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### **Economic Barriers of Autism Spectrum Disorder: A Bibliometric Analysis**

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#### **Abstract**

The purpose of this study was to analyse the literature on economic barriers related to autism spectrum disorder (ASD) using bibliometric methodology. It was also aimed to contribute to the understanding of research trends on the economic aspects of ASD. The relevant literature was obtained from the WoS database and analysed using the Bibliometrix package via R Studio. The dataset covered the years 2003-2024 and 95 articles were accessed. The selected documents were analysed and visualized using MS Excel and Biblioshiny applications. The findings showed that the first article about the relevant literature in the WoS database was written in 2003 and the articles written in the last 5 years accounted for more than half of the literature. Information on the most publishing journals, universities and countries and the most cited publications were also obtained. The most repeated words were child and economic burden with 28 repetitions, while expenditures and prevalence shared the second place with 14 repetitions each. Additionally, the word recruitment ranked highly with 7 repetitions in the relevant articles, which was consistent with the topic of the study. It is anticipated that the findings of this analysis will provide direction and a foundation for future research.

#### **Keywords**

Autism Spectrum Disorder, Bibliometric Analysis, Health Economics

#### **JEL Classification**

I10, I14, I18

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## Otizm Spektrum Bozukluğunun İktisadi Bariyerleri: Bibliyometrik Analiz

### Öz

Bu çalışmanın amacı, Otizm Spektrum Bozukluğu (OSB) ile ilgili iktisadi bariyerleri ele alan literatürü bibliyometrik yöntemle analiz etmektir. Ayrıca, OSB'nin iktisadi yönü üzerine araştırma eğilimlerinin anlaşılmasına katkıda bulunması hedeflenmiştir. İlgili literatür WoS veri tabanından elde edilmiş olup R-Studio üzerinden Bibliometrix paketi kullanılarak analiz edilmiştir. Veri seti 2003-2024 yıllarını kapsamakta olup 95 makaleye erişilmiştir. Seçilen belgelerin analizi ve görselleştirilmesi MS Excel ile Biblioshiny uygulamaları kullanılarak yapılmıştır. Bulgular, WoS veri tabanında ilgili literatür hakkında ilk makalenin 2003 yılında yazıldığını, son 5 yılda yazılan makalelerin literatürün yarısından fazlasını oluşturduğunu göstermiştir. En çok yayın yapan dergi ve üniversite, en fazla makale yayınlayan ülkeler, en çok atıf alan yayın bilgisine de ulaşılmıştır. En çok tekrar edilen kelimeler 28 tekrar ile çocuk ve ekonomik yük iken harcamalar ve prevalans 14'er tekrar ile ikinci sırayı paylaşmaktadır. Ayrıca araştırmanın konusu doğrultusunda söz konusu makalelerde işe alım kelimesi 7 tekrar ile üst sıralarda yer almıştır. Bu analizin sonuçlarının yeni çalışmalar için bir temel ve yönlendirme görevi görmesi öngörülmüştür.

### Anahtar Kelimeler

Otizm Spektrum Bozukluğu, Sağlık Ekonomisi, Bibliyometrik Analiz

### JEL Kodu

I10, I14, I18

## 1. Introduction

Autism Spectrum Disorder (ASD) is a neurodevelopmental disorder that causes individuals to experience significant difficulties in social interaction, communication and behaviour, usually beginning in childhood. It is important to understand the life experiences of people diagnosed with ASD, their employment as productive individuals, the barriers they face in education and community life in order to improve their social participation and quality of life. Studies show that the difficulties faced by people with ASD in education, health and employment processes result in significant costs at both individual and societal levels.

The goal of this study is to analyse the literature on economic barriers related to ASD using bibliometric methods. Although many dimensions of ASD have been analysed using bibliometric methods, no bibliometric study on the economic dimension of ASD has been found in the literature. This study aims to contribute to the relevant literature in this regard.

