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A SOCIAL COHESION RESEARCH REPORT: WHAT DO PARENTS OF SYRIAN CHILDREN WITH SPECIAL NEEDS THINK?

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Health and Psychosocial Support Program

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Abstract

The Republic of Türkiye has been hosting more than 4 million Syrian since the Syrian civil war began in 2011. Türk Kızılay which carries out numerous projects to improve the quality of life of Syrian individuals and ensure their cohesion, aimed to create a research plan for this research project and carry out the research process by following a scientific methodology. The general purpose of the research was to examine the opinions of Syrian individuals who have children with special needs about their daily lives and needs. Türk Kızılay research team analyzed the interview records obtained through a qualitative research model under 7 themes: One Day of the Participants, Communication, Problem Behaviors and Coping Strategies, Educational Support, Clinical Diagnosis Difficulties, Needs, and Fears. In the research project carried out with the parents of Syrian individuals with special needs under temporary protection status, Türk Kızılay obtained the opinions of the parents on different themes. At the end of the study, Türk Kızılay determined that the daily routines of parents, their communication with their children, ways of coping with problem behaviors, psychological, social and economic needs and concerns about the future are similar to families with children with special needs who are citizens of the Republic of Türkiye. On the other hand,results suggest that they had problems in their participation in their children's education, in the diagnosis and treatment processes in hospitals, and that they had language problems. Türk Kızılay expects the results of its research to contribute to increasing the integration of Syrian individuals and children with society.

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A SOCIAL COHESION RESEARCH REPORT:

What Do Parents Of Syrian Children With Special Needs Think?

Current Situation From the Eyes of Health and Psychosocial Support Program

The Republic of Türkiye has been hosting more than 4 million Syrian individuals since the Syrian civil war began in 2011. The Republic of Türkiye has guaranteed the right to access education as one of the basic services with the temporary protection status it provides to Syrian individuals. Education is one of the areas of participation in social life that serves as a bridge for Syrian individuals' social cohesion with society. Today, it is known that interaction-based cohesion requires integrative schools to be quality schools for every learner.

Türk Kızılay Community Based Migration Programmes (CBMP) Health and Psychosocial Support Programme aimed to investigate to what extent Syrian individuals benefit from the right to education that will enable them to become a social bridge with the Republic of Türkiye. Academic studies have revealed that although Syrian individuals are satisfied with the education system in Türkiye, they have difficulty adapting to the education system and need a Turkish language education. Despite this, it is not known what the parents of individuals with special needs, who are one of the disadvantaged groups, think about their children and themselves participating in education in Türkiye. On the other hand, researchers have determined that the special education needs of individuals with special needs who continue their education in institutions affiliated with the Türkiye Ministry of National Education are difficult to recognize due to their language and cultural differences, their level of participation in education is low, and their parents experience problems in the diagnosis and evaluation processes.

For this reason, Türk Kızılay Community Based Migration Programmes Health and Psychosocial Support Programme aimed to investigate to what extent Syrian individuals benefit from their right to education.

What Could Be the Underlying Cause of the Problems?

The related program team listened to parents' early stories and wanted to investigate in depth their children's special needs, their impact on daily life, their expectations and their opinions about the future. In this way, it was evaluated that it would be possible to give voice to parents of Syrian children with special needs as their principal caregivers and to make suggestions for the future.

What Did the Health and Psychosocial Support Program Investigate?

The Türk Kızılay CBMP has carried out many projects to improve the quality of life of Syrian individuals andsupport their social cohesion. The Türk Kızılay established a research plan for this project and carried out the research process. The general purpose of the research is to examine the opinions of Syrian individuals who have children with special needs regarding their daily lives and needs. The research plan and method were determined by taking the opinions of expert academics. Interview themes were established under the title of education. A pool of interview questions was established in line with these interview themes. Available questions for the inclusive education perspective were selected from this pool. A total of 13 questions were determined in two areas. Questions in the first domain concerned parents' social interaction with their children, communication, and behavioral problems. The second area was about what areas they needed support in. Expert opinions on the interview questions was received from an academician working in special education. A pilot interview process was conducted with one parent. After the pilot interview was completed, a working group was formed.

