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*by* Sanaul Haque

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## Public Perception of Individuals with Autism Spectrum Disorder and Their Families in Almaty, Kazakhstan

**Scholar Name:** Insana Karymsakova

**Scholar's Affiliation:** Nazarbayev Intellectual School of Science and Mathematics in Nauryzbay District of Almaty

**Scholar Email:** insanakarymsakova5@gmail.com

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### Introduction

**Background and Context:** Autism spectrum disorder (ASD) covers a range of disorders in the development of the nervous system. This spectrum is characterized by repetitive behaviors, interests, activities, and problems in social interactions. ASD is a complex disorder of the development of the nervous system, which is characterized by behavioral and psychological problems in children [1]. According to [2], the median prevalence of ASD is 100/10,000 populations. The symptoms of ASD usually appear by the age of two. The cause of this disorder is still not known. Many children with this disorder are completely or partially deprived of basic skills such as receptive, expressive language skills, social and self-care skills, and etc. Although early research in ASD focused primarily on children, there is increasing recognition that ASD is a life-long neurodevelopmental disorder that has a potentially detrimental impact on adult functioning [3]. At present, there is no fully effective treatment method for ASD, and several key factors influence the prognosis of disorder include early diagnosis time, early language communication level, intelligence level, disease severity, family participation, appropriate intervention, and social support. Therefore, early individualized long-term comprehensive training, drug therapy and combined family participation can improve the prognosis of pediatric patients [4].

**Research Problem:** The research problem is the lack of understanding and low public awareness of autism spectrum disorder (ASD) in Kazakhstan, including widespread misconceptions and incorrect perceptions about ASD. Despite the fact that ASD has been studied for quite a long time, the importance of this problem has only begun to be betrayed now with the increasing number of people with this diagnosis. The importance of this problem is very rarely raised in society, which prevents people with ASD and their families from integration, and sometimes can even affect the development of this disorder. By understanding the attitude of society towards these people, specific actions can be taken in order to improve their quality of life.

**Research Novelty:** The novelty of this study lies in the fact that it will use both quantitative and qualitative research methods, and it will mainly focus on the needs of people with ASD and their families. It will also examine not only public perception of children with this disorder, but also adults with ASD and give possible solutions for addressing this problem.

**Research Questions:** How does social perception of ASD influence the integration and well-being of individuals with ASD and their families in Kazakhstan?

What specific <sup>10</sup> actions or initiatives by the government or society can effectively enhance the social integration of individuals with ASD and met <sup>9</sup> their needs?

**Research Aim:** The aim of this research is to explore <sup>11</sup> the impact of social perception on people with ASD and their families.

**Research Objectives:**

- To identify the social perception of <sup>11</sup> people with ASD and their families.
- To describe <sup>11</sup> the influence of social perception on their social integration and overall well-being.
- To explore specific needs of these people that must be addressed by society and the government.
- To understand what specific actions should be taken regarding the problem of integration of people with ASD and their families.

## Literature Review

**Introduction to the Topic of ASD:** An article [1] provides a comprehensive overview of ASD, covering its diagnostic criteria, causes, and the impact it has on individuals and families. Authors emphasize the importance of understanding the diverse manifestations of autism, since the spectral nature of the disorder means that each person can experience ASD in different ways. This diversity often leads to confusion and misunderstanding among the general public, which can lead to negative stereotypes and social exclusion of people with ASD. The article highlights that these public misconceptions can hinder early intervention efforts and contribute to the social isolation of affected people and their families. This work is crucial to this research because it provides a fundamental understanding of ASD.

**Researches on the Social Perception of ASD:** Awareness is a vital part of social integration and understanding of people with autism spectrum disorders (ASD). Public awareness campaigns, defined as knowledge and understanding of a subject or condition, aim to change attitudes and break down stereotypes related to ASD. According to the study [5], in Kazakhstan the level of awareness regarding ASD is very low which in turn increases the chances of misconceptions and stigmatization. The majority of participants expressed fear or annoyance when considering the behaviors of children with ASD that occur in public spaces. Rural residents were more likely to view ASD-related behavior as threatening or dangerous.

International studies [6][7] also examined low public awareness about this disorder among different groups. Despite the fact that the situation with public awareness in other countries also remains low, a large number of studies on this topic help to increase these indicators, which cannot be said about the limited number of works in Kazakhstan.

