

## Social determinants of health of children with autism spectrum disorders in East-Azerbaijan province

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### Abstract

**Introduction and objective:** Autism Spectrum Disorders (ASD) are a group of disorders that are classified as neurodevelopmental disorders and their main characteristic is impairments of social communication abilities and limited of interests and behaviors. In this study, we aimed to study the Social Determinants of Health (SDH) status of children with autism spectrum disorders in East Azerbaijan province.

**Methods:** The present study is a descriptive-analytical cross-sectional study conducted in 2018. The sample size was estimated 112. The standard questionnaire of SDH of children with ASD was used to collect data. Data analysis was performed using descriptive and analytical statistics using SPSS software version 19.

**Results:** According to the results, most of the participants (children with ASD) were male (81.3%) and had social security insurance (54.5%), the occupation of the most of their fathers were self-employed (58%). 3.6% of the children did not have a health insurance. the most imposed stress due to SDH factors were related to parental mental health concerns (99.1%), lack of required services (97.3%), cost-effective care services (93.8%), access to needed healthcare (93.8%), and the least stress includes worries about physical violence of adults at home (59%). The results of the analysis of the relationship between SDH scores and demographic information of children with autism spectrum disorder showed that there is a significant relationship between having stress due to lack of insurance and the mother statuses in terms of alive or divorce (p-value = .023) but has no significant relationship with other childhood demographic information.

**Conclusion:** According to the results of the study, the SDH status of families of children with ASD is at an unfavorable level, which leads to anxiety in families, imposing excessive costs on them and thus a serious threat to improving the situation of children with ASD.

**Keywords:** Autism Spectrum Disorders; Social Determinants of Health; Stress; Mental Health.

### Introduction and objective:

Autism Spectrum Disorders (ASD) are a group of disorders that are classified as neurodevelopmental disorders and their main characteristic are impairments of social communication abilities and limited interests and behaviors<sup>1</sup>. ASD is a condition characterized by communication problems and social interaction and repetitive behaviors<sup>2</sup>. People with ASD have many problems with socio-emotional factors and cannot interpret them correctly. Such deficits in emotional cognition are found in a variety of statuses, including facial expressions, speech, and body language<sup>3</sup>. Autism spectrum disorders have gained a great deal of attention in recent years around the world due to their increasing prevalence and the devastating effects it has on individual, family, and social health and the high costs it imposes on the health system<sup>4-6</sup>. According to the World Health Organization, an average of 1 in 160 children has ASD<sup>7,8</sup>.

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In the past, experts believed that ASD was a cultural/social problem caused by the industrialization of societies or even the social welfare of individuals. However, today it is not considered as a socioeconomic-driven issue and it is accepted that neurobiological and genetic factors are the main potential causes<sup>2</sup>.

Understanding the socioeconomic status of children with autism is important in terms of social and contextual determinants of health for two reasons: First, our knowledge of autism is incomplete and may be based on deviations; for example, most studies on the socioeconomic status of children with ASD are from high-income countries and evidence from low- and middle-income countries are limited<sup>9</sup>. Second, most research is concerned with capacity building through the training of service providers, the development of appropriate diagnostic tools, and evidence-based therapies<sup>10,11</sup>.

Differences in the background status of individuals in terms of social determinants of health (SDH) may lead to differences in the quality of services or access to services<sup>12,13</sup>. Various studies<sup>12,14,15</sup> emphasize the importance of recognizing the SDH status of children with ASD. Understanding the social, economic, cultural, and supportive status of families of children with autism can lead to broader research into access to services, service quality, service effectiveness, and even epidemiological studies in ASD children, and to identify other factors that may indicate any health inequality. However, to our knowledge, no study has been conducted in this field in East Azerbaijan province. Therefore, in this study, we aimed to study the SDH status of children with autism spectrum disorders in East Azerbaijan province.

## Method

This research is part of the comprehensive Azeri Blue Buddies: Interdisciplinary

Longitudinal Autism Researches (ABBILAR) project. The ABBILAR project is a research initiative at Tabriz University of Medical Sciences in the field of comprehensive management of ASD at the individual, family and social levels. The present study is a descriptive-analytical cross-sectional study. The research environment included all private and public autism centers in Tabriz and Ajab Shir, among which were four private centers in Tabriz and one private center in Ajab Shir affiliated to the Welfare Organization and one public center affiliated to the medical university. The target population was children aged 2-14 years old with ASD and their parents. Convenience sampling method was used.

