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Challenges in Healthcare Access and Social Inclusion of Children with Autism Spectrum Disorder: Evidence from Kazakhstan and International Studies

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ABSTRACT

Autism spectrum disorder (ASD) is a neurodevelopmental condition with a steadily increasing global prevalence. Despite advances in early diagnosis and intervention, children with ASD and their families continue to face significant challenges related to healthcare access, social inclusion, and stigma. These challenges are particularly pronounced in low- and middle-income countries but remain relevant worldwide. This narrative literature review synthesizes evidence on social, medical, and structural barriers affecting children with ASD, with a focus on healthcare access, comorbidity-related medical vulnerability, and public stigma in Kazakhstan and internationally. Databases including PubMed, Scopus, Web of Science, Google Scholar, eLIBRARY.ru, and KazNEB were searched for Russian- and English-language publications. Access to ASD-specific services – such as early intervention, behavioral therapy, and speech and neuropsychological support – remains limited due to shortages of trained specialists, long waiting lists, and high out-of-pocket costs.

Children with ASD frequently have comorbid chronic conditions, increasing their need for general healthcare, yet health systems are often poorly adapted to their sensory, communicative, and behavioral needs. Persistent stigma across social, educational, and medical settings further restricts access to care, while socioeconomic inequalities exacerbate disparities. Overall, children with ASD, particularly those with comorbidities, constitute a highly medically vulnerable population. Addressing these challenges requires integrated policy approaches, workforce development, expansion of publicly funded services, and targeted efforts to improve public awareness and reduce stigma.

Keywords: autism, stigma, early intervention, health service access

Introduction

Autism spectrum disorders (ASD) are a group of neurodevelopmental conditions characterized by impairments in social communication, restricted interests, and repetitive behaviors [1]. According to the Diagnostic and Statistical Manual of Mental Disorders (DSM-5), ASD encompasses diagnoses of autism, Asperger syndrome, and other pervasive developmental disorders [2, 3].

ASD is not associated with a child's social background, the level of education of their parents, or their mentality and culture. However, the diagnosis of ASD in children, as well as the social integration of such children, are highly dependent on the healthcare and education systems in a particular country [4, 5].

According to the World Health Organization, the prevalence of ASD worldwide is approximately 1 in 100 children, but in some countries, such as the United States, this figure reaches 1 in 36. According to the Centers

for Disease Control and Prevention, approximately 1 in 31 8-year-old children (≈3.2%) in the United States was identified as having ASD in 2022 [6].

An analysis of studies conducted between 2000 and 2020 included multiple studies from Europe, North America, and other regions: for Europe, the median prevalence of ASD is ≈59 per 10,000 (i.e., ~0.59%), with a wide range from 8 to 420 per 10,000 [7].

According to a recent Kazakhstani study, "Epidemiological Trends in Autism and Other Neurodevelopmental Disorders in Kazakhstan (2016–2022): A Regional and National Perspective," the registered prevalence of childhood autism (ASD) in Kazakhstan increased from ~14 per 100,000 children in 2016 to ~59 per 100,000 in 2022 [8].

According to a global review conducted in 2022, 0.77% of children globally are diagnosed with autism [9].

Analyzing the available literature, it can be concluded that children with autism spectrum disorders and their families face multiple challenges both at the societal level and when seeking medical care. These are problems like:

1. Social Isolation and Stigma

Children with ASD are particularly vulnerable to isolation and stigma. Society often demonstrates low tolerance for individuals with developmental disabilities. Parents of children with ASD report instances of discrimination and denial of admission to kindergartens and schools. Children and adolescents diagnosed with ASD also experience difficulties that limit their interactions with society, peers, family members, and relatives. This behavior often leads to social isolation and, consequently, alienation. In the case of ASD, stigma is primarily expressed as misunderstanding, fear, rejection of "other" children, and blame directed at their parents [10]. Research shows that children with ASD often exhibit problems with nonverbal communication, understanding social cues, emotional reciprocity, and behavioral flexibility, which makes it difficult to establish friendships with peers [11].

