training consist of students diagnosed with mild, moderate, severe and very severe mental disabilities. The main reason for choosing parents with mentally disabled children in this study is that no study has been found with parents with mentally disabled children as the study group in sociological studies in Turkey. In addition, the other reason why only parents with mentally disabled children were selected is that the study group was tried to be homogenized. Including the parents of children with different types of disabilities in the scope of the research would greatly expand the scope of the research and would also lengthen the data analysis process of the research. In the context of these reasons, the research sample was shaped in this way. Following pilot studies, in-depth interviews were held with 40 parents from the end of June 2021 until November 5, 2021.

Data Analysis

The data obtained from this in-depth and face-to-face research was analyzed using the content analysis method within the qualitative research technique. In this context, the data in question was coded, themes were created and the themes and codes were arranged again, the findings were defined and finally interpreted. Short and understandable codings were made based on the data obtained during the analysis phase. Theoretical and conceptual framework was taken into consideration when creating these codes. After the coding phase, the codes were brought together through their common aspects and themes were obtained under the upper heading of the codes. In the third part of the analysis phase, the available codes and themes were brought together and an attempt was made to make them orderly and harmonious, suitable for the definition and interpretation of the data. In the interpretation part, which is the last stage of the analysis, it was tried to express how the findings of the research and the theoretical part of the research are connected in terms of overlapping sections. Coding the interviews in the findings section of the research ensured that the

participants' opinions were conveyed confidentially and easily. While the following sequences such as P1, P2, P3... indicate the participant order, the numbers immediately following it and the letters next to it indicate the age and gender of the participant (45W, 30W, 40M,...). Finally, at the end of the coded quotes, explanations regarding the participants' marital status as 'Married', 'Divorced', or 'Widow' were included (P3, 26W, Married).

FINDINGS

Characteristics of Respondents

At the beginning of the interviews, before starting the interview questions, a sociodemographic form was applied to the participants and an attempt was made to obtain information including socio-demographic information such as age, education level, profession, marital status, and economic status. Considering these demographic characteristics of the participants, 39 of the parents participating in the study were female and 1 was male. In terms of educational status, 20 parents are primary school graduates, 8 are secondary school graduates, 4 are high school graduates, and 3 are university graduates. In addition, to the question about education, 3 of the parents answered "high school dropout" and 2 of them answered "none". 34 of the female participants are married, 4 are divorced, and 1 is a widow. The male participant parent is married. The male participant answered the question about their profession as a farmer, while 37 of the female participant parents answered as a housewife, 1 theologian, and 1 textile worker. The average age of the parents is 39. While it was revealed that the parents education levels were generally low in terms of education, it was determined that the maternal parents were housewives and took care of the disabled child and did not work in any job. The economic level of the parents includedin the research is 3,471 Turkish lira.This monthly income shows the lower income group for 2021.

Expectations from the State

Participants who have children with mental disabilities were asked about their expectations from the state, local governments, and the people and communities they are associated with. Therefore, participants were asked the question: 'What are your expectations from the state?. The participants (21 participants) primarily and predominantly cited education services and their related expectations. Of the 21 participants, 15 stated that education was their priority, while the remaining 6 cited expectations for both education and health services. Of the remaining 19 participants, 6 prioritized health services, 4 highlighted shuttle and transportation services for their children's development, and 3 mentioned money and material aid. Others requested clothing, notebooks, salaries, and services that would secure a future for their children. They also expressed expectations regarding payment, such as determining the rightful beneficiaries and ensuring appropriate action is taken. Conversely, one participant commented positively on the services, while another simply answered, 'I can't think of anything'. The resulting findings confirm that expectations for 'education' constitute the participants' primary need. Regarding the education factor, participants listed the following expectations: 'full and day-long education,' 'increased lesson hours,' 'education suitable for the

disabled individual's disability,' 'a separate and special school for the disabled,' 'smaller class practices,' 'one-on-one lessons and home tutors,' 'comprehensive education, with abundant and varied materials in educational settings,' and 'swimming courses'. A few narratives reflecting these views are as follows:

> “I'm just not happy about this training. That (participant smiles) So education, not education. It needs to be researched and done. For example, the environment for those children needs to be tailored to them.” (P25, 43W, Married)

> “The state should provide continuous education to children, for example, more in special education. “For free.” (P3, 26W, Married)

> “According to the child's level, there should not always be two strings of beads or fake stickers. So, the ones and the two need to teach A, B and C as well. If my child writes 1 or 2, he also writes A. They need to make some effort. Spoken language education should also be given.” (P12, 45W, Divorced).

