Autism spectrum disorder (ASD): Lines of care and public policies in Brazil

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ABSTRACT

Over the years, public policies aimed at Autism Spectrum Disorder (ASD) have evolved in Brazil. Despite this, we still face challenges, such as expanding access to specialized services and raising societal awareness of ASD. It is important that the diagnosis is made early by a multidisciplinary team, so that appropriate treatment can be started as early as possible. Treatment involves several interventions and should be personalized. In addition, it is essential that public policies ensure access to quality diagnosis and treatment for all. The purpose of this chapter is to analyze the Ministry of Health guidelines for the treatment of Autism Spectrum Disorder and to discuss possible long-term consequences. Challenges related to the diagnosis and treatment of autism in the context of the Unified Health System are also addressed. This is a narrative literature review, which aims to understand the development of Autism Spectrum Disorder (ASD), its Lines of Care and Public Policies in Brazil, through the analysis of the scientific production available in the databases Scientific Electronic Library Online (Scielo), National Library of Medicine (PubMed), books and other informative media. Autism Spectrum Disorder (ASD) in Brazil still faces challenges, such as a lack of trained professionals and unequal resources. To ensure adequate and quality care, it is necessary to invest in training and training of professionals, awareness of families and joint work between government, civil society and families, making it possible to build a more inclusive and welcoming society for people with ASD.

Keywords: Autism, Public Policy, Public Health.

1 INTRODUCTION

The concepts of autism, schizophrenia and psychosis have become very confused over the years and have been used interchangeably by doctors, and it was only in 1940, by the physician Leo Kanner, that the first modern descriptions of what is now considered Autism Spectrum Disorder began (Brasil, 2015).

Treated over time as childhood psychosis, autism, from 1980 onwards, began to be considered Pervasive Developmental Disorder (PDD), a definition that lasted for a long period and that had its change in 2013 when the fifth version of the Diagnostic and Statistical Manual of Mental Disorders (DSM-V) was published, in which autism is now defined as Autism Spectrum Disorder (ASD). being in the group of neurodevelopmental disorders, being the term used to this day (Brasil, 2015).

The understanding of Autism Spectrum Disorder (ASD) in Brazil was gradual and progressive, resulting in the inclusion of autistic children in the scope of Brazilian health since the 90s. This milestone was possible thanks to the emergence of reference centers for mental health, support institutions, and psychosocial care centers. Prior to this period, discussion on this topic was scarce (Nicoletti, 2021).

The discussion around autism and the establishment of policies for this public became more relevant with the publication of Ordinance No. 336/2002, which at that time established the Child and Adolescent Psychosocial Care Centers (CAPSI) as a priority structure for psychosocial care for children with autism in the context of public health. It is important to emphasize that autism is a complex and multifactorial disorder, which makes it difficult to define it precisely, this ordinance represents a significant advance in the search for understanding and adequate care for the needs of children with autism (Honda, 2021).

Pinto *et al.,* (2016) defined autism as a behavioral syndrome that compromises the motor and psychoneurological development of the individual, causing difficulties in language, social interaction, and cognition of the child.

With an unknown etiology, the syndrome is considered to have a multicausal origin that encompasses the genetic, neurological, and social issues of the child, with an estimated 70 cases per 10 thousand inhabitants, being four times more frequent in boys (Almeida, 2019).

Fernandes *et al*., (2017) argue that, in Brazil, the incidence of autism is 27.2 cases per 10 thousand inhabitants, with an estimate that approximately 500 thousand people suffer from autism, and on average, one in 66 children is diagnosed with the syndrome, which makes it a public health problem, and there should be an evaluation of the clinical manifestations, as well as early detection and joint action of different professionals.

This chapter aims to analyze and discuss the guidelines and the line of care proposed by the Ministry of Health in relation to the treatment of Autism Spectrum Disorder, raising and discussing possible consequences in the medium and long term. We seek to provide an overview of the issue of ASD treatment in the context of the Unified Health System (SUS) and to point out some challenges that may arise. To analyze the trajectory of Public Policies aimed at ASD in Brazil and to raise the challenges for diagnosis and treatment described in the scientific literature

2 METHOD

This is a narrative literature review, carried out during the months of July and August 2023, which aims to understand the development of Autism Spectrum Disorder (ASD), its Lines of Care and Public Policies in Brazil, through the analysis of the available scientific production. The review compiles information on these specific topics, allowing the identification of relevant knowledge gaps on the subject (Medeiros; Teixeira*,* 2016).