Furthermore, sensory differences (sensitivity to noise, light, and touch) make visiting public places a difficult challenge for these children, which naturally limits their social participation.

Most children with ASD do not display any obvious outward signs of disability, and others sometimes overlook the problem and perceive the child's behavior as "wrong," "strange," or "abnormal." Parents also face so-called "affiliate stigma"—when a child with ASD is perceived as a "reflection" of the family, and in this case, the parents themselves become the target of judgment and alienation [12,13].

2. Limited access to medical and rehabilitation services

In the Republic of Kazakhstan and Central Asian countries, there is a shortage of specialists—child psychiatrists, neuropsychologists, speech therapists, and behavioral therapists (ABA specialists). There are also no uniform protocols for diagnosing and treating such patients. In 2023, the number of psychiatrists per 10,000 population was 0.4, and the number of psychotherapists was 0.01. The incidence of children with ASD increased from 8.6 (2015) to 161.3 per 100,000 children aged 0-17 years (2023), and the primary incidence increased from 4.3 to 33.6 per 100,000 (2015-2022). Research has shown that 81.4% of children receive interventions, but only 4.3% of them have access to ABA therapy. The average age of diagnosis is 2.5 years, and 79.8% of parents have low awareness – the main barriers are the lack of specialists, the high cost of services and, again, stigma [14,15]. In recent years, Kazakhstan has increasingly focused on the diagnosis, care, and support of individuals with autism spectrum disorders (ASD), both within the scientific community and within the healthcare system. However, data from Kazakhstan remains limited. Research reveals the presence of sociocultural barriers: the public perception of autism is often accompanied by low awareness, persistent stereotypes, and stigma, which hinders early access to special and medical care, as well as the full integration of children with ASD into the educational and social environment [15,39].

3. Financial and emotional difficulties for families

A significant portion of services for children with ASD are provided on a fee-based basis. Parents often experience emotional burnout and a lack of psychological support. Due to long wait times for assistance from public healthcare, many parents of "special" children are forced to resort to paid services. For example, parents pay for ABA therapy, neurologist visits, remedial training, and so on [16]. Currently, the parents themselves experience emotional distress and a lack of psychological support [17].

For example, another study, "Disparities in the quality of and access to services in children with autism spectrum disorders: a structural equation modeling," conducted in Iran, found that the quality of and access to services for children with ASD significantly depend on the family's socioeconomic status. Children from low-status families are more likely to experience limited access to medical services, and in these cases, services are often partially covered or not covered at all by insurance [4].

4. Problems of Inclusion in Education

Despite the implementation of inclusive programs, only a small proportion of schools and kindergartens are equipped with the personnel and resources to work with children with ASD [18]. A review of international and domestic inclusive education practices emphasizes the need for specialized teacher training, the development of an "inclusive culture" in schools and society, and support from psychological and pedagogical services. Not all schools and kindergartens in Kazakhstan and globally can provide such qualifications—this is an obstacle to high-quality support for children with special educational needs, including those with ASD. [19,20] Children with ASD primarily require an individualized approach: program adaptation, specialized methods, support, communication, and socialization. In the absence of qualified teachers, insufficient training, and inadequate resources, inclusion often becomes not support, but stress for a child with ASD and their parents [21].

Given the above, the purpose of this literature review is to analyze current research on the difficulties children with autism spectrum disorders face when interacting with society and receiving healthcare services in Kazakhstan and worldwide.

Methods

This study conducted a narrative review of the literature on social adaptation, inclusion, and access to healthcare for children with ASD.