In the following sections, we first review the relevant literature on the economic dimension of the ASD. We then describe the methodology, and the bibliometric analysis. We present our findings, provide some discussion and conclude.

## 2. Autism Spectrum Disorder and Its Economic Dimensions

Autism Spectrum Disorder (ASD) is a neurodevelopmental disorder that causes individuals to experience significant difficulties in social interaction, communication and behaviour, usually beginning in childhood. Although the etiology of ASD has not been completely understood yet, it is suggested that it is the result of a complex interaction of genetic and environmental factors. While some individuals can survive with mild symptoms, others exhibit symptoms that require more intense and continuous support. Therefore, different clinical pictures are observed in each individual (Feng et al., 2022: 1).

According to DSM-IV (Diagnostic and Statistical Manual of Mental Disorder) criteria, ASD is one of the most diagnosed and researched disorders in the international literature (Cavkaytar et al., 2016). The word *autism* is derived from the Greek word *autós* meaning *self*. It was the Swiss psychiatrist Eugen Bleuler, who first used this term in 1908 to describe the withdrawal from reality in schizophrenia patients (Gaviria-Marin et al., 2018).

In 1943, American child psychiatrist Leo Kanner redefined ASD by examining 11 cases and stating that these cases were different from schizophrenia (van Nunen et al., 2018: 248). As a result of these analyses, it is argued that ASD individuals generally experience deficits in three areas. Firstly, social interaction and communication difficulties and repetitive/restricted behaviours are noticed. It can also show itself with significant impairments in non-verbal behaviours such as eye contact, facial expression and body postures. In addition, stereotypical repetitive behaviours and loss of interest in social functions, communications and activities are within the scope of these deficits (Sharma et al., 2018).

Understanding the life experiences of individuals diagnosed with ASD, their career development processes, and the barriers they face in social and academic areas is important to improve their social participation and quality of life. Additionally, early diagnosis and intervention programs not only improve the quality of life of individuals, but also create an impact that alleviates the social and economic burden. Studies have shown that less than 40% of students with autism successfully complete their education, and although these individuals face many difficulties in academic and social areas, they benefit from supports at low rates (Anderson, 2018; Gurbuz et al., 2019; Van Hees et al., 2015).

Economic studies have shown that the difficulties faced by people with ASD in education, health and employment processes result in significant costs at both individual and societal levels. In a study conducted in the USA in 2015 which was covering the years 2015-2025, the economic burden of ASD was tried to be estimated. In this study, the total annual direct medical, direct non-medical and productivity costs were estimated to be 268 billion dollars (162-367 billion dollars range; 0.884-2.009% of GDP) for 2015. For 2025, these costs are projected to reach \$461 billion (range \$276-1011 billion; 0.982-3.600% of GDP) (Leigh & Du, 2015). In another study, it was concluded that the cost of providing support to an individual with ASD was 1.4 million dollars in the USA and 0.92 million pounds sterling (1.4 million US dollars) in the UK in 2013 (Buescher et al., 2014). Therefore, analysing the economic effects of ASD on society is important in terms of contributing to the development of more effective and inclusive strategies by policy makers and social scientists.

### **3. Methodology**

In this study, bibliometric analysis method was used to analyse the international literature approaching ASD from an economic perspective. Bibliometric analysis is a technique that assists researchers in overviewing a large volume of academic literature. It is done by quantitatively analysing information on publication history, mapping and visualizing the features and progress of scientific outputs in a particular research area (van Nunen et al., 2018).

This method is used to evaluate and measure the performance and research models of authors, journals and countries (Hernández-González et al., 2023: 1). Since the existing scientific literature on a particular research field or topic is usually very large, this makes it difficult for researchers to have a structured overview of the relevant information (Shekarro et al., 2023). Therefore, bibliometric analysis has become a popular method to explore and analyse large volumes of scientific data.