From the above quotes, it can be stated that the education service constitutes the most important expectations of the participants and emerges as an important area that they want to be completed or improved in the context of this service. In particular, the parent's statement in the first quote that education does not have its original quality and the "more on special education" approach in the second quote reveal the problems that families experience regarding education and the importance they attach to education in this sense. On the other hand, the third quote, which expresses the positive impact of education and that children can respond to education no matter how disabled they are, also emphasizes that the desire for "spoken language education" should be diversified.Although education is important for all children, it is even more important for disabled children who have limited social and economic opportunities. Because special education allows disabled children to be more included with those without disabilities and to have more access rights with their peers (Aron and Loprest, 2012: 97). On the other hand, it is seen that the second expectation of the participants is mainly in the field of health. Some of the narratives of the participants who highlight their expectations from the state in terms of health are as follows:

> “They give these health reports for 2 years, it is obvious that our children cannot recover in two years. Currently, the hospital gives it for a year. They give it for 2 years, 3 years, some also give it for one year. But they usually give me 2 years. They gave it for 2-3 years, but there are also people who gave it for 5 years. I think this needs to be extended further. Because in a certain year the child will not recover anyway. Once we go to RAM, we go. Besides, CP is not a disease that can be cured instantly. Likewise, children with autism and Down syndrome. You see, we can't support these children anymore anyway. We don't have to go on our lap every 2 years, so they can

> extend this to 5 years. Anyway, if I had a (well) child, I would take it myself and have that medical report canceled." (P33, 30W, Married)
>
> "Autism School. For example, as I said, in big cities it is 2 hours away. I would like him to be closer." (P40, 47W, Married).
>
> "You know, they give this 3-month physical therapy to spa patients. They can give unlimitedly. Those kids need physics anyway. "They get worse when they don't see physics" (P10, 28W, Married)

The above findings reveal that the participants have expectations in the field of health as an important topic after training. Parents especially express their opinions about the difficulty in obtaining a RAM report and the limited treatment in health services. The fact that the reports given to families with disabled children are not long-term and that parents of disabled children, especially mothers, go to hospitals far away from where they live and try to get reports by going through different stages and examinations creates a significant burden and difficulty for them.While the first interviewee's quote in particular reveals this, the "demand for institutions to be close" for education and treatment in the second quote, which is also linked to the first quote, constitutes an important expectation for families in terms of health. On the other hand, in the third quote, the fact that the family with a disabled child states that the duration of physical therapy and other health services is short in terms of their child's health is an important point emphasized by the families.In terms of Health Services, if the accessibility problem that arises between the needs of parents with disabled children for services and their provision is not taken into account sufficiently, it causes disabled people to face significant problems in terms of Health Services (Castro, Lefevre and Others, 2010: 1). This situation emphasizes how important health services are in addition to education in terms of families' expectations.

Expectations from Local Governments

Regarding the expectations asked to the participants in terms of 'local governments', it is seen that 19 of the participants expect material and moral assistance from local governments, and they generally diversify this assistance under the expressions 'should help' and 'those in need should be helped'. On the other hand, 10 of the remaining participants expressed their expectations as physical spaces and places, while 4 participants expressed their expectations from local governments as social activities and event activities. Apart from this, the remaining 7 participants answered their expectations from local governments by saying 'I don't know and I don't have much expectations'. Participants' expectations from local governments regarding aid include 'coal aid', 'clothes', 'food', 'salary', 'home care' and 'service to children', 'diapers', 'medicine', 'wheelchair', 'material'. It has been seen that it embodies the aid of 'psychological counseling service'. It was also observed that the participants included the opinion that the people to be helped should be identified well. Some of the narratives of the participants in question are as follows:

> “Help, they should help us. “They should meet the needs of our children.” (P3, 26W, Married).

> “The headman was distributing it from the district governor's office, I did not receive anything before that. So they should give it equally to everyone. For example, it is known that my child has a disability. In other words, parents cannot say, "My child is disabled, give me coal"[...]there are also those who are not in a good situation." (P5, W45, Married).

> “In terms of health, for example, some patients cannot take their medications, […]there is a need for sensitive people to help in this regard. Because medicines are very expensive, materials are very expensive, wheelchairs are very expensive, I think it would be great if they could help in this regard.” (P31, 46W, Divorced).

On the other hand, as in the second quote, it is seen that parents have important expectations that the aid received through local governments should be distributed equally and fairly, and that medicines should not be expensive, as mentioned in the third quote. In this respect, it shows that families need policies and services to address such problems and concerns, and that local governments stand at an important point regarding families' expectations. It also can be seen from the above quotes that the participants expect the assistance that may be required from local governments in terms of their different needs for families with disabled children and disabled individuals. In addition to these participants, there were also participants who stated their expectations from local governments in terms of physical needs and places. These needs are stated as suitable and compatible private parks for disabled individuals, courses where they can improve themselves, pools, ramps where wheelchairs can move easily, places where disabled individuals can work and sinks with seats. Some of the narratives of the participants who expressed their expectations from local governments in terms of physical needs and spaces are as follows:

> “For example, something needs to be done specifically for disabled people in parks. What do they say to them, the park is social, I couldn't think of it (Ramp), these are places where cars can pass. Some disrespectful people put cars in places where disabled people can pass. They have to follow them or something like that” (P24, 39W, Divorced).