A literature search was conducted in the scientific databases PubMed, Scopus, Web of Science, Google Scholar, eLIBRARY.ru, and the Kazakhstan National Electronic Library (KazNEB). Publications published between 2016 and 2026 were included in the review, based on the relevance of modern approaches to the problem and the date of the earliest included article. The search strategy was based on the following keywords and their combinations: "autism spectrum disorder," "children with ASD," "access to healthcare," "social inclusion," "barriers," "Kazakhstan," "stigma," "social isolation," and their English-language equivalents. Based on this search and abstract analysis, 3,159 publications were found in the aforementioned

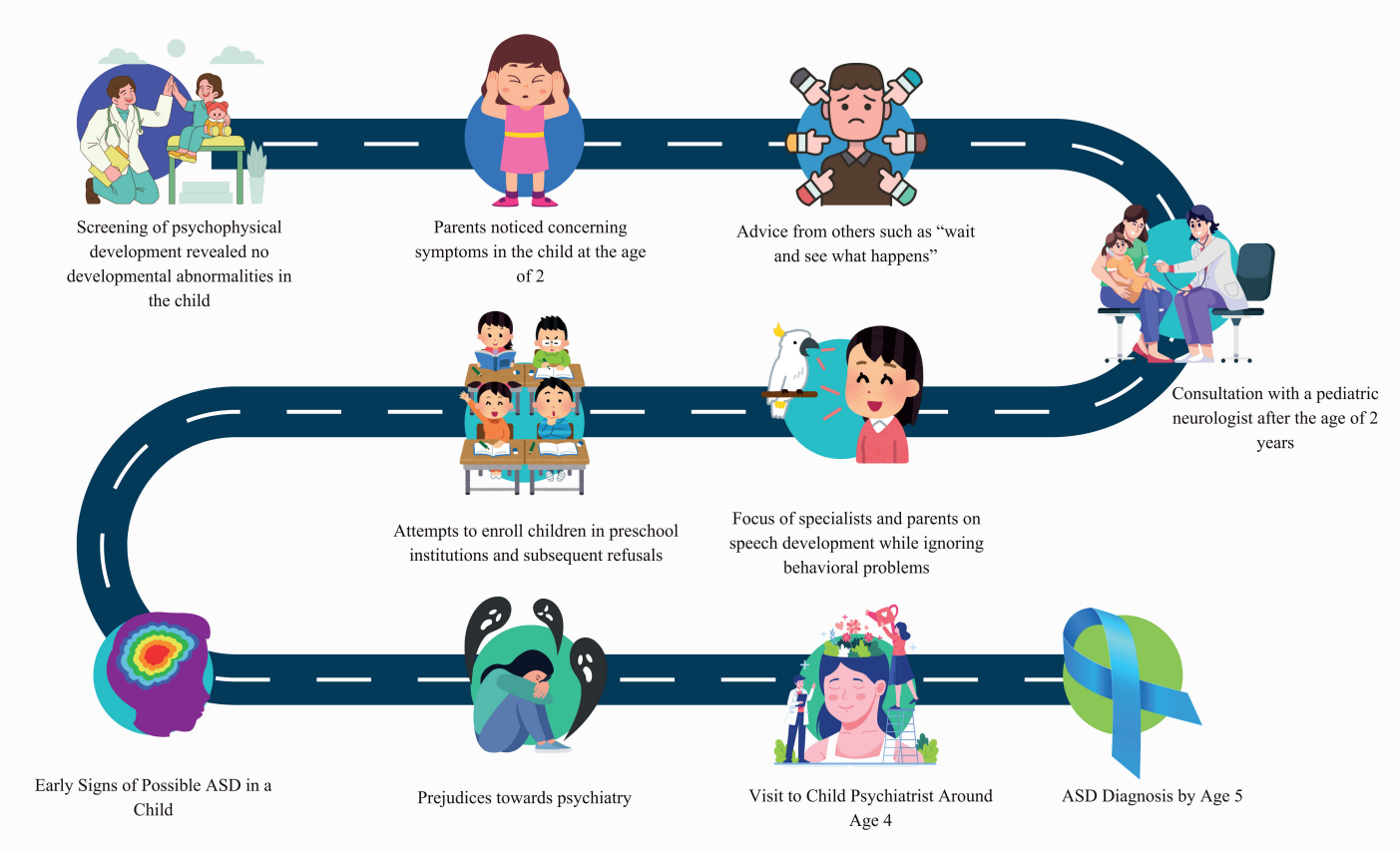

Figure 1 – Family pathways to ASD diagnosis for children in Kazakhstan

scientific search databases. The final review included 56 studies that met the following criteria: studies focused on children with ASD and social adaptation, inclusion, access to health services; cross-sectional, qualitative, review study designs; Russian, English and Kazakh languages of publications. The authors of this review analyzed the abstracts and main conclusions of these publications for compliance with the stated aim, with the subsequent inclusion of relevant publications in the review.