Data is analysed with bibliometric software such as Gephi, Leximancer, VOSviewer and with the use of scientific databases such as Scopus and Web of Science (Merigó et al., 2017). The main purpose of this method is to find out the latest developments, research topics and tendencies in a specific research area. Thus, bibliometric studies can provide solid foundations for advancing a field in new and meaningful ways (Zhang et al., 2022: 1). Bibliometric analysis can enable scientists to receive a one-stop overview, identify knowledge gaps, and derive new ideas for

research. Consequently, it reveals the possibility of strengthening contributions to various fields (Donthu et al. 2021).

The data used in this study was obtained from the Web of Science (WoS) database and analysed using the Bibliometrix package through R Studio. We collected our data set by searching through WoS the keywords “*autism spectrum disorder, economic effect, economic cost, economic burden*”. Table 1 presents an overview of the data set. 95 articles covering the years 2003-2024 were accessed. The average age of 95 articles published from 69 different sources and contributed by 632 researchers was 4.94 years.

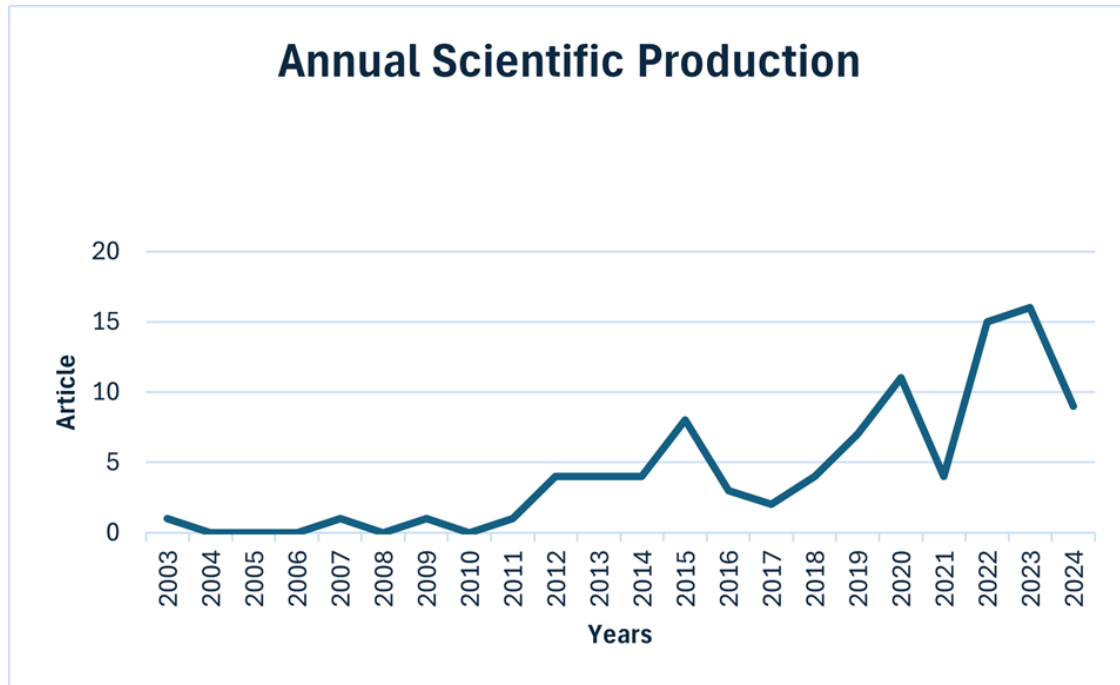
Table 1

*An Overview of the Data Set*

<b>An overview of the data set</b>	<b>Results</b>
Time period	2003-2024
Number of resources	69
Number of publications	95
Annual growth rate (%)	11.03
The average age of publications	4.64
Number of authors	632

#### **4. Findings**

The distribution of 95 articles accessed from the WoS database with the keywords used to investigate the economic dimension of Autism Spectrum Disorder by years is shown in Graph 1.