> “So there are parks everywhere. Everything is detailed, but it is not for my child, not for a visually impaired child, not for a mentally disabled child. So you can't leave it alone because the children around you don't perceive it either. It's not for my child. You just have to choose the time. In order to entertain that child, you have to take him alone, late at night, very late, so that no one else is there. Because you can't do anything because of the children around you." (P25, 43W, Married).

It emerges from the above quotes that the expectations of families with disabled children from local governments are especially the parks and special areas where they have problems for their disabled children and want them to be compatible. The emphasis made by families in terms of their physical and spatial expectations reveals the importance of social awareness, especially as in the first quote. As a result, this expectation causes thoughts and feelings that are ignored, excluded or left out. While families emphasize their important expectations regarding "ramps" and "parks", as in the 1st and 2nd quotes, the neglect of disabled ramps and the failure to design parks and social activity centers for disabled individuals and their families can be considered as an expression of an important intellectual deficiency. In addition, families with disabled children expect ramps suitable for their wheelchairs and transportation, and pool services that they think will contribute to the development of their children, from local governments. On the other hand, some of the narratives of the participants (4 Participants), who expressed their expectations from local governments as social activities and events for themselves and their disabled children, in addition to some aid and physical spaces, are as follows:

> “Well, at least that's what I'm saying as a municipality, one day a week. They can organize an activity or a trip for such children. You know, in terms of motivating the family and making them happy. Or, you know, a horse can be taken for a ride. It's not a big deal but other than that. All or the municipality has a pool. We allocate one day a week for special children.” (P32, 31W, Married).

> “For example, I said, let's buy it every 15 days and organize picnics. Their families are also mothers and parents, they are not interested. I said once, boost your morale. For example, in the winter, we should have an indoor area, I mean, we should cook the food there, make cakes, pastries and pastries. Let's organize a picnic in the summer and have breakfast. Let's go to a seaside. That's why I say it. Now, I was trying to have a picnic, but since there were fires, we decided to make the picnic a thing, you know, let it last for a while.” (P39, 30W, Married).

In particular, the first quote above reveals that descriptions found in the expressions of families such as "motivate", "make happy" and "lift your morale" in the second quote indicate that parents with disabled children need social activities that will relieve them psychologically and cause them to spend time together. This appears to be an important expectation. In this context, it is seen that parents of disabled children have physical, spatial and psychological expectations from local governments. If a disabled person can easily leave his home and continue on the road, if he can withdraw his money from an ATM, if he can reach his destination by public transportation or his own motorized or non-motorized vehicles, if he has no problems in meeting his most basic human need, the toilet, in the places he is in, then this is a free city, otherwise. In this case, it can be stated that it is a disabled city (Sunay, 2022: 391).

Expectations from Rehabilitation Centers

Families were also asked what they expected from Rehabilitation Centers as another unit. In response to this question, it was observed that most of the participants (15 Participants) stated that the lessons should be longer and longer, that a good education should be provided, that these trainings should be provided free of charge, and that the training should be provided in a way that parents can also follow while paying attention to the education provided. Some of the quotes from these participants regarding their opinions are as follows:

> “If they have a situation, they can give the child an extra hour of education. It happens 2 days a week. Better” (P12, 45W, Divorced).

> “We talked about this in simple terms last time, I gave the special education center as an example. This is an institution, a private education center, and most and everything is covered by the state. Physical therapy centers must be in separate rooms. Parents must come in and see it whenever they want. For example, what is being done to my child and what is not being done to him. Here, for example, when I enter, after a certain period of time, something happens: the parents ask me to go out. They want them to go out. For example, I complain about him. You know, the windows and doors should be from above. Parents need to see their children from the outside. So this is not provided.” (P37, 31W, Married).

> “Oh, sir, believe me, there are many teacher changes in rehabilitation centers, for example. Oh so much! It's really very much. This is true in every institution that aims to understand the child. It's not something specific to special education, but I mean, it's only there where a normal civil servant does his duty, you know, they shouldn't do that. These children are truly human beings. The material in front of you is human. It is very rare that we come across such a teacher to truly understand his feelings. So he just does his job there, brings a few toys, lets them play, then gets up. This is not it, can I really give something to this child? He has to make an effort.” (P4, 40W, Married).