Data synthesis was qualitative and descriptive. Analysis was conducted using a thematic approach, including the identification, grouping, and interpretation of key themes, such as barriers to access to healthcare, manifestations of social stigma, factors of social isolation, and mechanisms for support and inclusion of children with ASD.

Access to ASD-related health service

Access to ASD-Related Healthcare Services. An analysis of existing research shows that limited access to ASD-related services is a widespread and systemic problem observed across all countries, regardless of income level. Early intervention services, including applied behavior analysis (ABA), speech therapy, occupational therapy, and neuropsychological support, remain underavailable compared to demand [22,23,47]. However, the nature and underlying causes of these limitations vary significantly between high-income countries (HICs) and low- and middle-income countries (LMICs). Financial Barriers

In low- and middle-income countries, including Kazakhstan, barriers are primarily structural and financial. Having a disability significantly impacts parents' perceived costs, as children with ASD require a higher level of care. A significant portion of services are provided on a fee-for-service basis, which shifts the financial burden onto families. Empirical evidence shows that parents often have to pay out-of-pocket for ABA therapy, specialist consultations, and other interventions due to limited public services and long waiting times [24, 48–50]. The costs of such services in Central Asia and Eastern Europe can be prohibitive, effectively limiting access to sustainable and intensive interventions. This results in a system in which access to healthcare is highly dependent on socioeconomic status, exacerbating health inequalities from an early age. In contrast, high-income countries tend to have more developed healthcare infrastructure; however, access challenges persist in various forms. Research from Europe shows that even in relatively well-resourced systems, inequalities in access depend on socioeconomic status, regional availability of services, and the presence or absence of coordinated financing mechanisms [25, 27, 51]. Thus, financial barriers are not completely eliminated, but interact with systemic and organizational factors. A key challenge in both low- and middle-income and high-income countries is the shortage of qualified specialists. The availability of child psychiatrists, neuropsychologists, speech therapists, and behavioral therapists remains insufficient to meet the growing demand. In Kazakhstan and other Central Asian countries, this shortage is particularly acute due to limited training opportunities and a small number of specialized centers, leading to delays in both diagnosis and treatment [24]. Notably, similar trends are observed in HICs. Research suggests that additional investment is needed in health services for children with autism, both in terms of the number of specialists and the competencies of those currently working with children with ASD [52,53]. This suggests that workforce shortages represent a global bottleneck, albeit with varying degrees of severity. Delayed Diagnosis.

Delays in diagnosis represent another critical aspect of access. Available evidence suggests that the path from initial parental concern to formal diagnosis is often long and fragmented. For example, research in the Russian Federation highlights systemic issues such as unclear clinical guidelines,

inconsistent diagnostic practices, and reluctance of health care providers to diagnose ASD, which contribute to delayed identification [28]. In low- and middle-income countries, these delays are compounded by low parental awareness and stigma, leading to underrecognition of early symptoms and delayed help-seeking [29]. Cross-country comparisons suggest that delays are determined not only by resource availability but also by cultural, institutional, and professional factors. For example, in Brazil, although parents often notice developmental problems around age two, formal diagnosis may only be made years later due to negative health care experiences and insufficient training of professionals [30].