*Graph 1.* Number of Articles Produced Annually

As it is seen in Graph 1, the first prominent research in literature on the related topic was conducted in 2003. Between 2003 and 2010, the studies in the literature on this subject were limited and stable. After the 2010s, the economic aspect of ASD started to be highlighted in literature and studies accelerated. The studies conducted in the last 5 years constitute more than half of the entire literature. Especially the peaks in the last 2 years show that the interest in the economic aspect of ASD has increased in the literature and has become a very popular topic.

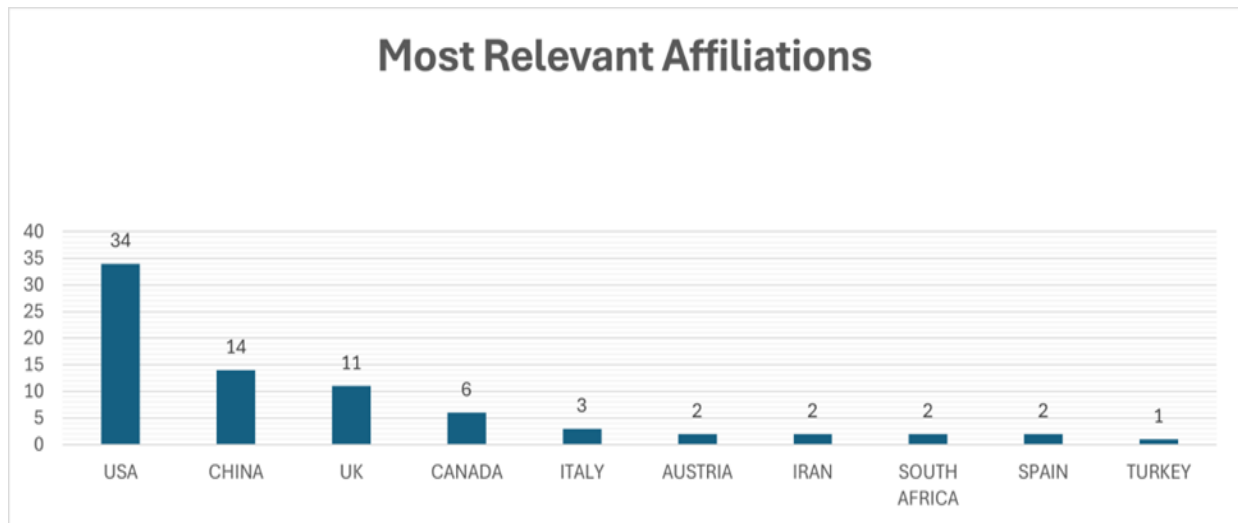
Table 2

*Distribution of Articles by Resources*

<b>Resources</b>	<b>Articles</b>
Journal of Autism and Developmental Disorders	9
Autism	5
BMC Psychiatry	3
Pediatrics	3
Plos One	3
Translational Psychiatry	3
Administration and Policy in Mental Health and Mental Health Services Research	2

BMC Health Services Research	2
Epilepsy \& Behaviour	2
European Journal of Psychotraumatology	2

