



# Studying the Situation and Needs of Parents with Children with Autism Spectrum Disorders in Mongolia

Battsengel Gelen, Byambajav Khashbat <sup>✉</sup>

Department of Special Needs Education, School of Educational Studies,  
Mongolian National University of Education, Mongolia

byambajav.kh@msue.edu.mn

**Abstract.** The article presents on studying the situation and needs of parents with children with Autism Spectrum Disorders (ASD) in Mongolia. According to the World Health Organization, one in every 100 children has an autism spectrum disorder in the world [1]. In Mongolia, there is a lack of knowledge, statistics, and experience in the areas of diagnosis, educational assessment, education, and support for children with ASD. Also in Mongolia, it is believed that the number of children with ASD is greatly increasing every year. For example, in 2022, a maximum of 702 children with ASD were registered. As a result of these statistics, there may be a need to reconsider the diagnosis and assessment of ASD in Mongolia. Because autistic disorder, its diagnosis and assessment were first translated from a foreign language and developed in Mongolia only in 2006 [2]. In connection with this condition, there is an urgent need for early diagnosis of children with autism spectrum disorders, the development of early support programs, the inclusion of children in these programs, and the appropriate support for their parents and families. Therefore, we conducted this study to clarify the concerns and needs of parents of children with autism in the current situation in Mongolia.

**Keywords:** Children with ASD in Mongolia · Support · Parents of children with ASD in Mongolia

## 1 Introduction

ASD is a major type of pervasive developmental disorder, which is a combination of qualitative impairments in the areas of social relationships, verbal and nonverbal communication, and imagination, as well as an extremely limited range of activities and interests [3].

The number of children with ASD is reported to be increasing every year. What's not so clear is whether this represents a true increase in prevalence or just greater awareness of the condition [4].

In the report of the statistical office of the National Centre for Mental Health of Mongolia over the past five years (2018-2022), 1725 children aged 0-18 years were registered with an ASD, of which 33.6% (n=580) were female and 66.4% (n=1145) men. Looking at the years, there were 248 children with ASD in 2018, 262 in 2019, 211 in 2020, 240 in 2021 and 702 in 2022. Of these, 75% (n=526) were male and 25% (n=176) female, i.e. a 3:1 gender ratio. Of these, 80.6% (n=566) are in the capital, Ulaanbaatar, and the rest are in the countryside. In addition, 75% of children with ASD are diagnosed at the age of 2-4 years [5]. According to the results of the report, the number of children with ASD in Mongolia is increasing year by year, but it should be noted that there is a lack of experience in diagnosing children and providing early support, education, health care, and social services. The most important diagnostic test for autism spectrum disorder is the ADOS (Autism Diagnostic Observation Schedule) [6] [7]. The National Centre for Mental Health of Mongolia is working to modify this method in its own country.

Also, since Mongolia began to implement the concept and policy of inclusive education, not only do children with ASD attend regular kindergartens, but the number of children with ASD enrolled in special schools and the level of complexity have also increased, teachers and specialists report. For example: in the 2022-2023 academic year, 27 children entered 3 groups of the 1st grade of the 63rd special school in the capital of Mongolia. Of these, 59.2% were children with ASD, i.e. approximately 4-5 children with ASD are in one class [8].

If we refer to previous studies in this regard in Mongolia,

1. Strategies for capacity building in a low-resource setting: Stakeholders' voices [9]
2. Exploring the ways in which mothers of children with ASD cope with stress [10]

Although the above studies have been conducted, there are still no studies that specifically examine the problems faced by parents.

Therefore, we conducted this study to determine the current situation, problems, and needs of parents with children with

ASD in Mongolia, analyse them, and formulate proposals.

## 2 Methodology and Data Analysis

In Mongolia, a non-governmental organization called Mongolian Autistic Association was established in January 2014. The original set for this study is 800 families registered with the NGO Mongolian Autism Association. The gender ratio of these people is 627 men (79.87%), 158 women (20.13%), 387 families with children aged 6-15, 375 families with children aged 3-5, and 23 adults [11].