> It emerges from the quotes that; Education services, rehabilitation centers, and expectations from these units, which families had previously put forward as their main expectations from the state, were also put forward as participants. It is seen that participants expect rehabilitation centers to provide free, longer and more qualified training. While the expectations of families with mentally disabled children are particularly focused on education services, it becomes clear that there is a lack of time and lack of qualifications in terms of education providers. Particularly, the descriptions of "1 extra hour (more) of education" in the first quote, the parent's desire to see their child during education in the 2nd quote, and "teacher who can understand emotions"

in the 3rd quote indicate that families' expectations from rehabilitation centers are that the time in education should increase and that the people providing education should be sufficient in terms of order and quality.In addition, some of the quotes of the participants (10 Participants) who stated that their expectations from rehabilitation centers are to eliminate material deficiencies, expand them and design physical spaces more appropriately are as follows :

“For example, we are studying physics regarding the rehabilitation center. For example, there are not many tools here. For example, there are not many tools that our children can make. We want them, for example.” (P24, 39W, Divorced).

“For example, some children develop with animals, so in my opinion, there should be a place where they are alone with nature. Rehabilitation should be a single-storey building like this in the city, for example. For example, it is done with clay and clay things that will develop children, from ceramics to clay, they also develop children a lot by touching them like this. They should do this kind of thing. They need to buy animals, such as ponies and horses, but they need to be alone with nature. Yes, I think all rehabilitation centers should be located in nature.” (P31, 46W, Divorced).

“You know, they can take a pool session instead of a physical session. Or an event on such a day. For us, for example, morale is also very important for children. For example, let's say that day, a garden is decorated, there are activities for the children, a clown comes. Kids have fun, they don't see this place just for such a thing. "We will do physics, we will get tired, we will cry, they won't see it from that perspective." (P32, 31W, Married).

It emerges from the above quotes that the participants care about the equipment of rehabilitation centers in terms of their children's development. At this point, due to the lack of materials, they expect the pools and activities that they think will be important for their children, and the rehabilitation centers where education is received, to be located in larger areas and in natural conditions. Equipment used by disabled children plays an important role in providing treatment more appropriately. The availability of tools and equipment is especially important in professional therapy, treatment or special treatment planning of disabled individuals and in fulfilling the physiological and parts of their care needs (BHTA, 2014: 6).

Expectations from Neighbours, Friends and Relatives

In addition to institutions such as the state, local governments and rehabilitation centres, families with mentally disabled children at home were asked what their expectations were from the groups of people they interact with, such as relatives, friends and neighbours. When the answers given by the participants were analyzed, it was determined that there were no major differences and the answers given by the families to these 3 groups were similar and overlapped with each other.

Families' expectations from their relatives, friends and neighbors are that they and their children should not be excluded, that they should be helped, that they should be met with tolerance and respect, that they should be friendly and caring, and that they should be met with 'understanding', especially from neighbours. Only 4 of the participants gave different answers to these questions. What are their expectations from relatives, neighbors and friends? While 2 of these participants answered 'I don't know', 1 of them merely stated that their relations with these groups were 'good'. Another participant, who had a different answer, expressed his expectations for these questions as 'They should not ask too many questions'. Some of the narratives of the participants, who similarly revealed their expectations from groups of people such as relatives, friends and neighbors, are as follows:

> “You know, I would like them to welcome you with understanding. I mean, this is a child after all. "You won't play with this at home, you won't play with that, what will you play with?" (P11, 38W, Married).
>
> “They shouldn't do anything. Don't let them snore. I don't want anything from them, as long as they don't snore. I mean, I don't know, it's what I see around me.” (P38, 44W, Married).
>
> “They should behave like normal children, why do they discriminate?” (P21, 38W, Married).

It emerges from the above narratives of the participants that; It is important for families with mentally disabled children to receive support rather than being excluded by their neighbors, relatives and friends. At the same time, since more mothers take care of their disabled children, have a significant workload and devote most of their time to their disabled children, it is important for families that relatives, friends and neighbors are in a position to support them and take care of their disabled children for a while. Approaching families in an acceptable and understanding manner will help ease their burden in terms of the difficult conditions they are in. In this context, the quotes in question suggest that parents have expectations such as not being excluded, being accepted, and being aware.

Expectations from Non-Governmental Organizations

One of the institutions that the participants were asked about and their expectations considered were non-governmental organizations. When the expectations of families in terms of non-governmental organizations were taken into consideration, it was determined that the participants (15 Participants) who gave similar answers answered this question with 'I don't know', 'I can't say', 'I can't think of it', 'I've never thought about it' and some of them left it unanswered. On the other hand, the majority of the participants (22 Participants) stated that in terms of their expectations from non-governmental organizations, they should 'identify and help the real rights holders', 'deal with families and individuals with disabled children', 'support', 'do whatever is necessary' and 'help'. They stated that their

expectations were that non-governmental organizations should generally help families with disabled children, with expressions such as 'providing material and moral assistance'. A few of the quotes from these participants regarding their expectations are as follows:

> “It should be investigated and the real rights holders should be helped.” (P9, 48M, Married).
>
> “It would be great if they paid more attention. If only they supported families” (P11, 38W, Married).
>
> “He can do everything he can, for example, for mentally disabled people.” (P23, 48W, Married).