The search was carried out in databases such as Scientific Electronic Library Online (Scielo), National Library of Medicine (PubMed), books and other informative media. The keywords used were "Autism", "Public Policies", "Public Health", and these were researched in the Health Sciences Descriptors (DeCS). Five crossings were conducted: "Evaluation of public policies for autism in public health"; "Public Health Intervention Strategies for Autism: An Analysis of Public Policies"; "Impact of public policies on public health for individuals with autism"; "Comparative analysis of public health policies for autism"; "Methodological approaches to the evaluation of public policies for autism in public health", respectively. In the query of the SciElo database, the following filters were used:

To be included in this review, scientific articles should meet the following criteria: Articles of a scientific nature, which had similar research objectives in which they analyzed the impact of public policies aimed at autism in Brazil, identifying the existing gaps in implementation and proposing strategies to improve lines of care for autistic individuals, as well as prioritizing articles available in full and dealing with lines of care and public policies for autistic people in Brazil. In the following languages: Portuguese, English and Spanish. Papers with cross-sectional study design, cross-section, case reports and experience reports, as well as master's and doctoral theses were accepted. The study was also only included in the study if it was carried out with people who had autism spectrum disorder and were also related to a theme directed to health, whether in the areas of medicine, collective health or other specialties, with a focus on health.

Articles that were not of interest to the subject of the research or that had not been published in indexed scientific journals were excluded.

3 RESULTS AND DISCUSSION

3.1 EVOLUTION OF PUBLIC POLICIES FOR AUTISM SPECTRUM DISORDER (ASD)

The history of public policies aimed at Autism Spectrum Disorder (ASD) has evolved over the years and according to Santos et al. (2020) in Brazil, the first government action for people with disabilities was in 1854 with the creation of the Imperial Institute of Blind Boys, in Rio de Janeiro. In the 1970s, the first initiatives for specialized educational care for children with mental disabilities emerged.

In 1999, the National Education Guidelines and Bases Law was approved, making the provision of special education mandatory for students with disabilities. In 2012, the National Policy for the Protection of the Rights of Persons with ASD was created, which aims to ensure the social inclusion of these people (Brasil 1997). However, there are still many challenges to be overcome, such as expanding access to specialized health and education services, as well as raising awareness about ASD in society in general.

Article 196 of the Federal Constitution of 1988 states that health is a right of all and a duty of the State, guaranteed through social and economic policies aimed at reducing the risk of disease and other health problems and at universal and equal access to actions and services to promote it. protection and recovery (Brazil, 1988).

To this end, the SUS is organized based on the guidelines of decentralization, regionalization and social control. In other words, it is proposed that health services should be close to the territory lived by people, respecting the identification of specificities of their regions in which all Brazilians can actively participate in the construction and qualification of this system, standing out for affirming universality, including actions of different complexities to meet the different health needs of the population (Brasil, 2005).

At the end of 2011, the Psychosocial Care Network (RAPS) was established by Ordinance No. 3,088. After the enactment, there was considerable progress in relation to the implementation of the network of community/territorial mental health services. In this sense, it is worth highlighting the strategic place of the Psychosocial Care Centers (CAPS) (Marçal, 2018).

In 2012, the National Policy for the Protection of the Rights of Persons with Autism Spectrum Disorder (ASD), also known as the Berenice Piana Law, was approved, and had a significant impact on the recognition and guarantee of the rights of people with ASD in Brazil. This legislation represents an important step forward in the fight for inclusion and equal treatment for individuals on the autism spectrum, providing clear and comprehensive guidelines for the promotion of their fundamental rights, such as health, education, work, and access to justice (Moulina, 2021).

From this law, the Brazilian State became responsible for offering comprehensive and multidisciplinary care to people with ASD, in order to provide a dignified life and the development of their potential. In addition, the Berenice Piana Law seeks to ensure the participation and accessibility of these people in all spheres of society, promoting social inclusion and combating discrimination and prejudice. Despite the progress made, there are still challenges to be faced, such as the effective implementation of the policies provided for in the law, the awareness and training of professionals who deal with people with ASD, and the expansion of resources for this population (Lima, 2023).

In 2014, it was an important milestone for the treatment of Autism Spectrum Disorder (ASD), with the implementation of new guidelines aimed at the care and monitoring of this condition. This set of guidelines sought to establish a professional standard of approach, aiming to improve the quality of life of people with ASD. Through a deeper understanding of the specific needs of individuals on the autism spectrum, guidelines were developed to help health, education, and social care professionals adapt their practices and offer appropriate support, considering the individuality of each person with ASD (Silva, 2020).

With an emphasis on the importance of empathetic listening, the role of the professional is fundamental in this process, as they must adopt a professional tone, establishing clear and assertive communication. In addition, the guidelines emphasize the need to use strategies such as modulation of tone of voice and language adequacy, taking into account sensory sensitivity and nonverbal communication of people with ASD. In this way, the goal is to provide a welcoming and inclusive environment, in which all individuals on the autism spectrum have equal access to opportunities for development and well-being (Costa, 2022).