**Problems Faced by <sup>11</sup> People with ASD and Their Families:** The number <sup>11</sup> of studies on people's awareness of this problem, especially in Kazakhstan, is very limited and does not cover all important aspects. However, research [8] examines <sup>11</sup> the experiences of parents raising children with ASD in Kazakhstan, focusing on their perceptions of the health, educational, and social support services available to them. The study identifies barriers that families are encountering while looking for appropriate services and brings attention to the gaps in systems of support in post-Soviet societies. The study highlights that delayed diagnosis of ASD is one of the major challenges faced by parents. Several parents saw the early signs of autism in their kids but were often delayed in obtaining an official

diagnosis because of a mix of factors. Conflicting opinions from specialists left parents confused and frustrated. The study finds that, while special education services have improved in some areas, the system has serious limitations. Parents found it hard to get assessments for their children, and there were long waitlists for services. Often, publicly funded programs were inadequate, with few possessing the trained specialists who could meet the needs of children with ASD. While some parents sought private educational services, they were not financially attainable for many families. The lack of inclusive education programs in regular schools, and the placement of many children in "correctional" schools, was further emphasized in the study. The recommendations included the need for better diagnostic standards, more integrated and individualized services, and the reduction of stigma through public awareness campaigns. In addition, study [9] demonstrates that parents in Kazakhstan also experience serious mental health problems. More stress, anxiety, and depression have been reported by the parents of children with autism spectrum disorder (ASD). Research indicates that 61% of parents in Kazakhstan experienced stress, 52.9% anxiety, and 53.7% depression.

**Role of Empathy:** The study [10] contributes to a growing body of research indicating that awareness on autism spectrum disorder (ASD) can have a substantial impact on social perception, particularly regarding warmth and social competence. The participants view the person more positively, particularly on these two critical dimensions of social impression when they learn that this person has been diagnosed with autism spectrum disorder (ASD). This study will also focus on the relationship between past knowledge of this diagnosis and attitudes towards these people.

### Methodology

**Study Design:** The research employed both quantitative and qualitative approaches. For quantitative part of the research descriptive type of design was used. In order to evaluate level of awareness, variables were measured and the statistics were described. On the other hand, for qualitative approach phenomenology type of design was used. This approach helped to describe participant's (parents of ASD child) lived experiences, thoughts, and needs, and to develop possible solutions to the problems they are facing.

**Sampling:** For quantitative approach probability sampling was used. More exactly, the stratified sampling method. General population was divided into subgroups based on the relevant characteristic (e.g., gender identity, age range, income bracket, job role). This method of sampling helped to receive data about different social perception of ASD and to potentially identify correlations between these perceptions and these characteristics. For qualitative approach non-probability sampling was used. Purposive sampling and if possible, snowball sampling. In purposive sampling, family members of individuals with ASD and school students were selected in order to understand different perceptions of this problem. Snowball sampling was used to find new interview participant, increasing the number of respondents.

**Data Collection Instruments:** Based on quantitative methods, a survey(questionnaire) with multiple answer questions was developed in both Kazakh and Russian languages. 50 participants were asked to answer these questions. The first part of questionnaire included the demographic part. The respondents were asked to indicate their characteristics, such as age, gender, level of education, etc. The second part of questionnaire included questions related to social perception of the population about ASD. This part also included some stereotypical questions to access participants knowledge about ASD. Different situations with ASD people were described there in order to analyze participants attitudes toward these individuals and their families. Respondents were asked to choose their possibly reflection to these

situations. Questionnaire was created with the help of Google platforms and was sent to WhatsApp groups. After data collection the results were presented as a percentage. Based on qualitative methods, 5 interviews were conducted with parents who raise children with ASD. Interview included some open-ended questions about the challenges families face in raising children with ASD. Follow-up questions were also asked in this part.

**Data Analysis:** Before analysis, the data was checked for completeness and consistency. The data was summarized by using statistics methods and was converted into percentage (quantitative approach). During the survey, respondents were also divided into those who have relatives or friends with autism and those who do not. Statistical analysis was carried out based on their answers to the questions (t-test). The qualitative data gathered from the interviews with parents of children with ASD was analyzed using thematic analysis. The audio or written responses from the interviews were transcribed. The transcripts were read multiple times to become familiar with the content and identify key concepts. The identified themes were interpreted to gain deeper insights into the experiences and challenges faced by parents. Patterns across different responses were explored to understand commonalities and differences in experiences, as well as attitudes toward ASD.

**Ethical Considerations:** All participants were fully informed about the nature of the research, its objectives and how the collected data was used. Each respondent received a clear and concise informed consent form, both in Kazakh and Russian, outlining the study's purpose, procedures, potential risks, and benefits. Personal information and responses of the participants was protected and submitted in an anonymous form if needed. All survey responses and interview data were anonymized to ensure that individual participants cannot be identified in the results. The study was designed to be non-judgmental and supportive, especially during the interviews with parents of children with ASD, where the focus was on understanding their experiences and challenges. In addition, participants were reminded that they were free to skip any questions they felt uncomfortable answering. Researcher approached sensitive topics with all care and empathy.

