

THE EFFECTS OF AUTISM ON ECONOMIC STATUS OF THE FAMILY

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Abstract- Autism hasn't been a problem effecting only the autistic individuals but has also become a social phenomenon affecting the family's economic situation. Thus, it has been wide open for sociological studies and has been the subject in this research. This study, conducted as a field survey including autistic individuals in Turkey, aims to put forward "The Effects of Autism on Economic Status of Family". This research is a qualitative research based on interviews with a total of 42 participants who are the families of autistic children and serve on the boards of two foundations and 15 associations from Turkey's seven regions and 14 provinces aiming to fight with autism. The knowledge, manners, experiences and basic perception and approaches of the participants having autistic children have been consulted to in the study. The data obtained from participants has been analysed and subjected to descriptive analysis. The data obtained has been evaluated in 7 different categories. Findings; it has been found that autism has negative effects on the economic situation of families, has preventing any new investments of families, has lead to buying specific services of family and affects the business lives of families. Therefore, this study is a considerably original work in terms of addressing an issue barely analysed in sociological context, collecting first-hand data and reaching striking findings and data. Moreover, it has been an important study as it indicates the presence of a deep link between autism and sociology.

Index terms- Autism, Family, Social Phenomena

I. INTRODUCTION

The word autism, consists of a combination of the Greek word "autos" (itself), and the Latin word "ismus" (a suffix regarding to an opinion, process, or procedure) [1]. The concept of autism, at first, has been described as the failure to establish relationships with reality and was called as childhood schizophrenia. The idea that autism is the onset of schizophrenia has changed by identifying the absence of hallucinations and delusions while they are seen in schizophrenia [2]. Since the persons with autism are constantly show communication disorders [3] their interaction and communication with other individuals gains a new qualification. Also, since; the persons with autism are hard pressed in interrelating between the events occurring in their interior world and the exterior world, their lack of forecasting skills [4], and also they fail "to comment on" or "share" their own experiences appropriately according to their age groups [5], their social interactions are weak. Thus, the term autism in this study is defined as; some repetitive behaviours those affecting individuals throughout life, limited communication skills and the lack of social interaction, [6], as well as a disorder disrupting individual's socializing function and alienating the individual in against their own nature and also society, in other words "that negatively affects the socialization of individuals and marginalizing (othering, externalizing) them against the outer world" [7].

Individuals of autism have limited attention to social stimuli. When called with their names they give very little response. They rarely establish eye contact with others [8]. Such non-verbal form of communication has a great effect on social behaviours. It is rare for

them to walk up to someone, to respond to others' feelings and imitate them, do something with social insights as well as to communicate with them are weak [9]. Persons with autism has difficulty in games that require high level of imagination, and in translating symbols to spoken words [10].

The Aim Of The Study

Autism hasn't been a problem effecting only the autistic individuals but has also become a social phenomenon affecting the family's economic situation. Thus, it has been wide open for sociological studies and has been the subject in this research. This study, conducted as a field survey including autistic individuals in Turkey, aims to put forward "The Effects of Autism on Economic Status of Family".

II. METHOD

The Model Of Study

This research benefited from qualitative research collection techniques. Yıldırım and Şimşek (2011) describe the qualitative research as "used in qualitative data collection methods like observation, interviews and document analysis and follows a qualitative research process for determination of perception and events in the natural environment in a realistic and holistic form"[3].

Study Group

Autism is not just an issue where the children live. Perhaps families suffer more than the children with this problem. Therefore, parents know closely how their children behave in society. That's why it is assumed that the families a high awareness level regarding to autism, and they can express what is happening in the social universe in a better way. It is

expected that the sample of this research will be more appropriate because the families are volunteers in the fight against autism and their high experience interest, information, and manners in this issue. In short, the participants with sufficient information equipment who are available for the field research are determined and who can provide necessary data for research, while the research sample is determined. It has been identified as the universe; 2 foundations and 15 association executives and members that can be accessed from a total of 25 foundations and associations established in 14 different provinces and Turkey's seven regions that will reflect the scope within and scope of features and by the families of autism individuals. In the selection of the sample it has been paid attention to three criteria. First, to interview at least one member plays a part in the management and the chairman of the foundations and associations board with among the sample; second, preferring a family that has an older (at least 10 years of age) child with autism can be members; and the third, carrying out the negotiations with members who has particularly older (at least 10 years old) female child with autism. In this election, it is especially taken into account that the families of children with autism that have acquired a certain social experience after living with them for a while.

First, it was determined to sample a total of 42 participants, coinciding with the first of the three criteria. During the talks, data were collected by asking the following questions abide by the social rules.

How is your child's abiding by the rules of society in social environment?

Social and Demographic Characteristics of Participants

Table 1 below shows the age, gender, education, marital status, income and occupational status on socio-demographic characteristics of the participants is given in a general framework.