### Data collection method

We used a standard questionnaire adopted from the study of Gottlieb et al. (2017)<sup>16</sup> for the data collection. The questionnaire was translated and retranslated and then provided to experts for content validity assessment. The final questionnaire consisted of two parts: demographic information of children, which includes 5 questions about the characteristics of children and their parents. The second part encompasses information about SDH in the form of 18 questions. Questions about demographic information and determinants were answered by the parents themselves, and questions about diagnostic and behavioral information were answered by the child's therapist by referring to his or her file. According to the standard instructions of the questionnaire, the status of social determinants of health became a nominal qualitative variable. Thus, the cases of having any level of stress code 1 and the absence of stress were considered as zero code in the analysis.

### **Determining the research sample and sampling method**

The sample size was calculated using the Morgan table. Taking into account that 160 children with autism received services from autism centers, the final sample size was 113 people.

### **Data collection method**

Data was collected using a standard questionnaire adopted from the study of Gottlieb et al. (2017)<sup>16</sup>. The questionnaire was translated and retranslated and then provided to experts for content validity assessment. The final questionnaire consists of two parts: demographic information of children, which includes 5 questions about the characteristics of the children and their parents. The second part included 18 questions about children's SDH status in three main areas, including economic, welfare, and support of the family. Questions about demographic and personal information were answered by the parents themselves, and questions about diagnostic and behavioral information were completed using the children's medical documentary. According to the standard instructions of the questionnaire, the status of social determinants of health became a nominal qualitative variable. Thus, the cases of having any level of stress in terms of each SDH question were assigned cod 1 and the absence of stress was assigned 0 in the analysis.

### **Reliability and Validity**

In order to evaluate the validity and reliability of the questionnaire using content validity index (CVI) and content validity ratio (CVR), the questionnaire was provided to the experts. For this purpose, two methods, qualitative and quantitative, have been considered. In the qualitative review of the content, the experts were

asked to provide the necessary feedback on the questions after the qualitative review. CVR and CVI were used to evaluate the content validity in a quantitative manner. A total of 10 people participated in this step. Participants had degrees in health care management, health policy, psychology, social medicine, child and adolescent psychiatry, and health economics. The questions were confirmed with a mean of  $CVR = 0.88$  and  $CVI = 0.81$ . The reliability of the questionnaire was also confirmed by Cronbach's alpha of 0.92.

### **Data analysis**

Statistical analysis included descriptive statistics (frequency and percentage for qualitative indicators; mean and standard deviation for quantitative indicators). After the normality assessment of the data using the Kolmogorov-Smirnov test, Chi-square test was used to determine the relationship between qualitative variables and SDH. SPSS-19 program was used for data analysis and the significance level of the results was considered 0.05. The results were reported in the form of tables.

### **Ethical considerations**

This study is the result of an approved plan and has been reviewed by the Research Ethics Committee of Tabriz University of Medical Sciences and has the ethics code IR.TBZMED.REC.1397.307. The informed consent of the participants was obtained using the informed consent form before entering the study.

### **Results**

According to the results, most of the participants (children with ASD) were male (81.3%) and had social security insurance (54.5%), the occupation of most of their fathers were self-employed (58%). 3.6% of the children did not have health insurance (Table 1)

**Table 1.** Demographic information of children with ASD

| Personal Information |                  | Mean      | Standard deviation |
|----------------------|------------------|-----------|--------------------|
| Child age            |                  | 8.81      | 3.30               |
|                      |                  | Frequency | Percent            |
| Child sex            | Male             | 91        | 81.3               |
|                      | Female           | 21        | 18.8               |
| Language             | Turkish          | 104       | 92.9               |
|                      | Farsi            | 7         | 6.3                |
|                      | Other            | 1         | .9                 |
| Place of birth       | Tabriz           | 79        | 70.5               |
|                      | Other districts  | 33        | 29.5               |
| Father status        | Alive            | 102       | 91.1               |
|                      | Dead             | 5         | 4.5                |
|                      | Divorced         | 5         | 4.5                |
| Father education     | Illiterate       | 6         | 5.4                |
|                      | Elementary       | 11        | 9.8                |
|                      | Middle school    | 23        | 20.5               |
|                      | High school      | 3         | 2.7                |
|                      | Diploma          | 34        | 30.4               |
|                      | Upper diploma    | 4         | 3.6                |
|                      | Bachelor         | 20        | 17.9               |
|                      | Master           | 9         | 8.0                |
|                      | Doctorate        | 1         | 0.9                |
| Father occupation    | Self-employed    | 66        | 58.9               |
|                      | Clerk            | 30        | 26.8               |
|                      | Factory worker   | 7         | 6.3                |
|                      | Engineer         | 2         | 1.8                |
|                      | Unemployed       | 2         | 1.8                |
|                      | Farmer           | 3         | 2.7                |
| Mother status        | Alive            | 108       | 96.4               |
|                      | Divorced         | 4         | 3.6                |
| Mother education     | Illiterate       | 1         | 0.9                |
|                      | Elementary       | 9         | 8.0                |
|                      | Middle school    | 21        | 18.8               |
|                      | High school      | 6         | 5.4                |
|                      | Diploma          | 41        | 36.6               |
|                      | Upper diploma    | 8         | 7.1                |
|                      | Bachelor         | 24        | 21.4               |
|                      | Master           | 2         | 1.8                |
| Mother occupation    | Homemaker        | 101       | 90.2               |
|                      | Clerk            | 9         | 8.0                |
|                      | Unemployed       | 2         | 1.8                |
| Insurance type       | Social security  | 61        | 54.5               |
|                      | Medical services | 13        | 11.6               |
|                      | Military         | 6         | 5.4                |
|                      | Iranian health   | 9         | 8.0                |
|                      | Oil company      | 19        | 17.0               |
|                      | None             | 4         | 3.6                |