**Practicalities:** Data collection will occur over a period of one month, followed by rigorous data analysis. The study will adhere strictly to ethical guidelines regarding participant privacy and data security.

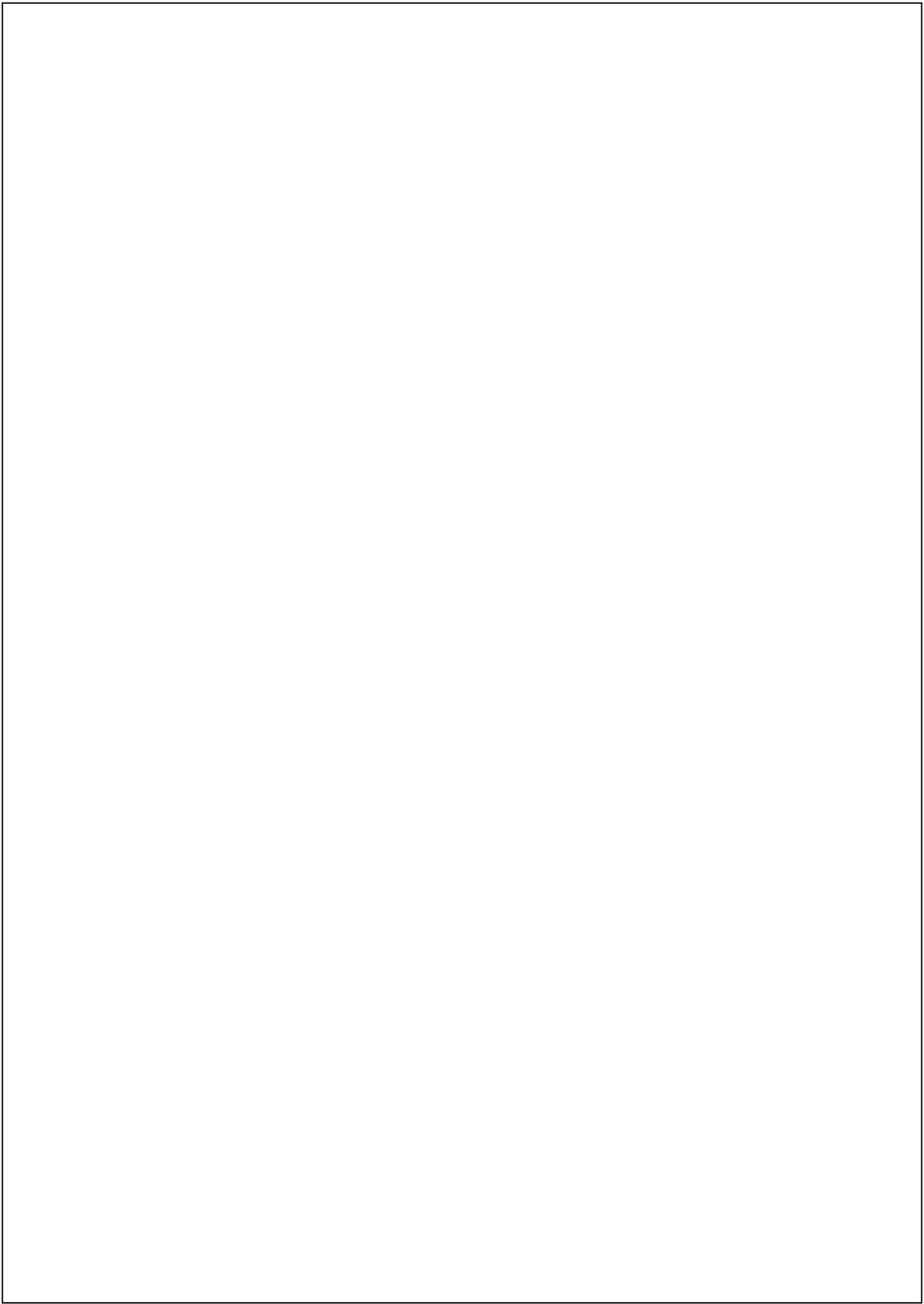
**Potential Limitations:** Difficulties in conducting the study may have arisen due to the limited number of respondents. In addition, some parents of children with this disorder may have provided inaccurate or emotionally biased answers, as they may have had strong feelings about their child's condition and the challenges they faced.

### Conclusion

This research will determine the level of awareness of people about ASD. It will probably show common misconceptions and gaps in knowledge about this disorder. The results of this study will show people's social attitudes toward people with ASD and their families and help in developing effective solutions to the problems faced by these individuals. The impact of this research is expected to be significant in raising public awareness of autism spectrum disorder (ASD) in Kazakhstan. This research will probably help in creating a more inclusive society, in early identification of symptoms for more effective correction of the disorder, and will be used further in many practical ways.

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