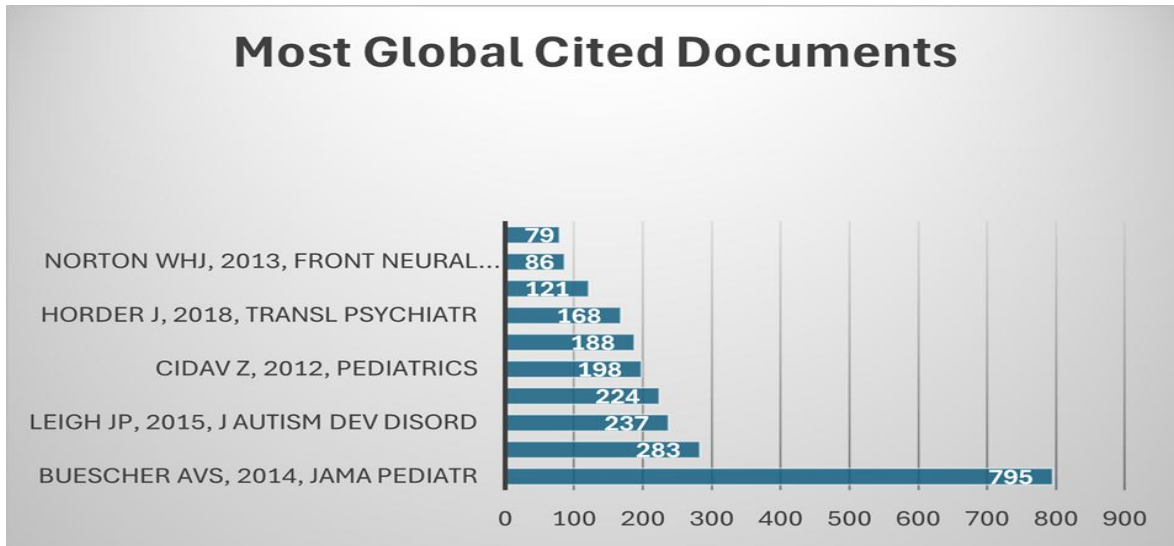
Table 2 shows the top ten resources with the most publications on this subject. A total of 69 journals produced 95 publications on the related subject. Journal of Autism and Developmental Disorders was the journal that published the most on this subject with 9 publications. When the top ten journals were examined, it was seen that all of the studies were published in journals in the field of ASD and pervasive developmental disorders.



*Graph 2.* Distribution of Publications by Country

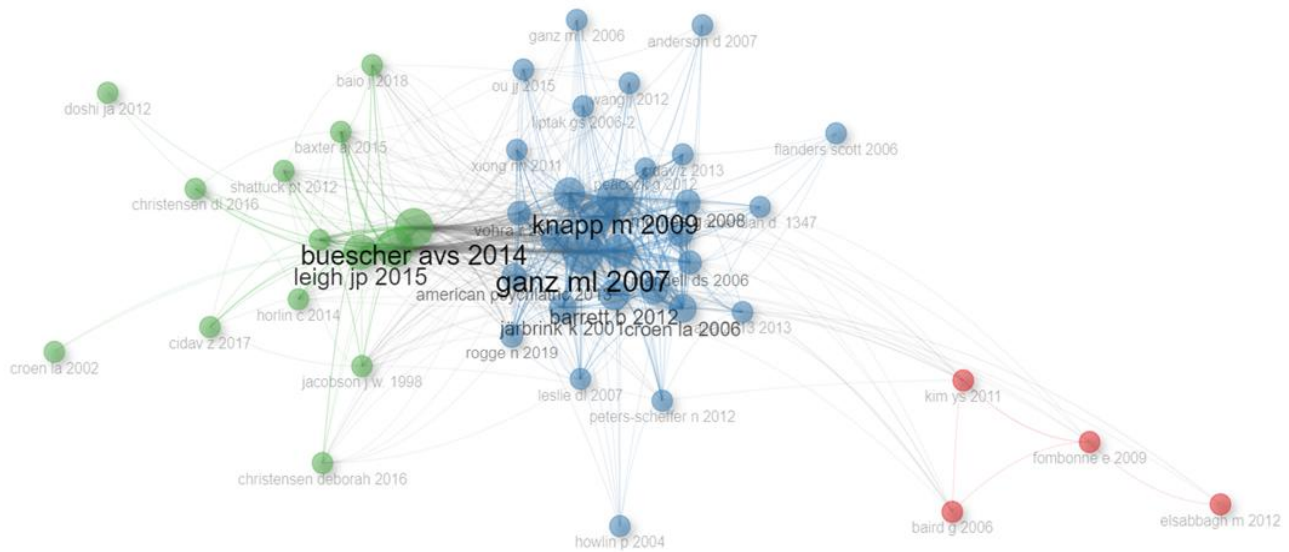
Graph 2 presents the distribution of the publications produced according to countries. As can be seen from the graph, the top 3 countries with the highest number of publications on this subject were the United States of America, the People's Republic of China and the United Kingdom. Publications from Turkey constituted 1.9% of the related literature.