In 2015, a new line of care was introduced for Autism Spectrum Disorder (ASD), a neurodevelopmental condition that affects communication, social interaction, and restricted, repetitive behaviors. This line of care was developed by health professionals and its main objective is to optimize early diagnosis, promote appropriate multidisciplinary interventions, and offer continuous support to families affected by ASD (Araújo, 2023).

Through a professional approach, this line of care seeks to ensure that the individual needs of each person with ASD are met, from childhood to adulthood, taking into account aspects such as improved quality of life, social inclusion, autonomy and independence. The tone of the paragraph is professional, conveying objective information about the importance of this line of care and how it can benefit those living with ASD and their families (Matias, 2023).

3.2 AUTISM AND THE STRANDS OF A DIAGNOSIS

Although the diagnostic and statistical manual of mental disorders provides the basic criteria for determining the diagnosis of autism, in practical terms, the diagnostic process is not as simple as it may seem. In addition to the great diversity of manifestations of autistic symptoms, there is also a great variety in relation to the time when the child begins to exhibit each of the different symptoms, as well as individual differences in the developmental profile of each child and the comorbidities that may be present in different cases (Apa, 2013).

According to Silva (2009), there have been enormous advances in recent times in terms of early identification and diagnosis of autism, but even so, many children, especially in Brazil, remain for many years without a diagnosis or with inadequate diagnoses. In several countries, such as the United States, for example, the average age of children diagnosed has been 3 to 4 years old, however, many parents are already beginning to notice that there is some problem with their child until the first year of life (Silva, 2009).

Some recommendations that would facilitate early diagnosis: Developmental assessment of children and psychiatric evaluation for all children should routinely include questions about the symptomatology of autism spectrum disorder (ASD); screening should include questions about the symptomatology of autism spectrum disorder (ASD); screening should indicate significant symptoms of ASD; a thorough diagnostic evaluation should be performed to determine the presence of ASD; and clinicians should coordinate appropriate multidisciplinary care for children with ASD (Volkmar *et al.,* 2014).

One of the main difficulties in making the early diagnosis of autism is the numerous adverse clinical conditions and associated comorbidities, which unfortunately end up being confused with ASD or aggravating the condition and resulting in mistaken diagnoses. That is why it is so important to train professionals, so that they know how to distinguish the characteristic clinical conditions of each disorder and the possible comorbidities associated with each case, no matter how similar they may seem (Oliveira, 2019).

3.3 THE CONSTRUCTION OF AUTISM CARE LINES

The Ministry of Health has developed the ASD Care Lines. The objective is to establish guidelines that guide health professionals and families in the treatment of people with ASD, ensuring comprehensive and humanized care, and the lines of care are composed of a set of guidelines, care strategies, procedures and technologies aimed at qualified care and improving the quality of life of people with autism (Brazil, 2015).

The first step in the therapeutic itinerary is early diagnosis. The diagnosis is made by a multidisciplinary team, composed of psychiatrists, psychologists, speech therapists, occupational therapists, among other professionals, so the earlier the disorder is identified, the greater the possibilities of appropriate and effective intervention (Lima *et al.,* 2018).

The treatment of ASD involves several interventions, such as behavioral therapies, educational interventions, occupational therapies, medications, among others. The type of approach used should be decided together with the multidisciplinary team, considering the individual needs of each child, it is worth mentioning that treatment should be continuous and personalized, closely monitored by the professionals involved (Rabelo, 2021).

3.4 THE RIGHT TO HEALTH AND PUBLIC POLICIES FOR THE PARENTERAL NETWORK OF PEOPLE WITH ASD

It is essential that public policies promote access to quality diagnosis and treatment for all, regardless of social class or geographic region. The National Policy for the Protection of the Rights of Persons with Autism Spectrum Disorder, approved in 2012, established guidelines to guarantee the right to health, education, accessibility, and social inclusion for people with ASD (Figueredo, 2023).

Public policies also play an important role in supporting the parenteral network of people with ASD, as family interactions can be affected by autism, as individuals with this condition may have difficulties in communicating and interacting socially, which can generate stress and tension in family relationships, which often need to adapt to meet the needs of this individual (Costa, 2022).

Coping strategies are another important aspect to be considered, as individuals with ASD may have difficulties in dealing with challenging situations, which can generate anxiety and challenging behaviors, so families need to develop strategies to deal with these situations and help the individual with ASD feel safe and comfortable (Lemos; Solomon, 2022).