Table1. Participating Socio - Demographic Characteristics

Variable	Gender		
	Female	Male	Total
Age			
26-35	1	-	1
36-45	8	2	10
46-55	12	11	23
55- +	6	2	8
Education			
Graduate	2	3	5
Master	10	9	19
High School / Middle School	4+7	2+1	6+8
Primary	4	-	4
Marital Status			
Married	19	21	40
Single / Divorced	1	-	1
Widowed	1	-	1

Job			
Housewife	13	-	13
Teacher	1	1	2
Academician	-	3	3
Nurse	1	-	1
Tradesmen / Free	-	3	3
Farmers	-	1	1
Retirement	7	3	10
Officer	-	3	3
Doctor	-	1	1
Private sector employees	2	1	3
NGO Manager	2	-	2
Monthly Income			
500-1000	-	-	-
1001-2000	3	-	3
2001-3000	6	7	11
3001-4000	3	3	6
4001-5000	4	3	7
5001-+	6	2	8

As shown in the table above, participants consist of the families that are the members of different age, education, profession, and income groups. Only in marital status it is different; forty out of forty two members are married. The ages of most of the participants are being over thirty and the average age is being around fifty shows that the majority of the families living with autism for many years. This means that they have enough social experience.

Data Collection Tool

In the study, observation and in-depth interview technique was used for qualitative study. Therefore, in-depth interviews were conducted through unstructured interviews with the individuals' status of compliance/non-compliance to the rules of society who are the object as well as participants that are the subjects of the research (parents of autistic individuals) in order to describe with all its simplicity. Alongside with the interviews and observations, it is tried to figure out how much the individuals with autism conform to social rules with the help of the various notes taken during the interviews, and some determinations during the data analysis performed.

Data Analysis and Interpretation

The knowledge, manners, experiences and basic perception and approaches of the participants having autistic children have been consulted to in the study. The data obtained from participants has been analysed and subjected to descriptive analysis. The data obtained has been evaluated in 7 different categories

III. FINDINGS

In this part of this study, the findings were obtained in accordance with the answers of the participants that were analyzed and interpreted.

We asked participants a question about how autism affected their family budget. Answers given to the question mentioned below is listed in 7 sub-categories:

"How did your child's being with autism affect your economic condition?"

The answers are:

1- Increasing expenses and giving more damage economically: "For example, when we go shopping, if he wants something, you do not have a chance to say no. He cannot understand if you have no money at that time. Sometimes you take that thing on debt. Or... We got Dijiturk, a cable TV service, and he threw its box down and broke it three times lately. Once, he used to throw down whatever he finds on the balcony, bicycle, chair, control, television, etc... Things taken with money, after all. They cost a lot... One time, he threw down the television. It broke down into two pieces and we had to pay for it. A few more things he threw, they broke the glass and the chest of the car. We had to pay hundreds of thousands for the losses... Also we hear that some other kids with autism caused fires at home while they play with matches... Or while you are on the road driving, they give harm to the car and you pay for it. Therefore, autism is an expensive and luxurious disease... Yes, within our friends, we call it "rich disease"... (P11 and P12). "

2- Blocking new investments, leading to austerity: "You know, it affects family budget in every way. Also, it has an impact on deciding, for example, I had the intention of purchasing a house by a long-term mortgage credit. But we could not get into any debt because our child's situation is uncertain... (P5)." "We limited our financial opportunities. We gave up on everything. So if we are going to buy 2 pair of shoes this year, we have 1 pair. If my wife is going to get something new, for example a coat, every 2 years, we've taken it out to 4 years. In short, we are also influenced in terms of economic circumstances (P18 and P19)."

3- Influence on entrepreneurs' and employees' commercial or business life: "My husband had some commercial ventures. We had to end them. In other words, we had to leave business life and to live with less income... We had a commercial life once but it ended because the child was getting need more caring after receiving the diagnosis of autism and also because we could not get any support from our family (P9 and P10)." "When I was at a young age, I promised myself that I would not be a government officer... I always thought I would deal with trade. I really made a good start in that direction after college. I established my own company very shortly. We grew up very shortly. But after my son was diagnosed with autism, I started to think that nothing really matters, and I lost my concentration, that is, about the trade... There was no ambition in the trade anymore... (P13)."