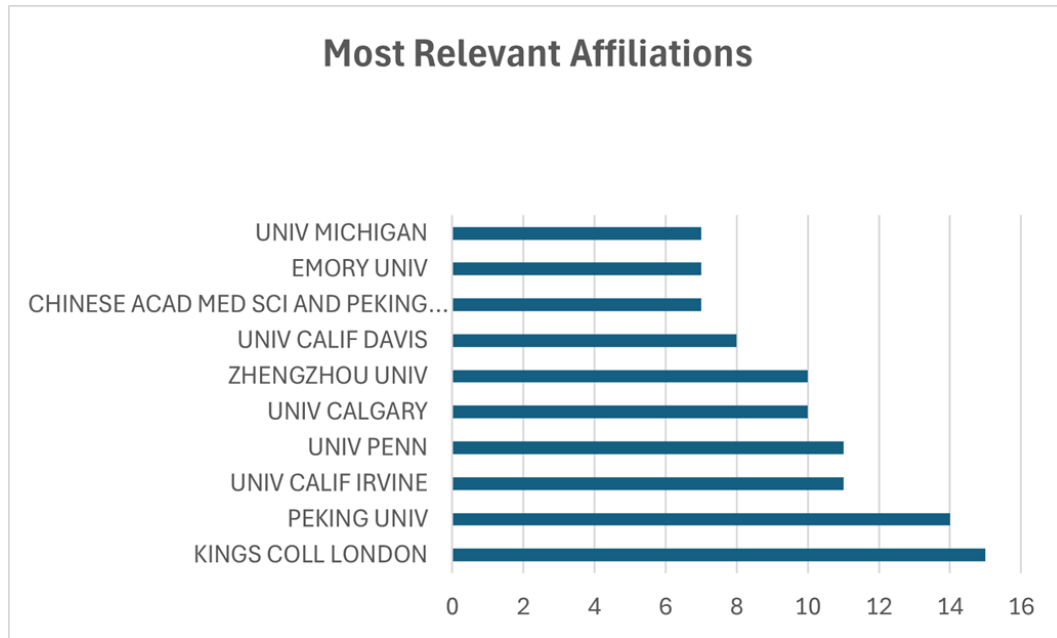
Graph 3. Most Cited Publications

Graph 3 shows the global citation numbers of publications in this field. The article *Costs of Autism Spectrum Disorders in the United Kingdom and the United States* by Buescher et al. (2014) was the most cited publication in this field. The article analysed both the economic effects experienced by individuals with ASD and their families and the impact of this situation on the whole society. The article *Economic burden of childhood autism spectrum disorders* by Lavelle et al. (2014) was the second most cited publication in this field. In this article, in addition to health expenditures of individuals with ASD, non-health and education expenditures were investigated. *Brief report: Forecasting the economic burden of autism in 2015 and 2025 in the United States* by Leigh and Du (2015) was the third most cited article. This article, which is rare in the literature, tried to predict the economic burden of individuals with ASD prospectively between 2015 and 2025.