Demographic Information of The Sample Group

Participant	Age of Child	Gender of Child	Diagnosis of Child
P1 (Father)	11	Boy	DS
P2 (Father)	11	Boy	ASD
P3 (Mother)	9	Boy	ASD
P4 (Mother)	10	Boy	ASD
P5 (Father)	14	Girl	ID + PD
P6 (Father)	8	Boy	ID
P7 (Father)	7	Girl	ID
P8 (Mother)	4	Girl	ID
P9 (Mother)	7	Boy	LD
P10 (Mother)	4	Girl	ASD + ADHD + SLD
P11 (Mother)	10	Girl	ID + Epilepsy
P12 (Mother)	6	Girl	PD
P13 (Mother)	4	Girl	SLD + HI
P14 (Mother)	3	Girl	ASD
P15 (Mother)	6	Girl	ASD + SLD + DD

P16 (Mother)	3	Boy	ID + PD
P17 (Mother)	5	Boy	DS
P18 (Mother)	2	Boy	ID + PD
P19 (Father)	6	Girl	ID
P20 (Mother)	8	Boy	ASD Risk

Note. ADHD = attention deficit/hyperactivity disorder; ASD = autism spectrum disorder; DD = developmental disability; DS = down syndrome; HI = hearing impaired; ID = intellectual disability; LD = learning disability; PD = physical disability; SLD = speech and language disorder.

The working group consisted of parents of Syrian children with special needs, to whom the Türk Kızılay had previously provided support. Clinical Psychologists or Child Development Specialists who work in Health and Psychosocial Support Programme conducted the interviews. Interviewers who are experienced in conducting interviews and can speak Arabic fluently have been trained by the Türk Kızılay to direct interview questions to parents in the context of free interview interaction, following ethical principles during the interview process. The research team conducted interviews with a total of 20 Syrian parents of children with special needs who have one or more disabilities or disorders. The study group consisted of parents of

children between the ages of 2-14, male or female, who have one or more special needs such as attention deficit and hyperactivity disorder, autism spectrum disorder, language, and speech disorder, learning disability, hearing impairments, orthopedic disability and mental disability.

The Türk Kızılay research team analyzed the interviews through qualitative research analysis under 7 themes: One Day of the Participants, Communication, Problem Behaviors and Coping Strategies, Educational Support, Clinical Diagnosis Difficulties, Needs and Fears.

What Did They Say to Health and Psychosocial Support Program?

Bir günleri nasıl geçiyor?What do they do during their day?

- "Her father and I take her to the park on the weekends."
- "After he eats, he makes a mess of the house and shouts. He always does this."
- "We play games."
- "When we let her watch TV, she sits quietly and watches cartoons with extreme attention...;"
- "She doesn't hear us or sense our presence while watching TV."
- "I do activities to help him learn and pronounce letters."
- "He does his homework in the evenings. His brother and I help him."

Parents reported that they generally have a positive day by playing games and taking care of their children. On the other hand, they reported observing negative problem behaviours in their children (e.g. shouting or hitting, etc.). Parents also reported that they usually supported the completion of homework.

Parents stated that they exhibited parenting behaviours such as increasing their children's social participation in daily life, trying to cope with inappropriate behaviours, and participating in their children's education as supported by previous research with most of the parents of children with special needs in Türkiye.

How do they communicate with their children?

- "His mother is looking after him. "It is a mother's duty to take care of their children, but I also take care of them."
- "He doesn't communicate with anyone. He's just watching TV."
- "He doesn't talk to us at all. "He only cries to show that he is hungry or thirsty."
- "To talk.."
- "The most important problem is that although he wants to talk, he cannot say the words he wants."

Parents stated that their children often initiate communication with their mother or father as a person in their daily routine; They reported that they expressed their communication purposes by speaking little or to a limited extent by not speaking at all. Fathers stated that their children

communicate frequently with their mothers and that mothers are more willing for communicating. Considering that the parents with whom the interviews were conducted are groups with delayed communication development, such as intellectual disability, autism or hearing impairment, it is thought that parents are expected to talk about their children's communication difficulties. However, the acceptance of the mother figure as the main communication partner is similarly one of the issues that parents of children with special needs with communication limitations in Türkiye complain about. Türk Kızılay has determined the communication styles that may indicate that the communication development of children and parents should be supported, in line with parental opinions.

How do they cope with their children's problem behaviour?