When the above quotes are taken into consideration, it is seen that the participants expressed their expectations for non-governmental organizations to provide more aid and emphasized their expectations for the real rights holders to be identified before this aid is provided. While one of the remaining three participants emphasized that no one was willing to help, another participant stated that it was an expectation not to be spoken to in a disturbing way. Apart from these, another participant expressed his expectation from non-governmental organizations as a 'social care home'. Apart from all these people and institutions, the majority of the participants (28) who were asked about their expectations from other units, if any, stated that they did not have any, and stated this as 'I can't think of it', 'No', 'I told you', 'I can't think of it'. In terms of their expectations from other units, without specifying any person or institution, 4 of the remaining 12 participants emphasized helping families with disabled children, while 6 participants stated educational expectations. Educational expectations are concretely stated as 'a separate school', 'regular supervision of education', 'educational activities for families while children are in class' and 'education of families', 'school for the disabled' and 'special teachers for disabled children in schools'. Apart from these, the remaining two participants said that roads should be designed according to disabled individuals and their families, while another emphasized that disabled individuals and families should not be remembered only during the election period or on disabled people's day.

Conclusion

In the interviews conducted with the participants who had mentally disabled children at home, they were asked what their expectations were from some groups of people and institutions, especially the state and local governments. When the findings were analyzed, it was seen that the expectations of the participants were shaped, especially in education and health services. Families stated that the training received at both rehabilitation and physical therapy centers was insufficient, particularly regarding time, which limited their children's ability to benefit fully from the education. The participants especially discussed the deficiencies in terms of education and health and their general expectations therefore; They concretized them as 'full and day-long education', 'increased lesson hours', 'education appropriate to the disability of the disabled individual', 'special disabled school',

'comprehensive and qualified education'. This result has also emerged as needs and expectations in studies conducted at different times (Sahay, Prakash and others, 2013, Malekshahi and others, 2020). Other comprehensive expectations for Education and Health Services are considered the fourth- or fifth-highest expectations in this developmental period **(**Washington-Nortey and Serpell, 2014). While a distant parallel exists with this study, it does not intersect with the Cihan (2021) study. This point shows that the expectations characteristics of the transactions in different studies may vary. On the other hand, the second most important expectations of families are about health services. Families emphasized that their most important expectation, especially in this service category, was 'the need to first give them the right to take a turn'. Other expectations that parents emphasize in terms of health are 'understanding of the staff in health institutions', 'price affordability of similar medical products such as medicines' and 'respirators', 'university hospitals providing free services', 'health services being completely free', 'handicapped people'. They stated that "hospitals for children are at an easily accessible point" or "located everywhere", "physical therapy and psychological support services are at an adequate level and are available in abundance", and "provision of ambulance services". This expectation for the field of health shows intersectionality with the studies of Castro, Lefevre et al. (2010), Washington-Nortey (2021). However, while this emerging intersectionality is at the forefront in terms of health in Turkey, other expectations are among the next expectations. Considering these findings, the awareness that is tried to be strengthened in public spots for disabled individuals and their families, the fact that there are articles in the legislation that take into account disabled individuals and children, and that although the right of priority of disabled individuals and their families is known, the deficiencies of disabled individuals and their parents continue, especially in terms of education and health. The issues of education and health, which have emerged as important needs and expectations that families focus on, have also emerged in previous studies. According to Hameed P.V (2021); In families with mentally disabled children, deficiencies in health services and the need for easy access to health services are at the forefront, especially in terms of families' expectations. It is possible to say that the problems continue to exist and the expectations of parents in this regard are of a significant size and weight. Disabled people, who face significant barriers and discrimination problems in our country, have problems that prevent them from being on an equal footing with others in society. These problems are primarily education and health problems (EğitimSen, 2022). When considered in terms of education, it can be thought that the underlying expectation is not only the lack of education in terms of time and materials, but also the exclusion and stigma experienced by families. This situation is particularly evident by the fact that some families do not allow their mentally disabled children to go to school or highlight the relationships they had at the school they attended.