We randomly selected respondents from members of this association. In September 2022, we interviewed 136 parents of children with ASD, and the members of the Mongolian Autism Association. The study was conducted by interviewing parents and summarizing the results.

The grouping of survey questions:

- General information about parents, and their children with ASD and the diagnosis of the child, the level of understanding of parents about ASD
- State support for the family and support for children's education and upbringing
- Communication between parents and children. The necessary support, from the point of view of the parents.

## 3. Results and Discussion

### 3.1. Information about Parents of Children with ASD

Among 136 people aged 20-60 years who had children with ASD, the highest frequency was 9 people aged 34 years. This means that there are a lot of young families with children with ASD, and it is necessary to create a support system for them. The age of the participants is indicated in the following graph.

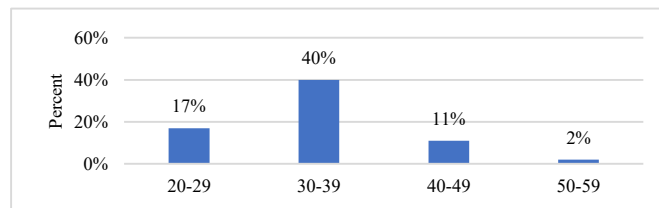


Fig. 1. Age of respondents

93.4% (n=127) of the 136 people who participated in the survey were from the capital city, while the remaining 4.6% (n=9) were from rural areas. Regarding their gender, 85.3% (n=116) were female and 14.7% (n=20) were male. When examining the educational level of the respondents, 90% had a bachelor's degree, and the remaining 10% had a high school education. Although most of the parents have higher education, the result is not very favourable in terms of employment. Specifically, the number of families in which both parents are employed was only 40%. One of the parents is employed was 51%, both parents unemployed accounted for 6%, and 3% of the participants did not answer this question. The reasons for parental non-employment are explained, which means that parents do not have the opportunity to work regularly because of the special care they need to provide for their children. In our country, it is reasonable to believe that the lack of teaching staff to support children with ASD in educational services, the lack of school and kindergarten environment, and the education system are the factors that lead one parent to take care of the child at home.

### 3.2. Information about Children with ASD

Considering the gender of children with ASD, 80.15% (n=109) are male and 19.85% (n=27) are female, which means males are 4 times more than females. The male-to-female ratio of children with ASD is typically 4:1, but there are studies that dispute this. In that study this ratio is closer to 3:1. There appears to be a diagnostic gender bias, meaning that girls who meet criteria for ASD are at disproportionate risk of not receiving a clinical diagnosis [12].

7.4% (n=10) of the parents who participated in the survey said that their children were twins, while the rest, 92.6% (n=126) answered that they were non twins.

In terms of age, the children were between 2-14 years old. Majority of them were children aged 3-4 years. The following figure shows information about the age of the children with ASD.

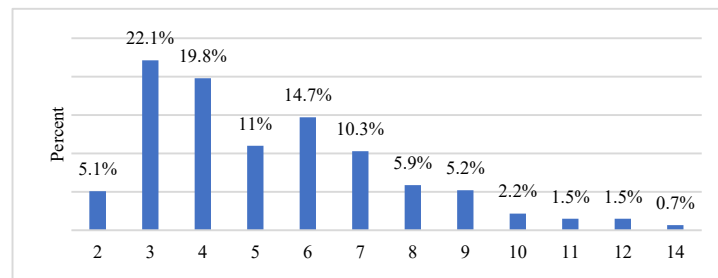


Fig. 2. Age of children with ASD

96.3% (n=131) of these children with ASD were diagnosed by a professional organization, and 3.7% (n=5) were not diagnosed at all. 79.4% (n=108) of all children were diagnosed by the National Mental Health Center of Mongolia, and 20.6% (n=28) by other professional organizations. The following figure shows the age at which these children were diagnosed with ASD. Most of the children, 77.2%, were diagnosed with ASD at the age of 2-3 years.