Similarly, socioeconomic factors play a significant role: higher parental education and income are consistently associated with earlier diagnosis, while socially disadvantaged groups experience delays in disease detection and limited access to services [31]. This highlights the role of social determinants in shaping diagnostic trajectories. Case Study: Kazakhstan

The situation in Kazakhstan illustrates how these factors converge (Figure 1). Despite early parental concern (around 2 years), the average age of diagnosis remains significantly delayed (around 5 years), reflecting systemic inefficiencies in patient referral pathways, specialist availability, and diagnostic capacity [32,33]. Other barriers include limited awareness among both families and healthcare providers, logistical challenges, and dissatisfaction with the quality of services. Importantly, research shows that even healthcare professionals may hold misconceptions about ASD, including its symptoms and diagnostic criteria, further undermining timely and accurate diagnosis [33, 54, 55]. Taken together, these findings suggest that access to ASD-related services is determined by a complex interplay of structural, economic, and sociocultural factors. In low- and middle-income countries, financial constraints and limited infrastructure are prevalent, while in high-income countries, organizational inefficiencies and staff shortages play a significant role. However, across all contexts, delays in diagnosis and inadequate access to early intervention remain persistent challenges. Addressing these challenges requires not only expanding service delivery capacity but also improving care coordination, professional training, and service integration across the health, education, and social sectors.

Access to non-ASD-related health service

ASD present not only with core neurodevelopmental features but also with a substantial burden of comorbid conditions, including somatic, neurological, and psychiatric disorders. This constellation of needs significantly increases their demand for a wide range of health services, from preventive and dental care to emergency and specialized interventions [34]. Importantly, these needs are not merely additive. Comorbid conditions frequently interact, complicating clinical management and requiring coordinated, interdisciplinary care. In practice, however, healthcare systems are often not adequately designed to manage such complexity. Consequently, children with ASD are at increased risk of delayed diagnosis, fragmented care pathways, and insufficient preventive support, which may ultimately contribute to poorer health outcomes [35].

A growing body of evidence consistently demonstrates the high prevalence of comorbidities in this population. For instance, a large case–control study reported significantly higher rates of diverse medical diagnoses across multiple organ systems among children with ASD compared with their neurotypical peers. Similar patterns have been described in retrospective and observational studies, which document a broad spectrum of co-occurring conditions, including neurological, genetic, sensory, and motor disorders, as well as sleep disturbances, gastrointestinal problems, feeding difficulties, obesity, and psychiatric conditions [36, 37]. Taken together, these findings suggest that comorbidity should be regarded as a typical feature of ASD rather than an exception, underscoring the need to move from episodic care toward more continuous and integrated service models.

At the systems level, the capacity to address these complex needs varies considerably across countries. Much of the existing evidence base on ASD-related healthcare originates from high-income settings, where diagnostic pathways tend to be more structured and access to specialized and multidisciplinary services is relatively well established [54,55]. In contrast, in low- and middle-income countries, barriers extend beyond limited resources and include systemic fragmentation. Shortages of trained professionals, restricted access to diagnostic services, and weak continuity of care hinder the implementation of comprehensive, integrated approaches [38,26]. These differences should not be attributed solely to economic disparities. Organizational features—such as the structure of primary care, referral mechanisms, and the integration of health and social services—also play a critical role in shaping both access to and quality of care. Consequently, improving care in these contexts requires not only increased investment but also context-sensitive adaptation of service delivery models [56].

Within this broader context, a substantial portion of the caregiving burden is shifted onto families, making social support systems a key component of the overall response to ASD. Evidence from Kazakhstan illustrates this particularly clearly. A study involving 390 parents of children with ASD identified significant financial and organizational challenges, with more than 70% of respondents reporting insufficient government support, high out-of-pocket costs for treatment and education, and limited access to qualified specialists, especially in rural areas [15]. These findings point to a systemic mismatch between healthcare needs and service provision, with families effectively compensating for structural gaps.

High prevalence of comorbidities among children with ASD not only amplifies the demand for healthcare services but also exposes limitations in how these services are organized and delivered. Addressing these challenges requires a shift toward integrated, interdisciplinary, and context-responsive models of care that can accommodate both the clinical complexity of ASD and the constraints of different healthcare systems.

