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# BULGARIAN ADAPTATION OF THE AUTISM SCREENING INSTRUMENT FOR ADULTS “AUTISM SPECTRUM QUOTIENT”: PRELIMINARY DATA

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**Abstract.** *There is no publicly available information about the number of people with autism spectrum disorders (ASD) in Bulgaria. According to international epidemiological studies, the percentage of people who meet criteria for an official ASD diagnosis is between 1% and 2% of the population (Brugha et al., 2018; CDC, 2017). In Bulgaria, that will add up to 80 000 people. The Autism Spectrum Quotient (AQ; Baron-Cohen et al., 2001) is a screening questionnaire for autism spectrum disorders in adults. The aim of the present report is to present preliminary data on the Bulgarian AQ adaptation by comparing the total scores of participants with an ASD diagnosis to the total scores of neurotypical controls.*

*The questionnaire was posted on social media, as well as sent to people receiving social services for individuals with ASD. In 2022 and 2023 the online questionnaire was filled out by 40 adults with ASD (mean age: 25,31 years; 27 male, 10 female) and 945 neurotypical adults (36,84 years; 250 male, 681 female).*

*There was a statistically significant difference in total scores between participants with ASD and those without (ASD:  $M=30,63$  points,  $SD=9,08$ ; Controls:  $M=22,52$ ,  $SD=9,25$ ;  $t(983)=5,43$ ,  $p<0,001$ ).*

*The statistically higher average total score of the adults with ASD provides preliminary evidence that the Bulgarian adaptation of the AQ can distinguish between adults with ASD and those without. Similar results are reported for the adaptations of the AQ to other languages and cultures.*

**Keywords:** autism, adults, screening, adaptation, Bulgaria

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## INTRODUCTION

In Bulgaria, there are still no official statistics on the number of children and adults who meet the diagnostic criteria for autism spectrum disorders (ASD). At the same time, public awareness of the characteristic symptoms and difficulties associated with autism is rapidly increasing through awareness campaigns, advocacy projects by parents' associations, and autistic protagonists in popular films and TV series. As a result, it is becoming more and more common for adults to recognize the symptoms of autism and seek a formal diagnosis or consultation with a specialist. The lack of available diagnostic tools for autism in adulthood, combined with the widespread practice of not making such a diagnosis after the age of 18 years, present two major obstacles to adults seeking diagnostic testing in Bulgaria. This paper presents preliminary data from the Bulgarian adaptation of an autism screening tool for adults as a first step in addressing this issue.

Autism spectrum disorders (ASD) include disorders that affect child development and whose symptoms begin to manifest in early childhood during the first three years of life (ICD-11, 2021). More specifically, ASD are called neurodevelopmental disorders because they are associated with different development of the nervous system. ASD are characterized with behavioral symptoms that manifest during the first two to three years of life, and these behavioral symptoms are in three main areas of functioning: 1) social interactions, 2) language and communication, and 3) restricted and repetitive patterns of behavior.

In the area of social interactions, people with autism often show a lack of eye contact, lack of reciprocity in communication, the person does not give or show objects spontaneously to others, emotions are not shared, and there is often difficulty in understanding others' points of view (American Psychiatric Association, 2013; ICD-11, 2021). In the area of communication, there are often delays in language development, varying rate and tone of speech (e.g., it may be monotone, but it may also have many abrupt changes within an utterance), and lack of integration between gestures, facial expressions, and speech. The domain of restricted and repetitive patterns of behavior is characterized by strict following of routines and rituals, circumscribed interests (e.g., numbers, colors, cars) with a desire to talk only about them, but also repetitive movements (e.g., full body rocking, flapping hands, walking in circles). The clinical presentation of ASD can be extremely heterogeneous, including both people who are high

functioning and can live independently, and people with very severe difficulties who require care around the clock. It is important to note that the difficulties of people with autism are related to their *behavior*, as a result a diagnosis of autism can be made based on observation of the person's *behavior*. Biomarkers or other medical tests for diagnostic purposes have yet to be identified.

The first written account of autism was by Leo Kanner in 1943 (Kanner, 1943). In his scientific work, he described only a few children with symptoms of autism. From then on until the 1970s, 1980s, and 1990s, autism was thought to be a very rare developmental disorder. Around that time epidemiological studies began to be conducted to determine what percentage of people in a country's population would meet the diagnostic criteria for ASD. Similar studies from North America published in 2000 showed that 1 in 150 people met these criteria; 2010: 1 in 68; 2020: 1 in 54; 2021: 1 in 44 (Brugha et al., 2018; Centers for Disease Control and Prevention, n.d.). Such studies also indicate that there is no difference in the prevalence of autistic symptoms based on race, ethnicity, geographic region, or socioeconomic status.