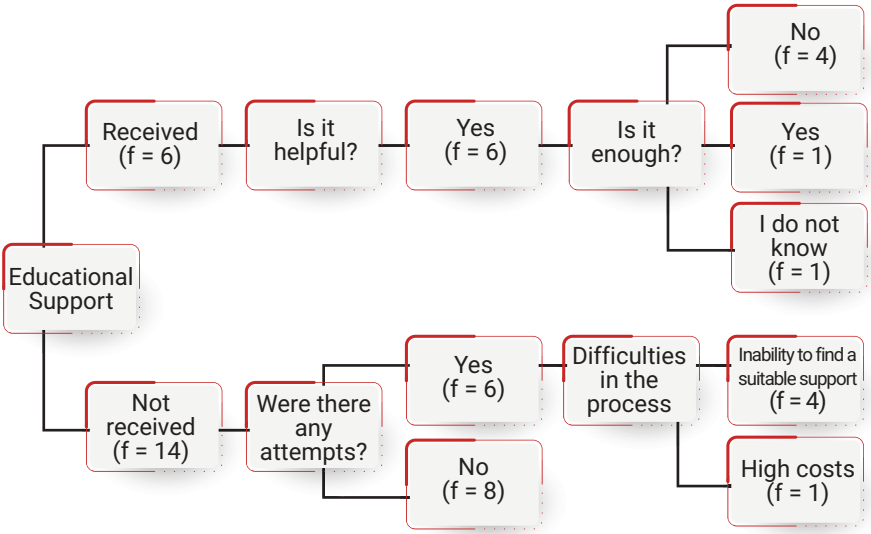
- "He has bad habits such as crying all the time and biting his own hands. "He can break the glass when he gets angry."
- "He can't sit still, he's always on the move. What worries me the most is that he harms himself. "I asked many doctors but I couldn't find an answer."
- "I give him what he wants. Actually, I do this to stop him from crying. Because in his state, he always cries, screams and sometimes hits himself, so when I want to stop him, I give up."
- "We always try to please him by giving him the smartphone or turning on the TV. "The thing that pleases him the most is holding his smartphone."
- "We sit for five minutes every day to reduce his hyperactivity. For example, if he moves a lot one day, I sit next to him and he relaxes. For example, I sit in a chair for 5 minutes for 3 days and repeat this."

Parents reported observing inappropriate behaviour in their children that was harmful to themselves or others. Research has indicated that having special needs due to a developmental disability or disorder may increase the risk of exhibiting inappropriate behaviour. Therefore, the fact that parents express that they observe problem behaviour in their children is interpreted as an expected result. However, another result, that parents often express that they responded to their children's wishes as a way of coping with their children when they exhibit problem behaviour, points to the fact that the solutions they find may not be appropriate and even if they are appropriate, they are short-term solutions. Because the problem behaviours of children with special needs must be managed. This behaviour management requires

systematic implementations based on a specific program. With these results, the Türk Kızılay has determined that there is a need for coaching educational practices for Syrian parents of children with special needs on ways to cope with problem behaviours.

What do they think about support for their children's education?

- "We do not receive support"
- "We cannot currently receive any educational support. "There is a center near our home, we applied there, but they said it was for Turkish citizens and did not accept us."



Parents frequently reported that they were not receiving educational support. Parents related their inability to receive educational support to the fact that they encountered some difficulties. They expressed these difficulties as not being able to find appropriate support and the high cost of educational support. Some parents think that they cannot receive educational support because they are not citizens of the Republic of Türkiye. Parents who stated that they received educational support stated that the education they received was inadequate. Research has shown that parents of children with special needs in Türkiye find the the special education sessions their children receive inadequate. The legal regulations of the Türkiye Ministry of National Education guarantee the right to private education for individuals with

temporary protection status through the preparation of an individualized education programme. It is a programme developed by the specialists and teachers at the Guidance and Research Centre for the individual requiring special education and then approved by the child's family. This programme is a special education programme prepared in line with the needs of the individual, the family and the teacher and includes support education services to be provided for the targeted purposes. However, even if Syrian children with special needs in early childhood (0-6 years) can receive an educational diagnosis at Guidance and Research Centres following their medical diagnosis, they do not have the right to receive 8 hours of individual education and 4 hours of group education free of charge from special education and rehabilitation centres like Turkish citizens with special needs. It is considered that parental opinions about parents not receiving sufficient support may be due to parents' lack of knowledge or awareness and various obstacles in the identification and placement processes of individuals in need of special education. It is understood that it is necessary to plan and provide parent-centred support to parents to increase their support resources and skills in coping with problems and to support their parenting competencies. In addition, efforts should be made to ensure that Syrian children with special needs can benefit from special education and rehabilitation centre services free of charge during certain hours. Türk Kızılay recommends disseminating information activities for parents about their rights and strengthening coordination regarding their children's participation in education.

What do they think about their children's hospital experiences?