Public Knowledge and Stigmatization

Stigma against children with autism spectrum disorders (ASD) and their families manifests itself in social, educational, and medical contexts, shaping not only public attitudes but also access to services and long-term outcomes. Importantly, stigma is not an isolated phenomenon but is closely linked to public awareness, cultural interpretations of developmental disabilities, and the structure of healthcare and education systems (Figure 2). Low awareness contributes to misinterpretations of behaviors associated with ASD, which in turn reinforces negative stereotypes and social isolation [39].

Empirical evidence from Kazakhstan demonstrates how limited awareness leads to social distance and emotional reactions. A 2023 study of 410 adults found low willingness to fully accept children with ASD in everyday social settings, regardless of where they lived (urban or rural). When respondents were asked to imagine meeting a child with autism in public,

the most common reactions were fear and curiosity, suggesting a lack of normalization of ASD in society [40]. This pattern is consistent with the results of another national study, which found that only 18.3% of respondents were able to correctly identify key symptoms of ASD and understand appropriate support methods, with the internet serving as the primary source of information [41]. Taken together, these findings suggest that stigma in this context is driven less by overt negative attitudes than by information deficits and uncertainty.

In contrast, data from European countries demonstrate a more nuanced relationship between knowledge and attitudes. For example, in Greece, relatively high levels of knowledge about ASD were associated with moderately positive attitudes [42]. Similarly, in France, although awareness of the term "autism" was nearly universal, deeper understanding remained limited, and some respondents still expressed a preference for social distancing [43]. These data indicate that raising awareness alone does not automatically eliminate stigma; rather, the quality and depth of knowledge, as well as societal perceptions of disability, play a crucial role. Even in countries with generally high levels of awareness, gaps in understanding the causes of ASD and related support mechanisms remain, as shown by recent data from Poland and multi-country European studies [44].

Comparative analyses across countries further highlight the structural and cultural determinants of stigma. A comparative study between the United States and China found that higher levels of knowledge about ASD in the United States were associated with lower levels of stigmatizing attitudes, whereas in China, lower levels of awareness were associated with significantly higher levels of stigma [45]. This suggests a general trend in which knowledge acts as a protective factor against stigma, but only when integrated into supportive social and institutional frameworks.

LMICs, including Central Asia countries, stigma is exacerbated by systemic factors. The legacy of centralized health systems, coupled with limited resources, a shortage of qualified professionals, and limited access to early diagnosis, creates an environment in which ASD remains poorly understood by both professionals and the general population [38]. In such settings, stigma is reinforced not only by cultural beliefs but also by structural invisibility—when children with ASD are underdiagnosed or excluded from formal systems, public awareness and normalization are reduced.

Furthermore, the relationship between stigma and health systems in LMICs is two-way. On the one hand, low awareness and stigma hinder early help-seeking and social integration. On the other hand, weak health systems characterized by limited diagnostic capacity, inadequate workforce training, and competing public health priorities (e.g., a focus on infectious diseases) contribute to persistent low awareness [46]. This creates a self-perpetuating cycle in which stigma, underdiagnosis, and limited-service provision feed off each other.

Thus, differences in stigma between countries should be understood not only as variations in societal attitudes, but also as a reflection of broader healthcare system capabilities, educational efforts, and the sociocultural context. Therefore, combating the stigma of autism spectrum disorders requires comprehensive strategies combining public education, professional training, and systemic improvements in access to diagnosis and treatment, especially in low- and middle-income countries.

Summary

Many countries worldwide face a shortage of specialists in autism diagnosis, late diagnosis, and inadequate access to evidence-based treatments. Economic barriers are particularly pronounced in low- and middle-income countries, including Central Asian states, where a significant portion of services are provided on a fee-for-service basis. Research shows that these children are more likely to suffer from somatic, neurological, genetic, and psychiatric disorders, sleep disorders, gastrointestinal problems, epilepsy, obesity, sensory impairments, and other