4- Causing expenses via the way to transportation and education: "This is the economic situation where

your child affects the family in every way... For example, we have gone to Ankara for a long time. We stayed at hotel for two or three months a year like four years. We covered our travel expenses by ourselves. We covered the hotel, the state can not afford it. It only covered part of the rehabilitation fee. We went to many hospitals. We went to private hospitals. We spent a lot of money in Ankara, Istanbul, Konya and around here. Other than that, even I did not need anything else, I sent him to kindergarten from the age of three to six... For example, I send him to a sport club... He is taking classes two hours a week these days... I spend money to these things. So these, or the kid has some special wishes. Of course there is a cost for these all... We made more expense when he was younger. We brought all of the training materials here (in Ankara). What happens in the rehabilitation center is the same in our home. So it was like costing us a brand new car. Apart from this, we also spend... We constantly spent money. (P3). "" We always go to Ege University in Izmir (from Denizli) ... Insurance did not cover at that time. So we were going to a private hospital. (In Denizli) there is no special education opportunity... We are going out of pocket now... We entrusted our workplace to someone and we, the mother-daughter, rented a house here, so its a second house plus education money... We paid 60 liras daily that day. In the year of 95s-96s... In other words, big bucks... We could bear up 7 months only... (P7 and P8). "" Of course, I am bringing Hakan out of town every day. (P16). " From June 18th until today (August 6th, 2012, Researcher) the money spent for Peak is 3.5 billion (3 thousand five hundred) ie. This includes camping with his team. You are sending a life coach with him... including one day on the other hand, he is getting sports training at school with his private tutor for 5 days a week. We spend the summer months taking private lessons, which are private lessons that we will have problems in school next year. He is taking English lessons on the one hand. When you sum up all of these; there is a serious expense. I do total of 18 years, let's say 2 year I haven't spent anything, for 16 years, I always say... There is a kind of American college in Izmir... quite expensive, the annual amount of training. I think I spend that much money every year for my son. So what if we think about spending about 10-15 thousand TL every year for a total of 16 years? "(P13).

5- Direct towards extra work: "It seriously affected. I am a freelancer but I had to work an additional 3 hours for Melik per day. Because, our support education we receive from the State is only 8 hours, monthly... We were in serious trouble financially because we supported it by our own facilities. So it's our loss. Say, what should we need to do to get this lesson? I have to work... Sure, that is a job loss... (P17 and P18). "

6- Lead to the purchase of special services: "While a normal child went to the kindergarten with 500 TL, our child was going with 700 TL. Also, it took a very long-term kindergarten period. Sometimes we were getting 1 or 2 hours of private nursery support... (P9 and P10)." "Of course we always have to make a special budget for Alper. For many years... Mmm, we paid for private tutors. Well, we got additional therapy sessions. This is something that affects the economic situation of all the families. We have bought special services from special educators or others who are called babysitters, either in our house or outside (P22)."

7- Making all the savings spending for the child: "Of course it affected me. We have a business, you know. A regular employee, a salaryman, has a house, a car, and a summerhouse after working about 20 years. We do not have any! All we have is our daughter. We made this to our daughter. We carry her in our arms, like a bag. We sold out our car. We visited doctors as well as doctors in alternative medicine. We did bio energy healing, and all the rest what we have heard... We never thought of money! We spent such money to buy a store, a car, and a house... (P7 and P8)." "Our whole savings goes to her. Governmental school program is not enough. We are always paying for personal tutoring. And also, we're trying to get her participate to various environments. We are taking her to swimming, riding bicycle. But she never wants to do these with me. I cannot get enough. That's why she is with his teachers, besides me. We are always adjusting our budget according to Deniz (P17)."

When we look at how the autism affects the economic situation of the family, according to the findings above, three important conclusions emerged. The first of these, is the fact that unquestionably autism has effect at some degree on the economic situation of every family and the family wastes in economic terms. The second is to see the economic power as the most important tool in the struggle against autism. Even, autism is a kind of "luxury disease" which rich people have, according to many participants (P20)." "So, life goes on. Because, the better the economic situation, the better it is to be able to cope with this situation. Because autism is a very expensive disease (P11)." The third is, the emphasis of families with a slightly better economic status on how difficult it is for families with poorly socioeconomic status to have autistic children. Because, they can only advance in this process by purchasing services from a special education teacher, life coach or therapist for the autistic child. On the other hand, what the families with low socioeconomic level have experienced in this process and how they

intervene with their children remain as an important question.

IV. RESULTS

There are some results about autism affects families deeply their economic well-being. In other words, having an autistic person in a family causes to shift from being producer to consumer for family members and to fall into a bad situation such as not being able to make investment, business development plans, etc. because of preventing from entrepreneurship as well as leading to higher costs in family budget. Due to autistic children, increased transportation and education costs or the purchase of special services for the education of those children and the fact that all the capital is their children are among the reasons why many families have to work extra every day and make savings despite they need to spend much. At the same time, autism has also led families to fall into the trap of those who offer alternative treatments and thus they suffer much economically. Because families have had to resort to many ways of looking for remedies. While some went to the pilgrims to pray for their children, some others went to mosques, churches, or even primitive tribal chiefs in Africa. Some went to holy tombs to tying pieces of cloth, to a divine man to melt lead, or to the fortune-teller while others sacrificed animals, fed poor people, and gave alms. Some tried all the possibilities of medicine and sometimes tried alternative treatment. As a result, families resorted to countless ways in search of remedies. During this process, too, they have often been unable to fall into the trap of the exploiters.

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