In Bulgaria, there are still no officially published and freely available statistics on the number of children and adults diagnosed with autism. This restricts the opportunities to change legislation and policy about people with developmental disorders. But the results from epidemiological studies in other countries can help estimate how many Bulgarian children and adults have autism because there is no reason to believe that the percentage of people in Bulgaria would be different.

Despite the lack of official statistics there has been an increase in awareness about autism among the general public, as evidenced by various awareness campaigns, the celebration of April 2nd - World Autism Awareness Day and the introduction of early intervention programs. Two studies have also been conducted on the needs of families of children with autism in Bulgaria (Barokova et al., 2022; Daniels et al., 2017). Data from these studies were collected in 2013-2015 (Daniels et al., 2017) and 2020 (Barokova et al., 2022) and show that families of children with autism experience tremendous difficulty in accessing health, psychological and educational services. Data collection on the needs of families is currently underway using the same online questionnaire as the previous two studies (Barokova & Andreeva-Sapundzhieva, 2024). Preliminary data indicate that 73% of parents who completed the questionnaire had been subject to discrimination or

negative attitudes in the last year because of their child's diagnosis. This demonstrates the need to continue to improve awareness of autism and to make a concerted effort at both the state and societal levels to reduce the stigma associated with psychological and psychiatric diagnoses.

In terms of diagnostic procedures, in Bulgaria, only a psychiatrist can make an official diagnosis of autism. It is a common practice not to diagnose ASD in people over the age of 18 years. After the age of 18 years, it is believed that other difficulties such as anxiety and depression take precedence over the symptoms of autism. This practice can be extremely confusing for people who, as adults, first seek a diagnostic consultation believing they have autism, and even more confusing for those who were diagnosed with ASD as children and subsequently have their diagnosis changed.

#### *Screening and diagnostic tools for autism in Bulgaria*

In the diagnostic process, it is good practice to use appropriate tools and psychological instruments. The psychological instruments for autism diagnosis and screening that are available, adapted and validated for the Bulgarian context are extremely limited. The Modified Checklist for Autism in Toddlers - Revised (M-CHAT-R; Robins et al., 2014; Eyubova, 2018) is available and adapted for the Bulgarian context. This is a screening tool for children between 16 and 30 months of age that can be filled out either by a parent or a pediatrician. The tool is a list of statements/items with which the parent indicates how much they agree. For the Bulgarian context, this checklist is distributed free of charge as a mobile application that automatically processes the results.

Another available and already adapted instrument is the Childhood Autism Rating Scale (CARS; Schopler et al., 1980), which is distributed in Bulgaria after training by a private company. The instrument is suitable for children over 2 years of age and helps to identify symptoms of autism and determine their severity. The key is that the scale is filled out by a clinician.

Another tool that has been adapted for Bulgaria is the Childhood Autism Spectrum Test (CAST; Williams et al., 2005). The CAST is distributed free of charge online. It is a questionnaire that consists of statements with which the parent indicates his or her level of agreement.

The gold standard diagnostic tool for autism is the Autism Diagnostic Observation Schedule - 2 (Lord et al., 2012). This is a tool that involves observing the behavior and performance of specific

tasks together with an administrator who leads a semi-structured interaction, which lasts between 40 minutes to an 1 hour. This tool has not yet been adapted for the Bulgarian context, but the rights for it have been purchased.

As seen in this review, screening and diagnostic tools for autism spectrum disorders are almost non-existent in Bulgaria, especially for people over the age of 18.

#### *Screening questionnaire for autism in adults (Autism Spectrum Quotient; Baron-Cohen et al., 2001)*

The autism screening tool for adults, the AQ, consists of 50 statements. Adults must indicate their level of agreement with each statement on a 4-point Likert scale. The statements are grouped under 5 themes: social skills, attention shifting, attention to detail, communication, and imagination. The first published study using this scale compared the scores of 4 groups of participants: 58 adults with Asperger's syndrome, 174 neurotypical adults, 840 Cambridge University students, and 16 UK Math Olympiad winners (Baron-Cohen et al., 2001). Overall, the results showed that the mean score of the adults with Asperger's syndrome was statistically higher than that of the neurotypical adults. Natural science students had higher scores than students from all other disciplines, and participants who won the math Olympiad had higher scores than students in the humanities. A score of 32 points was identified above which the scores of 79.3% of adults with Asperger's syndrome and only 2% of neurotypical adults fell. As a result, 32 points was defined as the cut-off score, which is the score above which adults are considered more likely to meet the diagnostic criteria for autism.