In addition, when the expectations of parents with mentally disabled children are examined, a significant part of the participants stated their satisfaction with the rehabilitation centers, while another group of participants stated that the education factor, which was previously prominent in

terms of their expectations from the state, is also valid for the rehabilitation centers and that they need to provide materials and services that will improve and facilitate education. They put forward expectations for specialized teacher qualifications. Families' expectations from rehabilitation centers include 'increasing and diversifying the materials', 'rehabilitation centers being located in nature', 'being in a structure that will enable disabled children to develop their handicrafts' and 'expected attention and care' as well as the importance of 'swimming lessons' and 'pool' activities focused on. Especially when evaluated from this perspective, as mentioned above, rehabilitation centers and the hardware adequacy in rehabilitation centers, which are at an important point for education, manifest themselves as an important need and expectation for parents of disabled children and disabled individuals. This result is in the same direction as the studies that concluded that parents need professional support (Sen and Yurtsever, 2007); and that guidance service is an important necessity (Ergün and Ertem, 2012). In terms of expectations, parents expectations from other units emerged as 'material and moral assistance' from local governments, 'social activities', 'private park' and 'service' services for disabled individuals and their families. Parents expectations are shaped similarly in terms of individuals and groups of people; they especially expect understanding and support from relatives, neighbors and friends, and not to have exclusionary actions towards them. Considering the underlying reasons for this result, it can be thought that it is mainly due to the heavy burden of having a disabled child, as well as the exclusion and stigma experienced by families within their social relations, as revealed in different studies (Hameed P.V, 2021; Malekshahi and others, 2020). Parents may need support due to difficulties they experience, problems such as exclusion and stigma.

Particularly, the fact that the participants spend a lot of time with their disabled children and get very tired during this time reveals the importance of the help and support that can be provided to them at this point. Participants may experience significant problems and psychological problems due to lack of these expectations. Among the problems that parents of disabled children and especially mother parents experience with their disabled children is that neighbors or relatives fail to realize the situation of disabled children and families and do not support and assist in this regard (Çitil and Doğan, 2019, p. 102). Especially when evaluated from this perspective, as mentioned above, rehabilitation centers and the hardware adequacy in rehabilitation centers, which are at an important point for education, manifest themselves as an important need and expectation for parents of disabled children and disabled individuals. This result is in the same direction as the studies that concluded that parents need professional support (Sen and Yurtsever, 2007); and that guidance service is an important necessity (Ergün and Ertem, 2012). In this context, significant improvements can be made in the areas of these groups of people to raise awareness and meet the expectations of families. Parents especially ask other families with disabled children to be patient and support their children, to struggle and to continue their interest. This situation reveals that; Despite all the psycho-social problems they experience, families still advise families with disabled children to be selfless and take care of their children. As mentioned above, this situation is consistent with studies

that emphasize the importance of support between family members and relatives (Ergün and Ertem, 2012; Malekshahi and others, 2020) and it is in line with the research (Yarbrough and others, 2014) that shows that parents should value their children and have a strong belief in them. In addition to these families, a significant majority of the families answer their expectations from non-governmental institutions by saying 'I don't know' or 'I can't say', while a significant portion of the families expect material and moral aid and support to be provided by non-governmental organizations.

ETHICAL INFORMATION ON RESEARCH

For the field research of this study, ethics committee permission was received from Bolu Abant İzzet Baysal University Human Research in Social Sciences Ethics Committee with number 2021/272.

DECLARATION OF INTEREST STATEMENT

There is no potential conflict of interest in this study.

GENİŞLETİLMİŞ ÖZET

Türkiye'de 2021 yılı verilerine göre yaklaşık 6 milyon engelli olduğu bildirilmektedir. Bunların önemli bir bölümünü de zihinsel engelli bireyler oluşturmaktadır. Zihinsel engelli bir birey veya çocuğa sahip olmak ailelerin hayatında önemli sosyal, kültürel ve ekonomik sorunlara neden olurken, bu durum sorunların çözümüne yönelik önemli beklentiler oluşturmaktadır.

Bu açıdan, zihinsel engelli çocuğa sahip ailelerin sorunlarının incelenmesi bağlamında, bu ailelerin sorunlarını azaltmak veya ortadan kaldırmak için devletten, yerel yönetimlerden, rehabilitasyon merkezinden ve ilişkili oldukları kişi ve topluluklardan sosyal, ekonomik ve kültürel ihtiyaç ve beklentilerinin belirlenmesinin önemli olduğu düşünülmektedir. Diğer yandan, zihinsel engelli çocuğa sahip ailelerin beklentilerini inceleyen ve ortaya koyan çalışmaların sınırlı sayıda olması bu araştırmayı önemli kılmaktadır. Çünkü hem ulusal hem de uluslararası literatürde engellilik üzerine çalışmalar bulunmakla birlikte, bu çalışmaların dışlanma, sosyal politika, kadın engelliliği gibi konulara odaklandığı görülmektedir. Ancak, zihinsel engelli çocuğa sahip ailelerin sorunları bağlamında, özellikle zihinsel engelli ebeveynler için ve sosyolojik açıdan beklentilerini ele alan az sayıda çalışma olduğu görülmektedir. Bu bağlamda zihinsel engelli çocukların ebeveynleri, yaşamlarında sosyal, kültürel ve ekonomik sorunlarla karşı karşıya kalmaktadır. Ebeveynler bu sorunlarla başa çıkmaya çalışırken, aynı zamanda bu sorunların üstesinden gelmek için istek ve beklentiler de geliştirmektedir. Bu nedenle, bu araştırmanın amacını, ailelerinde zihinsel engelli çocuk bulunan ebeveynlerin devlet, yerel yönetimler, rehabilitasyon merkezleri ve ilişkili oldukları kişi ve topluluklar bağlamında sosyal, kültürel ve ekonomik beklentilerini belirlemek oluşturmuştur.

