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Review article

The Socio-Economic Burden of Autism Spectrum Disorders: a Review of the Literature

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Abstract

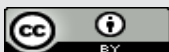
Autism spectrum disorder (ASD) poses complex challenges, involving social, communication and behavioural intricacies, with its rising worldwide prevalence. In Kazakhstan, Soviet classifications have a lasting impact on the identification and care processes for ASD, creating distinctive barriers. ASD's socio-economic impact is far-reaching, affecting education, employment and the overall welfare of families. These obstacles are substantial owing to the rising number of diagnoses, the lack of a cure, and the extended social and medical aid that results in high economic costs.

The significant variation in expenses per person with ASD worldwide underscores the necessity for precise and comprehensive approaches to combat the economic repercussions on individuals, families, and society. This study analyses the socio-economic costs associated with ASD on a global scale, focusing on regional disparities and advocating for targeted aid measures. There is an urgent need for research in Kazakhstan to investigate medical, non-medical, and indirect expenses to inform tailored policies and support programmes aimed at enhancing the quality of life for families of children with ASD. Their aim is to tackle the intricate challenges that these families face in healthcare, education, and social integration domains.

Key words: autism spectrum disorder, ASD, autism, socio-economic burden.

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Introduction

Autism spectrum disorder (ASD) is a serious developmental disorder associated with significant social, communication and behavioural difficulties [1].

The needs and abilities of people with ASD are varied and can change over time. Some can function successfully in society and live independently, while others require ongoing medical and social support. ASD also has a significant impact on access to education and employment. As a result, families caring for children with ASD face a number of challenges. Their prospects and quality of life are strongly influenced by public attitudes and the level of support provided by state and local authorities.

In Kazakhstan, the processes of identifying and providing professional care for children with ASD continue to be shaped by the legacy of the Soviet institutional system. In the context of the Soviet classification of mental disorders, autism was regarded as one of the schizophrenic disorders [2].

In the early 2000s, the Republic of Kazakhstan began to introduce state-funded social services for children with special needs at the community level. In 2002, the Law on Social, Medical and Pedagogical Correctional Support for Children with Special Needs was adopted, which served as the basis for the creation of a state infrastructure for the identification and treatment of children with special needs. In 2008, the Act on Special Social Services was adopted, providing access to a variety of social services for children with special needs. Simultaneously, various commercial educational and recreational services for children with special needs were established, predominantly in metropolitan areas. Inclusive education was designated as a primary focal point in the State Programmes for Education Development of the Republic of Kazakhstan spanning from 2011 to 2020. The lack of public services has given way to the initiatives of non-profit organisations, including autism centres established by the Asyl Miras Charitable Foundation and parent organisations for human rights [3].

Prevalence of ASD. The World Health Organisation estimates the prevalence of autism spectrum disorder is one in 100 children [4]. It should be acknowledged that this approximation signifies a mean and the authentic incidence of ASD may fluctuate significantly relying on the research techniques implemented. A few meticulously organised studies indicate much larger caseloads [5]. Currently, the occurrence of ASD among low- and middle-income nations is inadequately understood [6].

The trend of increasing prevalence of ASD. Based on epidemiological data collected over the

Search strategy

For this study, research studies were searched in five different databases. These included Scopus and Web of Science, SpringerLink, ResearchGate and eLibrary. The key words used to search for research studies were 'autism', 'ASD', 'costs', 'costs', 'economic burden', 'economic costs', 'financial burden' and 'socioeconomic burden'. The literature search yielded articles from over 10 different countries around the world (USA (n = 41), China (n = 3), India (n = 3), Australia (n = 3), UK (n = 3), Canada (n = 2), Greece (n = 2), Kazakhstan (n = 2), Colombia, Korea, Oman,

past five decades, there is an increasing trend in the prevalence of ASD worldwide [7,8]. This phenomenon can be explained by several factors, including increased awareness, expanded diagnostic criteria, improved diagnostic methods and data collection systems.