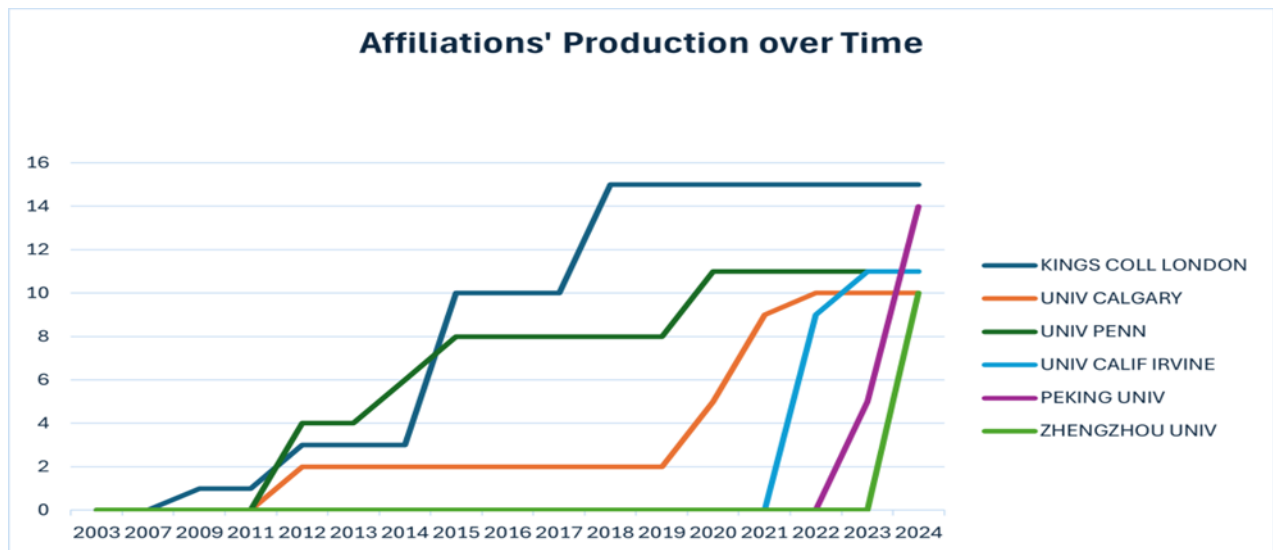
*Figure 1.* Common Citation Analysis of Publications

Figure 1 shows the co-citation map created according to the most frequently cited studies in the dataset. In other words, this map shows the distribution of the sources referenced in multiple studies at the same time. While the publications that are seen in bold font on the map are the most cited publications, the thickness of the links between them shows the collaboration strength of these articles. Buescher et al. (2014), Lavelle et al. (2014), Leigh and Du (2015) were the most cited in their clusters in the co-citation analysis. Ganz (2007), with his study *The lifetime distribution of the incremental societal costs of autism*, was at the critical node in the cluster represented in blue.



*Graph 4.* Number of Publications by Universities

Graph 4 shows the distribution of authors according to the universities where they work. Accordingly, King's College London was the university with the highest number of publications with 15 publications, while Peking University and University of California ranked second and third.



*Graph 5.* Publications of Universities by Years

Graph 5 presents the number of publications of universities according to years. As seen in the graph, in the last 2 years, California, Beijing and Zhengzhou universities increased their number of publications in this field significantly.



Figure 2. Word Cloud

Figure 2 shows the distribution of the words used more than once in the titles and keywords of these publications. As can be seen 50 words were noticeable and these words were repeated a total of 392 times. The most repeated words were *child* and *economic burden* with 28 repetitions, while *expenditures* and *prevalence* shared the second place with 14 repetitions each. In addition, in line with the subject of the study, the word *recruitment* ranked high with 7 repetitions in the articles issued.