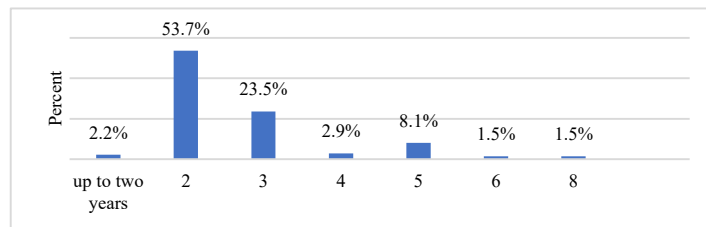


Fig. 3. Age at diagnosis of children with Autism Spectrum Disorder (ASD)

75% (n=102) of these children had a diagnosis of F84.0 or childhood autism, 2.2% (n=3) had F84.1 or atypical autism, 0.7% (n=1) had F84.5 or Asperger syndrome. The remaining 22.1% (n=30) answered that they do not know the accurate diagnosis.

After diagnosis, 67% of children received some form of support in health, education, or social care, while the remaining 33% did not receive any support. Looking at the form of support, health services are provided by the family clinics and The National Center for Maternal and Child Health of Mongolia, while education services are provided by public schools and state-owned kindergartens. But recently, parents have become interested in the educational services of private institutions.

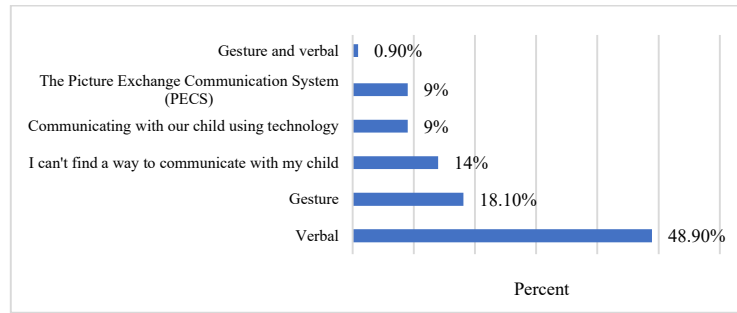
Most of the children who participated in these studies are preschoolers, and 32.35% of those children are in regular public kindergartens, 16.17% in special kindergartens, and 12% in private kindergartens. But for school-aged children 10.29% are in public schools, 14.7% in special education public schools, 7.35% are in private schools, and the remaining 8.08% are at home.

The following results were obtained from the satisfaction survey of parents regarding education services provided to their children. According to the results of the study, 78.6% of the parents rated the educational services provided to their children as insufficient to moderate, and 21.3% rated them as good or very good. According to interviews with parents, the main reasons available for assessing it as insufficient or average are that the teacher does not work by taking into account of the child's characteristics, there are many children in one class, and the teacher does not know how to work with children with ASD. They also highlighted the problems such as the lack of a psychological and adaptive environment for learning in the classroom for children with ASD.

According to the views of modern researchers, the main specificity of autism is primarily the immaturity of communicative behavior. In children with autism, both the development of speech and communicative behavior are impaired [13]. When asked what methods and forms parents communicate with their children, 48.9% said non-verbal communication, while 14% said they could not find a way to communicate (Figure 4).

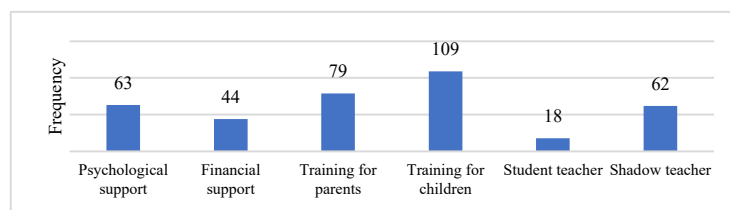
In addition, we asked parents what methods they use when their children exhibit problematic behaviour. In the answer, 45.5% of the total responses did not support the child's behaviour but rather stopped the bad behaviour, and 21.8% responded directly to the child's behaviour and tried to fix it. 28.8% responded that they observe the child's behaviour and do not react immediately, waiting for the child to be normal. The remaining 3.8% answered that they just "tolerate" it.