Since 2008, there has been a rise in the number of children diagnosed with ASD in Kazakhstan, resulting in frequent visits to neurologists. According to official statistics spanning from 2010 to 2012, the incidence rates of ASD among children in Kazakhstan were 1.4, 1.3 and 2.3 per 100.000 children respectively [9].

At the end of 2020, the National Statistics Service of the Republic of Kazakhstan, under the Agency for Strategic Planning and Reforms, recorded an increase in the number of registered children with disabilities to 94.660, up 3.3% from the previous year's 91.573 cases [10].

Lack of a cure and economic costs. To date, there is no effective pharmacological treatment for ASD, and children with these disorders require long-term and ongoing medical and social support. Autism spectrum disorders are a significant burden for individuals, families and society and have a substantial economic cost [11].

If we delve deeper into the study of this issue, it becomes clear that autism is a form of disability that has a negative impact not only on the child with the disorder, but also on the whole family, especially the parents. Not only do parents have to give maximum attention and care to their autistic children, but they also have to deal with the additional responsibility of providing for the financial side of family life.

Parents may face varying degrees of economic strain in meeting the financial needs of their autistic children, and this can occur when their financial resources are exhausted. Factors thought to contribute to the economic strain on parents financially are not limited to additional medical expenses. These also include limitations in employment opportunities and increased time commitment [12].

Supports and services for an individual with autism may be necessary throughout their life journey [13]. However, it is worth noting that research studies investigating the costs associated with ASD to date have predominantly been conducted in the United States of America, utilising data from the UK and some European regions. In Asian countries, research on this issue has remained sparse, making it difficult to draw accurate conclusions [14].

The aim of this study is to highlight the socio-economic burden of ASD based on global experience.

Ireland, Sweden, Italy and Iran (n = 1 each). Inclusion criteria were pre-specified and included publications directly relevant to the economic aspects of RA and studies available in English and Russian. Exclusion criteria included articles that were not directly related to the economic aspects of ASD. Articles from January 2000 to January 2020 were included in the search.

The burden of ASD

The increasing number of diagnoses of ASD has led to growing societal concern about costs, and this issue is highly relevant today. Therefore, there is a need for research aimed at assessing the costs associated with ASD in order to ensure a more efficient allocation of limited resources [15].

Accurately defining the costs associated with autism is challenging because they include both direct and indirect costs associated with the diagnosis and treatment of autism. Direct costs include the services of physicians and other medical professionals, the cost of equipment, household items, hospitalisation, ambulance services, drugs and pharmaceuticals, and other medical costs [16].

As previous studies have confirmed, the costs of caring for people with autism are borne not only by the patients themselves, but also by their families, local, state and federal government agencies, insurance companies and society as a whole [13]. Although it is sometimes difficult to distinguish between these types of costs, this study analyses costs at the individual, group and organisational levels to gain a deeper understanding of this complex issue.

According to studies conducted in different countries, the cost per person with ASD varies according to the country and the level of functioning of the individual:

1. In the United States, the cost per person with autism was found to be \$3.2 million [17].
2. In the United Kingdom, the lifetime cost of ASD has been estimated based on level of functioning and cost. In Australia, the national cost of ASD has been estimated to be between \$4.5 and \$7.2 billion [18, 19].
3. In Scotland, the annual cost of ASD has been estimated to be almost £2.3 billion [20].
4. A study in Ireland found that the additional annual cost of having a child with ASD was €9489.6 or approximately \$10.780 [21].
5. A study in China looked at the difference in costs for families with and without children with ASD. It was found that the additional annual cost of having a child with ASD was \$2.984 [22].
6. A study conducted in Egypt found that families with a child with ASD face additional annual costs ranging from \$37.560 to \$55.080 [23].

These findings highlight the considerable variation in costs associated with ASD and the importance of conducting research in this area to better understand the economic burden that families and society as a whole bear in caring for people with ASD.

Estimation of socioeconomic costs in the United States. In the United States, data from the Medical Expenditure Panel Survey (MEPS) and the National Health Interview Survey (NHIS) were used to estimate the economic costs associated with ASD. These data included information on medical and non-medical care costs associated with ASD. They also included data on health care use and non-medical care costs from a nationally representative survey of parents of children with ASD and were compared with a control group of parents without children with ASD.