According to the results of data analysis, the most imposed stress due to SDH factors were related to parental mental health concerns (99.1%), lack of required services (97.3%), cost-effective care services

(93.8%), access to needed healthcare (93.8%), and the least stress includes worries about physical violence of adults at home (59%) (Table 2)

**Table 2.** SDH status of children with autism spectrum disorders (ASD)

| r  | Social Determinants of Health                                 | Stress caused by each item |            |           |            |
|----|---|----------------------------|------------|-----------|------------|
|    |   | Yes                        |            | No        |            |
|    |   | Frequency                  | percentage | Frequency | percentage |
| 1  | Health insurance  | 90                         | 80.4       | 22        | 19.6       |
| 2  | Access to health care   | 105                        | 93.8       | 7         | 6.3        |
| 3  | Mental Health Concerns  | 111                        | 99.1       | 1         | 9.         |
| 4  | Failure to receive the required services                      | 109                        | 97.3       | 3         | 2.7        |
| 5  | Adequate physical activity                                    | 69                         | 61.6       | 43        | 38.4       |
| 6  | Children's access to entertainment programs in the summer     | 86                         | 76.8       | 26        | 23.2       |
| 7  | Physical condition of the house                               | 62                         | 55.4       | 50        | 44.6       |
| 8  | Cost or stability of housing                                  | 58                         | 51.8       | 54        | 48.2       |
| 9  | Not earning income at the end of the month                    | 92                         | 82.1       | 20        | 17.9       |
| 10 | Affordability of food supply                                  | 91                         | 81.3       | 21        | 18.8       |
| 11 | Access to healthy food  | 90                         | 80.4       | 22        | 19.6       |
| 12 | Cancellation of general subsidies                             | 95                         | 84.8       | 16        | 14.3       |
| 13 | Affordable care services                                      | 105                        | 93.8       | 7         | 6.3        |
| 14 | The cost of transportation or travel                          | 81                         | 72.3       | 31        | 27.7       |
| 15 | Keep their job or find a job                                  | 89                         | 79.5       | 23        | 20.5       |
| 16 | Child safety at school or kindergarten                        | 81                         | 72.3       | 31        | 27.7       |
| 17 | Adults with physical violence at home                         | 53                         | 47.3       | 59        | 52.7       |
| 18 | Cancellation of specific medical subsidies (for ASD services) | 90                         | 80.4       | 22        | 19.6       |

The results of the analysis of the relationship between SDH scores and demographic information of children with autism spectrum disorder showed that there is a significant relationship between having

stress due to lack of insurance and mother status in terms of "alive" or "divorced" (p-value = .023) while had no significant relationship with other childhood demographic information (Table 3).

**Table 3.** the relationship between stress felt from insurance and demographic information of children with autism spectrum disorder

| Personal information |                    | Stress for lack of insurance |          | p-value |
|----------------------|--------------------|------------------------------|----------|---------|
|                      |                    | yes                          | no       |         |
| Child sex            | Male               | 73(65.1)                     | 18(16.0) | 0.605   |
|                      | Female             | 17(15.1)                     | 4(3.5)   |         |
| Father status        | Alive              | 84(75)                       | 19(16.9) | 0.044   |
|                      | Dead               | 4(3.5)                       | 0(0)     |         |
|                      | Divorced           | 2(1.7)                       | 3(2.6)   |         |
| Father education     | Illiterate         | 4(3.5)                       | 0(0)     | 0.521   |
|                      | Without university | 59(52.6)                     | 14(12.5) |         |