Araştırmaya katılacak görüşmeciler belirlenirken, saha özellikleri nitel araştırma örneklem türlerinden birden fazlasının seçilmesini gerekli kılmıştır. Ana araştırmacılar belirlenmeden önce, soruların netliği ve cevaplanabilirliği açısından bir pilot çalışmanın önemli olacağı düşünülmüş ve 3

katılımcıyla pilot çalışma gerçekleştirilmiştir. Ancak, pilot çalışma sırasında bu planın düzgün çalışmayacağı anlaşılınca, görüşülen kişilere ulaşmak için farklı bir yöntem izlenmesine karar verilmiştir. Pilot çalışmanın gerçekleştirildiği kişiler arasında, kartopu örnekleme yoluyla ulaşılan 2 aile görüşmeye katılmayı olumsuz yanıtlamıştır. Bu nedenle, araştırmanın amacı ve problemine uygun bilgiye ulaşmak için farklı bir kanal olarak araştırma bölgesindeki İlçe Milli Eğitim Müdürlüğü'ne başvuru yapılmıştır. İlçe Milli Eğitim Müdürlüğü, araştırma bölgesindeki en büyük ve en fazla öğrenciye sahip Rehabilitasyon Merkezi'ne bilgi verdikten sonra, ilgili eğitim kurumu ziyaret edilerek tanışma yapılmıştır. Görüşmeler, rehabilitasyon merkezinin uygun gördüğü yer ve zamanda başlamıştır. İkinci Rehabilitasyon Merkezi'ne ulaşmak için, ilgili Rehabilitasyon Merkezi'nin kurucusunu tanıyan bir tanıdık aracılığıyla iletişime geçilmiş ve görüşmeler, Rehabilitasyon Merkezi yöneticisi ve yetkililerinin uygun gördüğü yer ve zamanda gerçekleştirilmiştir. Üçüncü ve son Rehabilitasyon Merkezi'ne ulaşmak için ise bireysel olarak hareket edilerek ilgili yetkililerle görüşülmüş, araştırma hakkında bilgi verilmiş ve kurum yetkililerinin uygun gördüğü yerde görüşmeler gerçekleştirilmiştir. Araştırmanın amacı bağlamında, evlerinde zihinsel engelli çocuğu bulunan katılımcılarla yapılan görüşmelerde, başta devlet ve yerel yönetimler olmak üzere bazı kişi ve kurum gruplarından beklentilerinin neler olduğu sorulmuştur. Bulgular incelendiğinde, katılımcıların beklentilerinin özellikle eğitim ve sağlık hizmetlerinde şekillendiği görülmüştür. Aileler, hem rehabilitasyon merkezlerinde hem de fizik tedavi merkezlerinde aldıkları eğitimin özellikle süre açısından yetersiz olduğunu ve çocuklarının yeterli eğitimden yararlanamadığını belirtmişlerdir. Katılımcılar özellikle eğitim ve sağlık açısından eksiklikleri ve genel beklentilerini dile getirmişlerdir; bunları; 'tam gün eğitim', 'ders saatlerinin artırılması', 'engelli bireyin engeline uygun eğitim', 'özel engelli okulu', 'kapsamlı ve nitelikli eğitim' şeklinde somutlaştırmışlardır. Bu sonuç, farklı zamanlarda yapılan çalışmalarda ihtiyaç ve beklentiler olarak da ortaya çıkmıştır. Diğer yandan, ailelerin ikinci en önemli beklentisi sağlık hizmetleri konusundadır. Aileler, özellikle bu hizmet kategorisinde en önemli beklentilerinin 'öncelikle kendilerine sıra hakkı verilmesi ihtiyacı' olduğunu vurgulamışlardır. Ayrıca, sağlık konusunda vurguladıkları diğer beklentiler arasında "sağlık kurumlarındaki personelin anlayışlı olması", "ilaçlar" ve "solunum cihazları gibi benzer tıbbi ürünlerin uygun fiyatlı olması", "üniversite hastanelerinin ücretsiz hizmet vermesi", "sağlık hizmetlerinin tamamen ücretsiz olması" da yer almaktadır. Bunların yanı sıra; "Çocuk hastanelerinin kolay erişilebilir bir noktada olması" veya "her yerde bulunması", "fizik tedavi ve psikolojik destek hizmetlerinin yeterli düzeyde ve bol miktarda bulunması" ve "ambulans hizmetlerinin sağlanması" gibi beklentileri de bulunmaktadır. Ortaya çıkan sonuçlara dikkat edildiğinde engelli çocuk sahibi ailelerin çocukları ve aileleri açısından önemle üzerinde durduğu eksiklikler ve bu bağlamdaki beklentileri eğitim ve sağlık alanlarında yoğunlaşmaktadır. Diğer taraftan, zihinsel engelli çocuğa sahip ailelerin