Since this first publication of the AQ, many studies have used it. In addition, it has been adapted to numerous other languages and contexts. When adapting a questionnaire or a scale for a new context, culture and/or language, all the items/statements are first translated into the respective language, then back-translated into the original language, and these back-translated items are compared to the original version. This procedure is repeated until the back-translation is considered equivalent in meaning to the original. Previous adaptations of the AQ typically collected data from two groups of participants: those with a diagnosis of autism and those without a diagnosis and/or expressed suspicion of such (Broadbent et al., 2013; Lugo-Marin et al., 2019; Pisula et al., 2013; Ruta et al., 2012; Wakabayashi et al., 2006; Zhang et al., 2016). In some cases, additional groups are included such as university students (for a control group; Wakabayashi et al., 2006;

Stewart & Austin, 2009), parents of children with autism who typically have higher mean scores than neurotypical adults (Lugo-Marin et al., 2019; Ruta et al., 2012), and adults with other diagnoses, such as schizophrenia, attention deficit hyperactivity disorder, or obsessive-compulsive disorder (Zhang et al., 2016).

Previous studies can be divided into two types according to their statistical analyses: those that perform factor analysis (Lugo-Marin et al., 2019; Stewart & Austin, 2009), and those that examine the internal consistency of the instrument with Cronbach's  $\alpha$  coefficient (Broadbent et al., 2013; Pisula et al., 2013; Ruta et al., 2012; Zhang et al., 2016). On the one hand, factor analysis allows to better understand the structure of the instrument and, according to the grouping of questions by factors, to consider whether and how they meet the diagnostic criteria for autism. Such analyses done for different languages show divergent factor structures (Lugo-Marin et al., 2019; Stewart & Austin, 2009). On the other hand, the factor structure of the original questionnaire was not considered in the process of designing it, and the sub-scales do not necessarily correspond to the diagnostic criteria. In that sense, the internal consistency of the instrument may be enough to evaluate it for screening purposes, namely that the statements reflect behaviors that distinguish autistic and non-autistic individuals based on a total score. The Cronbach's  $\alpha$  coefficient ranges between 0.60 and 0.80 for different adaptations (Broadbent et al., 2013; Pisula et al., 2013; Ruta et al., 2012; Zhang et al., 2016).

## Method

### Translation

First, official permission was obtained from the author of the instrument (Prof. Simon Baron-Cohen) for its adaptation to Bulgarian. Then, all 50 items were translated into Bulgarian by a psychologist. These items were shared with clinical psychologists who work with children and adults with autism. They provided feedback on the wording of the statements. Then a psychologist with a degree in English philology back-translated the items into English. This back-translation was compared to the original items by an autistic English-speaking consultant whose native language is English. The purpose of the comparison was to ensure that the back-translation (and therefore the Bulgarian version) did not substantially differ in meaning from the original version. In the comparison, the consultant marked

several items that differed. For these, the process of translating into Bulgarian and then back-translating and comparing was repeated several times until it was agreed that all the items corresponded in meaning to the original ones.

### Procedure

Ethical approval for this project was obtained from the Ethics Committee of the Department of Cognitive Science and Psychology at New Bulgarian University. All participants gave informed consent prior to their participation.

The questionnaire was uploaded to an online data collection platform, and a link to the questionnaire was circulated on social media, in online publications, and on mailing lists of resource centers for people with autism. Online data collection took place between July 2022 and September 2023. The questionnaire took between 5 and 7 minutes to complete. Participants first rated the 50 AQ statements and then answered questions about demographic information such as gender, age, education, income, and whether they have had an autism diagnosis.

### Participants

The online questionnaire was completed by a total of 985 participants. For the purposes of this report, participants were divided into 2 groups: one of participants diagnosed with ASD, and one of participants who did not have a diagnosis and served as a neurotypical control group. Group 1: there were a total of 40 participants with ASD with a mean age of 25,31 years ( $SD = 7,03$ ), 27 of whom reported that they were male, 10 female, and the remainder did not report their gender. Group 2: neurotypical adults consisted of 945 adults with a mean age of 36,84 years ( $SD = 12,62$ ): 250 of them were male, 681 were female, and the rest did not report their gender.

### Results

The total score of group 1 was 30,62 points ( $SD = 9,08$ ), and of group 2 was 22,52 ( $SD = 9,25$ ). The difference in the scores of the two groups of participants was statistically significant ( $t(983) = 5,43$ ,  $p < 0,001$ ). When considering a potential cut-off, a total score of or above 32 points for this Bulgarian sample accounted for 57.2% of participants diagnosed with ASD. At the same time, only 16.4% of participants in group 2 had a score above 32 points. The distribution of scores by group can be seen in Figure 1. Cron-

bach's  $\alpha$  for the entire scale was also calculated. The coefficient for the Bulgarian adaptation was 0,887.