The research covered several aspects, including inpatient and outpatient health services, emergency

medical care, services of physicians and general practitioners, other health care providers, expenditure on pharmaceuticals, home health care and education. The education category included a wide range of services and activities such as speech and language therapy, physiotherapy and occupational therapy, vision therapy, social worker services, personal health care, community education services and summer school services [24].

The authors of the study distinguished between actual and public expenditure on special education. Actual expenditure included government funding as well as local, federal and private funding for special education. These methods of analysis were used to estimate costs for both children and adults aged 22 to 64 with ASD. Adults with ASD are characterised by higher health care utilisation, including more outpatient visits and drug prescriptions per year, and higher annual Medicaid expenditures than adults without ASD, and although comorbidities play a significant role in increasing health care utilisation and expenditures for adults with ASD, they contribute only marginally to the differences in health care utilisation and expenditures between adults with and without ASD [25].

There is a significant economic burden associated with caring for children with ASD, much of which falls on the education system, particularly the cost of special education in public schools. It should be noted, however, that these costs are often underestimated. Families with children with more severe symptoms of ASD face even higher costs of care. The use of strict criteria can help identify those most in need of support. Comprehensive strategies should be developed to ensure adequate funding to meet the needs of this group, and future cost-effectiveness analyses should inform how these resources are used to achieve the best outcomes for children with ASD.

As part of a study in Northern California, a survey was conducted of parents using the services of the Kaiser Permanente Health Plan. The survey covered medical costs associated with Kaiser Permanente's Medicaid services, excluding dental and custodial services, as these are not included in the programme. Also excluded were patients' out-of-pocket costs, including co-payments (typically between \$5 and \$15) and some overhead and administrative costs associated with membership in the Kaiser Permanente Health Plan. The study also included psychiatric visits, including those where medication was administered [26].

The importance of finding more effective treatments, including medical approaches that target the underlying symptoms of ASD, is emphasised. The question remains whether better management of children with ASD will lead to more efficient use of health services and lower overall costs. Further research may help to answer this question and provide a more accurate picture of how to optimise healthcare costs for this patient group.

Assessing socio-economic costs in Europe and elsewhere is an important aspect of studying the costs associated with ASD. Surveys have been carried out in a number of countries, including the UK, Sweden, Ireland, Greece, Iran, Oman, China and South Korea,

covering direct medical costs, direct non-medical costs and indirect costs.

It is important to note that each of these countries may have had different features in the questionnaire, including questions that are not reflected in other countries. For example, the UK questionnaire included questions on accidents and emergencies and on volunteer groups for voluntary services [27].

These characteristics may be due to differences in health systems, social programmes and cultural differences between countries. Understanding these differences in cost estimates can help to better analyse the total economic contribution of ASD in different regions of the world and to develop more effective strategies for managing costs and resources to support people with ASD and their families.

A 2015 UK study found that questions about the costs of educating children with autism tend to focus on the direct costs associated with this type of disorder, while indirect costs, such as the costs of mainstream education (which is also used for children with autism and typically developing children), are often overlooked [28]. An exception is a 2012 study that considered both direct and indirect costs of education for children with autism aged 2-4 years [27]. This is an important finding as it provides a better understanding of the financial burden on families in the early stages of autism diagnosis and treatment. The research data analysed highlights the need to consider both the direct and indirect costs of educating children with autism, which contributes to a more accurate assessment of the economic burden on families and allows the development of appropriate support strategies in this area.

In Sweden, the questionnaire includes different types of special education, speech and language therapy, personal assistance in school, school transport and assistive devices and special meals in the estimated education costs associated with ASD [29].

In the Netherlands, education cost estimates take into account three types of education provided to children with ASD, depending on the severity of the disorder: regular education, less intensive special education and intensive special education [30,31].

Estimating the costs of living and caring for people with ASD is an understudied area in the literature. However, in cases where people with ASD do not live with their family and require residential care, the cost of accommodation can be a significant proportion of the total costs associated with the disorder.