One of the alternatives to deal with these challenges is to participate in parent training programs offering guidance and strategies to help families cope with the difficulties of ASD, which may include information on communication, behavior, and social skills, as well as counseling and emotional support. In addition, social support is an important alternative for families dealing with ASD, being inserted into support groups, family therapy, breathing services, and other forms of practical and emotional help. These resources can help families cope with the stress and anxiety associated with the condition and find ways to support the individual with this condition (Marcato; Lima, 2022).

It is important for families to seek help and support to deal with the challenges of ASD and improve the quality of life of all family members, through public policies it is possible to have funding for support services, parent training programs and other forms of practical help, raising awareness about autism and reducing the stigma associated with this condition (Proença, 2023).

It is estimated that about 2 million people in Brazil have some degree of autism, according to data from the Brazilian Institute of Geography and Statistics (IBGE). However, despite the existence of public policies aimed at this population and it is an increasingly well-known condition, there are still many gaps with regard to autistic people fully exercising their citizenship, making it necessary for government powers to promote actions that guarantee their social inclusion and access to basic rights (Carvalho, 2022).

3.5 SDG 2030 AND ITS PERSPECTIVES FOR AUTISM SPECTRUM DISORDER

The 2030 Sustainable Development Goals (SDGs 2030) is a global agenda adopted by the United Nations (UN) in 2015, with the aim of promoting sustainable development worldwide by 2030. Among the goals of this global plan is the promotion of health and well-being for all people, regardless of their condition (Bertei, 2022).

It is relevant to highlight the issue of autism and its relationship with health, because it is a condition that can manifest itself in different ways in each individual, it is essential that there is comprehensive attention to the health of these people, considering their needs and particularities. The implementation of the SDG 2030 goals can be an important strategy to ensure access to quality health and social inclusion for people with autism (Gonçalves, 2020).

It is important to highlight the relevance of health in the inclusion of people with autism and to ensure inclusion it is essential that they have access to adequate and quality health services. This includes everything from early diagnosis and specialized treatment to the promotion of actions aimed at improving the quality of life of these people and their families (Santos, 2017).

In addition, there needs to be an awareness on the part of society in relation to autism, in order to combat prejudice and discrimination. The social inclusion of people with autism necessarily involves the promotion of inclusive education, access to the labor market, and participation in cultural and sports activities (Lima, 2022).

The study of public policies becomes fundamental, since through studies and research it is possible to identify the main demands and needs of autistic people, as well as the best strategies to ensure their social inclusion, since the study of public policies allows evaluating the effectiveness of actions already implemented and proposing new measures to improve assistance to autistic people (Loureiro, 2023).

However, there is still a need to promote more studies focused on autism, since it is important that universities, research centers, and government institutions invest in research that can contribute to improving the quality of life of autistic people and promoting their social inclusion (Caron Neto *et al.,* 2022).

Among the main areas that need further study, we can highlight inclusive education, mental health, accessibility and employability of autistic people. These are topics that demand a multidisciplinary approach and that can generate significant results for the autistic population (Silva, 2022).

Therefore, according to Da Silva and De Freitas (2022), it is essential that society as a whole mobilizes to promote studies focused on autism and to pressure government authorities to promote public policies that guarantee the social inclusion of autistic people.

In summary, public policies are key to ensuring that people with autism have access to essential support services. In addition, it is important to raise awareness about the disorder and promote social inclusion. With these actions, we can work to achieve the SDG 2030 target related to autism and ensure healthy lives and promote well-being for all (Costa; Fernandes, 2018).

Only in this way will it be possible to ensure that this population can fully exercise their citizenship and have access to the basic rights that are due to them, in addition, public policies can play an important role in supporting families, as it becomes important that individuals and their families have access to these resources to help them deal with autism effectively (Soares *et al.,* 2023).

4 FINAL THOUGHTS

Autism Spectrum Disorder (ASD) is a complex condition that requires an integrated and individualized approach. The lines of care and public policies in Brazil play a fundamental role in ensuring adequate and quality care for these individuals.

Through the implementation of inclusive policies, such as the Berenice Piana Law, which ensures the rights of people with ASD, and the National Policy for Comprehensive Health Care for People with Autism, which seeks to expand access to early diagnosis and multidisciplinary treatment, Brazil has made progress in promoting inclusion and strengthening rights. However, there are still challenges to be overcome, such as the lack of trained professionals and the inequality in the distribution of resources.

It is necessary to invest in training and training of health and education professionals, in addition to promoting awareness and empowerment of families, to ensure an efficient and accessible care network. Only through joint work between government, civil society and families will it be possible to build a more inclusive and welcoming society for individuals with Autism Spectrum Disorder.

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