## Discussion

Preliminary results from the Bulgarian adaptation of the AQ confirm that the instrument has relatively sound psychometric characteristics. In particular, the total score of participants with autism was higher than that of neurotypical participants. Furthermore,

the cut-off score from the original version, which is 32 points, could be used as the cut-off for the Bulgarian adaptation of the instrument as well, albeit the lack of an extensive validation procedure. The high Cronbach's  $\alpha$  coefficient for the full questionnaire, which corresponds in strength to the same coefficient in other adaptations of the AQ (Broadbent et al., 2013; Pisula et al., 2013; Ruta et al., 2012; Zhang et al., 2016), indicates that the instrument has good internal consistency.

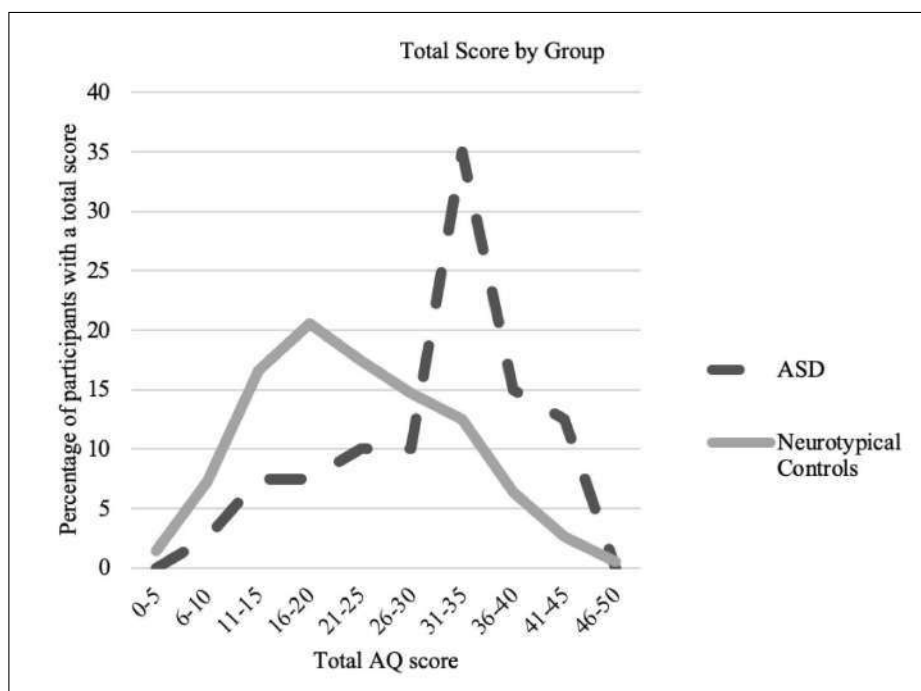


Figure 1. Distribution of total scores of participants by group.

## Conclusion

The purpose of this paper is to present preliminary results from the Bulgarian adaptation of the screening tool for autism in adulthood, the Autism Spectrum Quotient. These preliminary results are a first step towards the Bulgarian adaptation of the instrument and demonstrate its sound psychometric properties. Data collection is ongoing to further examine the reliability and validity of the tool before it is freely distributed online to address the lack of screening and diagnostic tools in Bulgaria.

### Limitations of the present study

The study also has its limitations. One of the main limitations is that it does not confirm the clinical diagnosis of participants with ASD, which has been done in some adaptations to other languages (Broadbent et al., 2013; Lugo-Marin et al., 2019; Pisula et al., 2013; Ruta et al., 2012; Wakabayashi

et al., 2006). It is possible that participants reported misleading information. On the other hand, because of the practice of not diagnosing individuals over the age of 18 with ASD in Bulgaria and the fact that participants completed the questionnaire on their own after finding it online, it is possible that the neurotypical participant/control group included individuals who potentially met the diagnostic criteria for autism. This potential inclusion of participants with autism in the control group would also explain the wider distribution of results for participants in Group 2. In contrast to the original study, where only 2% of neurotypical adults scored above 32 points, this was 16.4% of the Bulgarian neurotypical participants. Another limitation of the study is that the two groups of participants were not equivalent in terms of demographic characteristics such as age, gender, education level, etc. Such equivalence is important for a more valid comparison of the groups.

### Future research

Future research on the Bulgarian adaptation of the AQ should examine the reliability of the instrument. Specifically, test-retest reliability for a particular sub-group of participants. The validity of the instrument should also be confirmed. This can be done by using an already validated diagnostic tool for autism to test participants in the ASD group. Other directions for future research include looking at the factor structure of the test and how well it matches the factor structure of other adaptations. Last but not least, it is also important to consider the scores of parents of children with ASD who typically also score higher than neurotypical adults (Lugo-Marín et al., 2019; Ruta et al., 2012; Zhang et al., 2016). In future analyses, it is also appropriate to look for gender differences and differences relative to the discipline of study of participants who are undergraduate students.

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