This shows that parents of children with ASD do not find ways to communicate with their children, and they have not yet found ways to deal with their children's problematic behaviors. We believe that this type of support is essential. But when asked, 'what kind of support do you need right now?' 29.1% answered that they needed child development training, 21.1% needed training for parents, 16.8% needed psychological support, etc. (Figure 6).

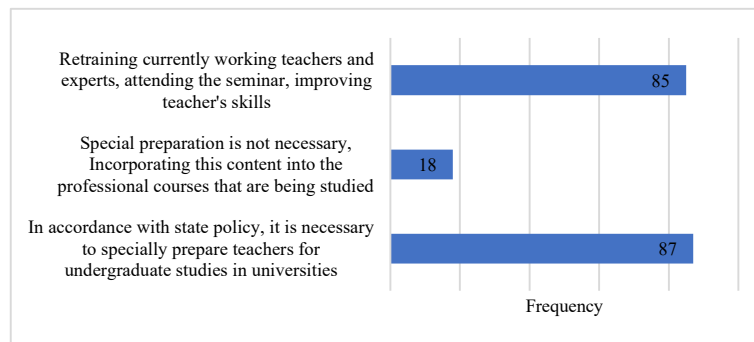


**Fig. 4.** The form of communication between parents and their children

We asked parents what support they absolutely needed right now. The majority of parents preferred to educate their children in regular kindergartens with an additional curriculum tailored to the child's specific needs and asked for parent empowerment, child development training, and shadow teacher support. A minority of parents supported sending their children to special kindergartens and schools. The results of this question are shown in figure 5.



**Fig 5.** Types of support parents need



**Fig. 6.** The respondents' opinion on how to train teaching staff to work with children with ASD

As can be seen from figure 6, parents believe that it is more important to specially train teaching staff to work with children with ASD through pre-service teacher education, and to retrain in-service teachers. When working with children with ASD, it is important to work with an educator and psychologist who specialize in programs that are appropriate for the child and based on his or her abilities [14].

In connection with this, students studying to become special needs education teachers at the Mongolian State University of Education, take a two-credit elective course, "Education of Children with ASD" acquire knowledge and skills to work with children with ASD, understand their unique characteristics, respect children and families, develop positive attitude and maturity.

The parents also asked students studying the above professions at the MNUE to work as shadow teachers in kindergartens and schools, as well as the department of special needs education to organize advanced training for teachers of education institutions.

### 3 Conclusion

As we said earlier, according to the statistics of the National Centre for Mental Health of Mongolia, 702 children with ASD were registered in 2022, which is 2.9 (n=240) times more than the previous year. Is this really a sharp increase in the number of children with ASD, or is there a need to clarify the difficulty of diagnosing children with ASD? If it is really an unquestionable number in today's Mongolian situation, it is highly crucial to clarify the problems faced by the families and guardians of children with ASD and to correctly define the form of support

accordingly. If the number of children with ASD increases year by year at this rate, according to the research results we received from the parents, our country is not ready to support families with children with ASD, or support children with ASD, and further provide equal education.

Based on the results of the above study, the following conclusions can be drawn. It includes:

- Improve the type, quality and availability of educational, medical and social services for children with ASD, as well as expand cooperation between these organizations.
- Train teachers to work with children with special needs education and improve the skills of existing teachers.
- Creation of a support system for families with children with ASD
- There is a need to develop a methodology suitable for working with children with ASD.
- Also, it cannot be denied that there is a need to pay attention to the means used to diagnose children with ASD and make the diagnosis more precise.

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