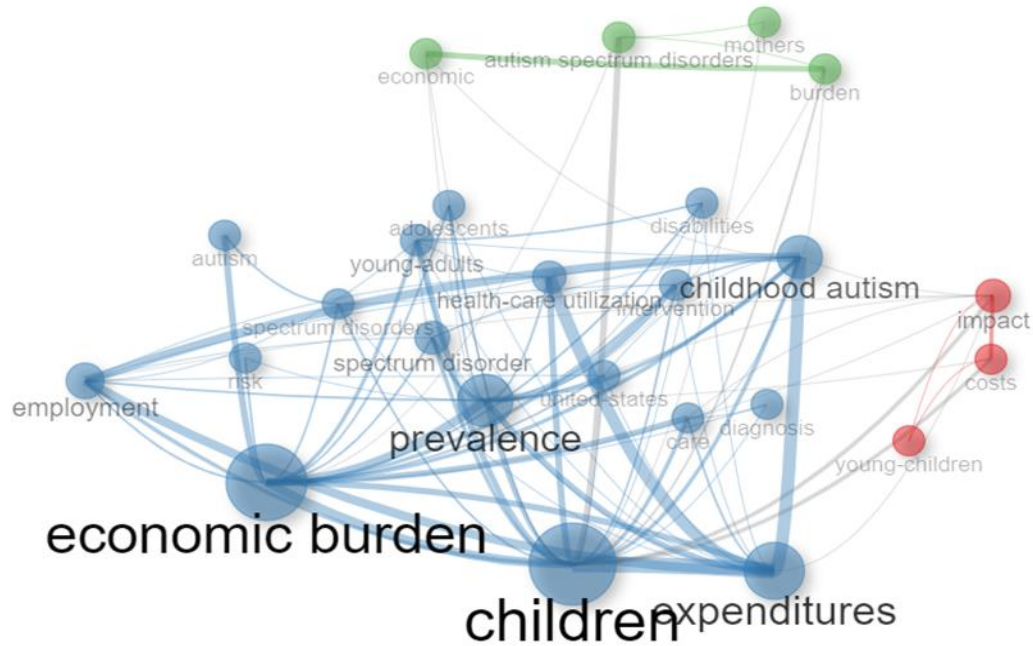


Figure 3. Co-occurrence Network of Keywords

Figure 3 shows the co-occurrence network of keywords. In this network, the keywords written in bold font appeared in more than one article, while the links between them showed the frequency of occurrence in the same text with those words. While the words *economic burden*, *child*, *expenditures* were gathered in a cluster, the words *prevalence*, *recruitment*, and *childhood autism* had a high connection with each other.

## 5. Conclusion and Discussion

The aim of this study was to examine the literature on the economic aspects of autism spectrum disorder and to reveal the development and trends in the related subject. In this direction, the data obtained from the Web of Science (WoS) database were analysed through the Biblioshiny application to create and visualize bibliometric networks.

The dataset covered the years between 2003 and 2024. It included 69 sources, 95 articles and 632 authors. The average annual growth rate of the dataset was 11.03%. The average age of publications was 4.94 years. While the studies conducted in the last 5 years constituted more than half of the literature, the number of studies conducted in the last 2 years was the highest in 21 years. Considering the number of articles written as of the 7th month of 2024, it is seen that this trend

continues. In this direction, although the economic aspect of ASD is relatively new in the literature, research on this issue continues to increase.

In the distribution of publications according to countries, the USA, China and the United Kingdom were in the first 3 ranks. Only one article from Turkey was included in the data obtained from the WoS database. Bilgiç et al. (2013) wrote *Use of complementary and alternative medicine in children with autism spectrum disorders: A multicenter study*. In the article, the frequency of use of complementary and alternative medicine (CAM) practices by families of children with ASD, the attitudes and beliefs of families about these practices, and the economic burden of these practices on the family budget were examined. When the relevant literature was searched manually through Turkish sources other than the WoS database, the article -in Turkish- titled *Economic burdens of families in autism spectrum disorder/Pervasive developmental disorder* written by Cinar et al. (2023) was reached. A questionnaire was used in the study and the findings showed that the most important economic burden of families was education, followed by doctor and psychologist expenses.

Individuals with ASD and their families suffer from various direct and indirect expenses in daily life due to this disorder. At the same time, the barriers to individuals' participation in social and labour life cause many economic costs. Although ASD is frequently analysed in the literature in many aspects such as early diagnosis, treatment, education and public services, the literature on the economic aspect of the subject is limited both nationally and internationally. In this regard, the present study is expected to shed light on future studies in the related field, considering the recent increased interest in the economic aspects of ASD.

### **Declaration of Research and Publication Ethics**

This study which does not require ethics committee approval and/or legal/specific permission complies with the research and publication ethics.

### **Researcher's Contribution Rate Statement**

The authors declare that they have contributed equally to the article.

### **Declaration of Researcher's Conflict of Interest**

There are no potential conflicts of interest in this study.

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