The questionnaires carried out in the USA, UK, Sweden and Greece included questions to assess the costs of accommodation, respite care and expenses incurred by families and individuals with ASD out of their own pockets. This includes various aspects such as the cost of specialised accommodation, respite care and other facilities needed to ensure comfortable and safe living for people with ASD [28, 31].

For example, to estimate out-of-pocket costs associated with RAS, the UK questionnaire includes costs of home improvements and the purchase of adaptations, durable goods, specialised equipment for older people, additional household items, cleaning services, repairs and transport. Other UK studies include damage costs, special dietary needs, clothing,

extra laundry, extra help, transport, special activities, therapy/education costs, sibling costs and court proceedings/advocacy [32].

A 2012 study included parents' out-of-pocket expenses related to RAS, such as home and garden adaptations and security, replacement and repair of damaged home and contents, specialised equipment such as prams and toys, attendance at workshops and training courses, travel for medical services and assessments abroad, and smaller expenses such as nappies, bedding, educational materials, extra clothing and special diets [27].

In 2015, the United Nations documented that more than 80% of adults with autism (autism spectrum disorder) are underemployed or not employed at all (United Nations Department of Public Information, 2015). Buescher and colleagues analysed the cost of lost productivity for people with autism in the United States and the United Kingdom [33]. They also estimated the economic costs of lost productive activity for people with autism in Greece, Iran and South Korea. Some studies, such as those in the United Kingdom, Australia and Sweden, have used data from surveys and interviews with parents or families of children with autism. These studies aim to assess the time parents and family members spend on paid work, unpaid work and leisure, taking into account their children's autism diagnosis and other related factors. Through such questionnaires and interviews with parents, family members and carers of children with autism, researchers asked questions about the impact of an autism diagnosis on their employment status and the issues involved.

For Ireland it is important to note that their questionnaire included additional questions on educational expenditure, covering aspects such as expenditure on therapeutic toys and sensory equipment, electronic equipment (e.g. iPads). In addition, the questionnaire included questions on travel costs, including fuel, transport and parking costs. The questionnaire also included questions on training costs, including the cost of refresher courses and attendance at seminars. Equally important were questions about expenditure on assistance dogs for children with autism spectrum disorders (e.g. training, veterinary costs and food costs). The questionnaire also covered living expenses, including the costs of special diets, special clothing, costs of hygiene care (e.g. nappies), costs of replacement and repair of injuries, and additional costs for heating, electricity, laundry and telephone [21].

Studies have been conducted in Australia to analyse the economic costs associated with ASD. The questionnaire used in these studies sought to collect and collate information on a wide range of costs, including direct medical costs, direct non-medical costs and indirect costs associated with caring for children with ASD from birth [19].

The first part of the questionnaire used in these countries collected demographic information about the respondents, such as gender, age of the child and parents, nationality, marital status, level of education and occupational status. The questionnaire also provided the opportunity to indicate the occupation of those caring for children with ASD, the number of children in the family and any health problems of siblings of the child with ASD. This information was collected in order to better understand the financial and social aspects of caring for children with ASD.

Conclusions

Autism is a diagnosis that requires a wide range of medical, educational and social services. Children with autism may require specialist medical consultations, therapies, educational programmes and additional support. While these services are important, they usually come at a cost to the family. These include both direct medical costs, such as counselling and medication, and indirect costs, such as specialised toys and equipment. These costs can increase significantly with the severity of autism and the specific needs of the child.

By examining data from different countries, it is possible to better understand the scale of the economic challenges associated with autism and to identify which areas require the most attention and support. Understanding which categories of expenditure are most significant and what resources are required to provide the necessary support will help to develop more effective strategies and support programmes for families.

Based on global experience, it is recommended that a study be conducted in Kazakhstan to assess the

financial impact of autism on families in the country. This study should cover different types of costs, such as medical, non-medical and indirect costs, in order to gain a better understanding of the financial challenges faced by families. The results of such a study will enable Kazakhstan to develop more targeted support measures for families, including ensuring access to health services, educational resources and social programmes. This will enable a better understanding and consideration of the economic aspects of autism when developing policies and support programmes that will improve the quality of life for families caring for children with autism in Kazakhstan.