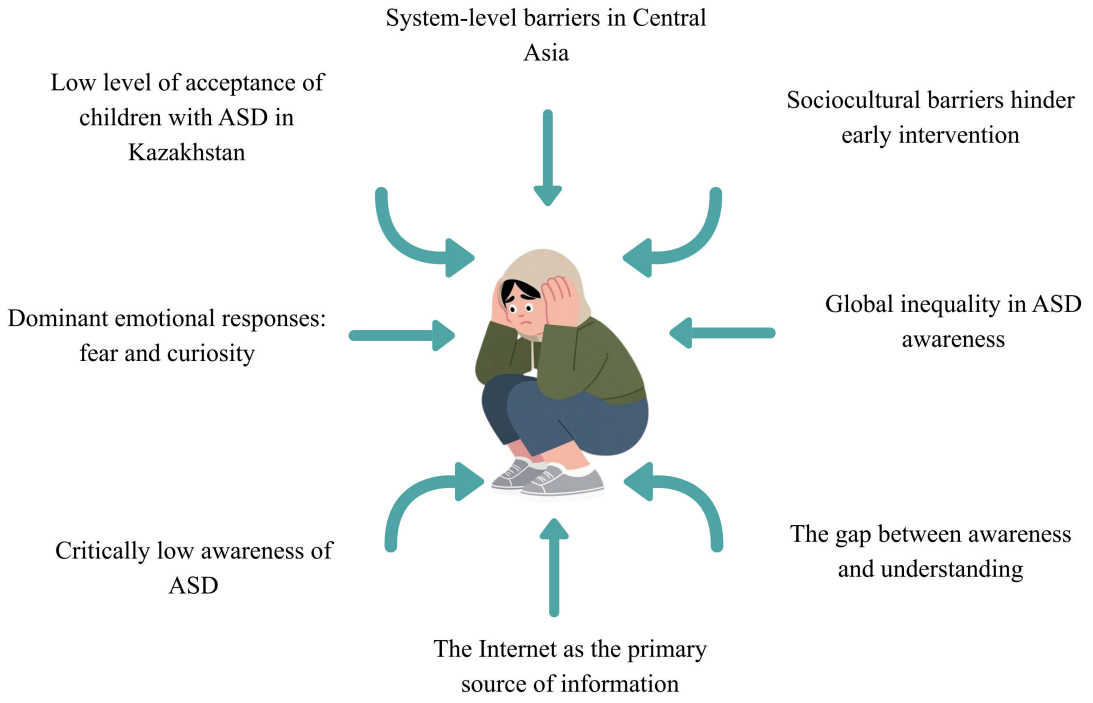

Figure 2 – Key factors limiting the acceptance and social inclusion of children with autism spectrum disorders

conditions. However, healthcare systems are often not adapted to working with children with ASD: doctors are often not trained in communication skills, and facilities are not sensory-sensitive, leading to diagnostic delays, refusals, avoidance, and deteriorating health outcomes. Stigma also remains a key factor hindering access to care.

Even in countries with developed healthcare systems (USA, EU countries), the growth in the number of children with ASD exceeds the rate of specialist training. Rural and remote regions are particularly vulnerable. In Central Asian and Eastern European countries, key barriers include high costs of services, staff shortages, weak interagency coordination, and late diagnosis.

Conclusion

The results of this literature review allow us to draw several important conclusions regarding service access for individuals with autism spectrum disorders. First and foremost, higher awareness of autism is associated with more positive and tolerant attitudes toward individuals with this condition. However, stigma remains a common problem, particularly given the lack of understanding of the characteristics and manifestations of autism. Furthermore, children with ASD, particularly those with comorbid chronic conditions, face increased vulnerability in healthcare due to existing barriers to accessing necessary medical care. These findings highlight the need to further improve support systems for individuals with autism and their families. Raising awareness of autism among the public and healthcare professionals is an important area of focus, as this can contribute to reducing stigma, earlier detection of developmental disorders, and timely assistance. Equally important is the development of human resources by training specialists with the necessary knowledge and skills to work with this patient group. Particular attention should also be paid to strengthening cooperation between healthcare, education, and social protection institutions, since a comprehensive interdepartmental approach allows for more effective meeting both the specific needs of people with ASD and broader needs related to their health and social adaptation.

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