|                   |                                     |          |          |       |
|-------------------|-------------------------------------|----------|----------|-------|
|                   | degree<br>With university<br>degree | 26(23.2) | 8(7.1)   |       |
| Father occupation | Self-employed                       | 52(46.4) | 14(12.5) | 0.250 |
|                   | Clerk                               | 24(21.4) | 8(7.1)   |       |
|                   | worker                              | 12(10.7) | 0(0)     |       |
|                   | Unemployed                          | 2(1.7)   | 0(0)     |       |
| Mother status     | Alive                               | 89(79.4) | 19(16.9) | 0.023 |
|                   | Divorced                            | 1(0.8)   | 3(2.6)   |       |
| Mother education  | Illiterate                          | 1(0.8)   | 0(0)     | 0.714 |
|                   | Under diploma                       | 63(56.2) | 14(12.5) |       |
|                   | Tertiary                            | 26(23.2) | 8(7.1)   |       |
| Mother occupation | Homemaker                           | 82(73.2) | 19(16.9) | 0.535 |
|                   | Clerk                               | 7(6.2)   | 2(1.7)   |       |
|                   | Worker                              | 1(0.8)   | 1(0.8)   |       |

## Discussion

This study aimed to determine the status of SDH of children with ASD in East Azerbaijan province of Iran showed that the families of children with AD are in a relatively stressful situation in terms of SDH.

Our study showed that children with ASD have different levels of difficulties in terms of SDH and their disorders. Different studies have corroborated our results that these children are in higher need of access to services and concerns thus special attention should be directed toward their SDH status. In the study of behavioral characteristics of children with ASD, in terms of verbal abilities, 67% of the children had verbal skills. However, 94.6% of children with autism did not have the appropriate speech ability for their growing age. According to studies, about one-third to one-half of people with autism never acquire sufficient speech skills to meet their daily communication needs<sup>17</sup>. According to Rapin and Sachman (2008), ASD disorder not only prevents a person from healthy speech communications and transmission of thoughts and ideas, but also causes some self-harming and aggressive behaviors in communicating with others<sup>18</sup>.

According to the results, the factor "Parents' mental health concerns"

accounted for the highest percentage of imposed stress. The results of the study of Islam et al. (2017) in Kerman showed that considering the interaction between the behavioral problems of children with autism and the stress on parents, it can be concluded that chronic stress caused by interaction with children with autism can cause psychiatric disorders such as depression and anxiety for parents<sup>19</sup>. According to the Magno study in Taiwan, mothers of children with autism experience higher levels of general anxiety and lower quality of life than mothers of mentally retarded children without autism, mothers of children with cerebral palsy, and mothers of normal children<sup>20</sup>. Estes et al. concluded that children's behavioral problems are significant predictors of stress and psychological distress among parents of children with ASD<sup>21</sup>. Raising a child with ASD is a frustrating experience for parents and families that pose a number of problems in various aspects, such as parenting self-efficacy, parenting stress, parental mental and physical health, marital relationships, sibling relationships and family. They generally create family well-being<sup>22</sup>. Tonal and Power also found in their study that many of children's mothers were forced to quit their jobs and stay home because of their child's problems. These mothers had less leisure time and received very little emotional support from their husbands<sup>23</sup>. Therefore, having a child

with special needs challenges the whole family and destroys the balance in the family integration, and restoring a harmonious balance requires a lot of effort from all members. According to the results of a study in Mashhad, attention to the healthy and efficient functioning of the family in the treatment process of these children is essential and brings mental health to the family and society<sup>22</sup>. Improving a child's status requires having parents who are emotionally well. If family relationships are associated with anger, frustration, depression, and fatigue, it will be very difficult to meet the needs of children<sup>24</sup>. The study of Saberi et al. showed that a positive parenting group training program significantly reduces stress on both parents and children<sup>25</sup>. According to the current study, the component of "failure to receive the required services" has posed a lot of stress to families. According to the study of Ahmadi et al. (2011), one of the most basic requirements of Iranian parents is the needs for the continuation of medical services for the rest of their lives<sup>26</sup>. Additionally, in another study conducted in the United States, medical services are not provided in schools and there is no regular process of support services for children from the beginning of childhood to the end of education and entering the community. Thus, at the beginning of diagnostic and therapeutic interventions, treatment and follow-up are emphasized, but the rest of the life process of these children is the responsibility of the parents<sup>27</sup>. Another study by Durkin et al. (2010) in the United States found that the prevalence of ASD among children is directly related to their socioeconomic status<sup>28</sup>. Therefore, receiving the services needed for these children is an important cause of concern and stress for parents.

### Study Limitations

One of the limitations of this study is its implementation in a province. Due to the

low sample size, it will probably not be possible to generalize the results nationwide. Also, in this study, the relationship between SDH and diagnostic components of autism spectrum disorders has not been investigated.

### Conclusion

According to the results of the study, the SDH status of families of children with ASD is at an unfavorable level, which leads to anxiety in families, imposing excessive costs on them and thus a serious threat to improving the situation of children with ASD. It is hoped that through the financial and social support of the Welfare Organization, the Education and Training Organization, and charity, an effective step be taken to improve the SDH status of these children.

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