beklentileri incelendiğinde katılımcıların önemli bir kısmı rehabilitasyon merkezlerinden memnuniyetlerini belirtirken, bir diğer grup katılımcı ise daha önce devletten beklentilerinde ön plana çıkan eğitim faktörünün rehabilitasyon merkezleri için de geçerli olduğunu, eğitimi iyileştirecek ve kolaylaştıracak materyal ve hizmetleri sağlamaları gerektiğini belirtmişlerdir. Uzmanlaşmış öğretmen yeterliliklerine yönelik beklentilerini ortaya koymuşlardır. Ailelerin rehabilitasyon merkezlerinden beklentileri arasında 'materyallerin artırılması ve çeşitlendirilmesi', 'rehabilitasyon merkezlerinin doğayla iç içe olması', 'engelli çocukların el becerilerini geliştirebilecekleri bir yapıda olması' ve 'beklenen ilgi ve özen' yer alırken, 'yüzme dersleri' ve 'havuz' aktivitelerinin önemi üzerinde de durulmuştur. Özellikle bu açıdan değerlendirildiğinde, yukarıda da belirtildiği gibi eğitim açısından önemli bir noktada olan rehabilitasyon merkezleri ve rehabilitasyon merkezlerindeki donanım yeterliliği, engelli çocuk ve engelli bireylerin aileleri için önemli bir ihtiyaç ve beklenti olarak ortaya çıkmaktadır. Beklentiler açısından, ebeveynlerin diğer birimlerden beklentileri, yerel yönetimler açısından 'maddi ve manevi yardım', 'sosyal aktiviteler', 'özel park' olarak şekillenmiştir. Diğer taraftan ebeveynlerin beklentileri, bireyler ve gruplar açısından benzer şekilde şekillenmekte; özellikle akraba, komşu ve arkadaşlarından anlayış ve destek beklemekte ayrıca kendilerine karşı dışlayıcı davranışlarda bulunulmamasını istemektedirler. Bu sonucun altında yatan nedenler göz önüne alındığında, engelli bir çocuğa sahip olmanın ağır yükü ve ailelerin toplumsal ilişkilerinde yaşadıkları dışlanma ve damgalanmanın temel nedenlerinden biri olduğu düşünülebilir. Diğer taraftan, özellikle katılımcıların engelli çocuklarıyla çok fazla zaman geçirmeleri ve bu süreçte çok yorulmaları, bu noktada onlara sağlanabilecek yardım ve desteğin önemini ortaya koymaktadır. Katılımcılar, bu beklentilerin karşılanmaması nedeniyle önemli sorunlar ve psikolojik sorunlar yaşayabilmektedirler. Bu açıdan, zihinsel engelli çocukları olan ailelerin komşuları, akrabaları ve arkadaşları tarafından dışlanmak yerine destek almaları önemlidir. Aynı zamanda, engelli çocuklarına daha fazla anne baktığı, önemli bir iş yüküne sahip olduğu ve zamanlarının çoğunu engelli çocuklarına ayırdığı için, aileler için akraba, arkadaş ve komşuların onları destekleyebilecek ve engelli çocuklarına bir süre bakabilecek konumda olması önemlidir. Ailelere kabul edilebilir ve anlayışlı bir şekilde yaklaşmak, içinde bulundukları zor koşullar açısından yüklerini hafifletmeye yardımcı olacaktır. Bu bağlamda, söz konusu bulgu ve sonuçlar ebeveynlerin dışlanmama, kabul görme ve farkında olma gibi beklentileri olduğunu göstermektedir. Diğer taraftan, görüşmeciler özellikle engelli çocukları olan diğer ailelerden sabırlı ve çocuklarına destek olmalarını, mücadele etmelerini ve ilgilerini sürdürmelerini istemektedir. Ayrıca aileler, yaşadıkları tüm psikososyal süreçlere rağmen engelli çocuğu olan ailelere fedakar

olmalarını ve çocuklarıyla ilgilenmelerini tavsiye etmektedir. Bu ailelere ek olarak, ailelerin önemli bir kısmı da sivil toplum kuruluşları tarafından maddi ve manevi yardım destek ve bakımını beklemektedir.

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