- "The hospital issue has become difficult for us. We are having trouble making an appointment. "They make appointments for distant dates."
- "It is difficult to communicate with Turks in the hospital. "We need to have a translator with us."
- "I encounter such problems all the time. I cannot deny that I have experienced discrimination. Discrimination is my biggest problem."

Parents reported that they encountered some difficulties in receiving diagnosis and treatment services in hospital processes related to their children's special needs. They frequently state that the most important of these difficulties are being able to make an appointment for an upcoming date, communicating due to language difficulties, and being negatively discriminated against because they are Syrian. The problems expressed are important in terms of children being able to receive support when they first notice the differences in their development, without the time gap between diagnosis and support becoming longer. Since there is no

supporting research finding, Türk Kızılay recommends conducting research on this subject with larger sample groups. In line with these views, it is recommended to improve the deficiencies in terms of informing parents by experts during the diagnosis and treatment process and increasing the quality of services provided to families in providing their psychological, information, and educational needs.

What are their social acceptance, psychological, and social needs?

- "...after getting tired and exhausted from the difficulty of dealing with my son's problems, understanding him, and living together, I need psychological support."
- "Other children and people do not understand him. The humans outside are destroying his psychology. Therefore, my child becomes more anxious. We need society to accept us. Humans out there need this education more than these children (implying children with special needs."

Parents reported that they experience problems in terms of social acceptance and psychological and social needs. They stated that their social acceptance in society was low, that they were psychologically worn out while meeting the education and care needs of their children due to their special needs, and that they had economic problems. It is noteworthy that the most frequently reported needs are psychological and social acceptance needs. Research has shown that parents of individuals with special needs in Türkiye experience more emotional, psychological, and economic difficulties than the families of children without special needs. These views show that they have difficulty meeting their social, psychological, and material needs (e.g., care, education). Türk Kızılay considers that to improve both the physical and psychological health of parents, there is a need to support parents in their coping processes and develop implementations that will make them feel important and valuable. In this regard, the Türk Kızılay recommends the development of policies for Syrian children and their families affected by disability in Türkiye, to disseminate parent-centred and inclusive educational approaches that ensure cohesion with society.

What are their fears about now and the future?

- "My child's future is uncertain. I worry about how my daughter will survive alone in the future without anyone around. At some point, his siblings will be busy with their family and their lives, and I don't want her future life to be full of challenges."
- "If his situation does not get better, how will he build his future, how will he get married and start a family? He always says his dream is to be a soldier, I'm afraid of how he will become a soldier."
- "No one but me can understand my child, not even his father. I'm the only one who can understand this. This worries me so much."
- "I am afraid of society. I am afraid of bullying. When you live in a society that does not take this special situation of your child into account, you are influenced by people's words because you live with them. We cannot deny this."
- "For example, when we get on the bus and my daughter's hair and shoes are dirty, the people next to her tell me to keep my daughter away from them."

Parents stated that fear or worry about their current life and the life they expected in the future. Parents often expressed their concerns that their children would not be able to become independent individuals who could lead their daily lives in the future or that their children would not "recover". Additionally, another source of concern they expressed was bullying, which they stated that they were exposed to in society and which they believed would continue to exist. Research shows that parents of children with special needs in Türkiye are worried that their children's care and education needs will not be met after the death of parents, or in the process of their death. Therefore, it was determined that Syrian parents also have similar concerns or fears.

Considering that parents are concerned about the loss of health and early death in terms of not being able to care for their children, it is understood that addressing their concerns about the future of their children and themselves is an issue that
should be seriously addressed in family services policies. Türk Kızılay recommends researching concerns and fears in larger sample groups.

CONCLUSION

In the research project carried out with the parents of Syrian individuals with special needs under temporary protection status, Türk Kızılay obtained the opinions of the parents on different themes. At the end of the study, Türk Kızılay determined that parents have educational, psychological, social, and economic needs and concerns about the future in their daily routines, communication with their children, and coping with problem behaviours.

In light of the results obtained from its research, Türk Kızılay has identified some suggestions for improving services in the fields of education and social support for Syrian parents with children with special needs and their children. Firstly, it is recommended to disseminate individual family education implementations and inclusive education practices to advocate for parents' legal rights and support their children's development or learning. Secondly, it is recommended to develop psychosocial support programs to meet the psychological needs of parents. Third and finally, it is recommended to examine parents' opinions, perceptions, and attitudes on the issues discussed in this research in larger sample groups.

Türk Kızılay expects the results of this research project to contribute to increasing the social cohesion of Syrian individuals and children with special needs into the community.

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