Conflict of interests. There is no conflict of interest.

Author contributions. All authors contributed equally to the search for sources on the topic and to the writing of the article. The authors have read and agreed to the final version of the manuscript and have signed the copyright transfer form.

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Аутизм спектрінің бұзылуының әлеуметтік-экономикалық ауыртпалығы: әдеби шолу

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Түйіндеме

Аутизм спектрінің бұзылуы (АСБ) бүкіл әлемде таралуына байланысты әлеуметтік, коммуникативті және мінез-құлқ қиындықтарымен байланысты күрделі мәселелермен көрінеді. Қазақстанда кеңестік жіктелер АСБ анықтау және АСБ кезінде медициналық көмек көрсету үдерістеріне ұзақ уақыт әсер етіп, ерекше кедергілер туғызады. Аутизмнің әлеуметтік-экономикалық әсері отбасылардың біліміне, жұмыспен қамтылуына және жалпы әл-ауқатына әсер ететін ауқымды салдарға ие. Бұл кедергілер диагноздардың көбеюіне, емдеудің болмауына және кеңейтілген әлеуметтік және медициналық көмекке байланысты айтарлықтай жоғары экономикалық шығындарға әкеледі.

Дүние жүзіндегі АСБ бар адамға жұмсалатын шығындардағы айтарлықтай айырмашылықтар жеке адамдар, отбасылар және қоғам үшін экономикалық салдармен күресудің дәл және жан-жақты тәсілдерінің қажеттілігін көрсетеді. Бұл зерттеу аймақтық айырмашылықтарға баса назар аудара отырып және атаулы көмек шараларын насихаттай отырып, жаһандық ауқымда АСБ-мен байланысты әлеуметтік-экономикалық шығындарды талдайды. Қазақстанда АСБ бар балалар отбасыларының өмір сүру сапасын арттыруға бағытталған жеке саясат пен қолдау бағдарламаларын негіздеу үшін медициналық, медициналық емес және жанана шығыстарды зерделеу бойынша зерттеулер жүргізудің шұғыл қажеттілігі бар. Олардың мақсаты - аталмыш отбасылардың денсаулық сақтау, білім беру және әлеуметтік интеграция саласындағы күрделі мәселелерін шешу.

Түйін сөздер: аутизм спектрінің бұзылуы, АСБ, аутизм, әлеуметтік-экономикалық ауыртпалық

Социально-экономическое бремя расстройств аутистического спектра: обзор литературы

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Резюме

Расстройство аутистического спектра (РАС) представляет собой сложную проблему, включающую социальные, коммуникативные и поведенческие тонкости, с ее растущей распространенностью во всем мире. В Казахстане советские классификации оказывают длительное влияние на процессы выявления и оказания помощи при аутизме, создавая своеобразные барьеры.

Социально-экономические последствия аутизма имеют далеко идущие последствия, влияя на образование, занятость и общее благосостояние семей. Эти препятствия существенны из-за растущего числа диагнозов, отсутствия лечения и длительной социальной и медицинской помощи, что приводит к высоким экономическим затратам.

Значительные различия в расходах на одного человека с расстройствами аутистического спектра во всем мире подчеркивают необходимость разработки точных и комплексных подходов к борьбе с экономическими последствиями для отдельных людей, семей и общества. В данном исследовании анализируются социально-экономические затраты, связанные с аутизмом, в глобальном масштабе, уделяется внимание региональным различиям и пропагандируются меры по оказанию адресной помощи. В Казахстане существует острая необходимость в проведении исследований по изучению медицинских, немедицинских и косвенных расходов для разработки специальной политики и программ поддержки, направленных на повышение качества жизни семей детей с расстройствами аутистического спектра. Их цель - решить сложные проблемы, с которыми сталкиваются эти семьи в сфере здравоохранения, образования и социальной интеграции.

Ключевые слова: расстройство аутистического спектра, РАС, аутизм, социально-экономическое бремя.