

Public Policies for the Treatment of Autism Spectrum Disorder in Brazil, the USA, and Europe in the Last 20 Years: Proposals and Challenges

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Políticas Públicas para el Tratamiento del Trastorno del Espectro Autista en Brasil, EE. UU. y Europa en los Últimos 20 Años: Propuestas y Desafíos

RESUMO

O Transtorno do Espectro Autista (TEA) é uma condição diretamente ligada ao neurodesenvolvimento, caracterizada por dificuldades na comunicação e interação social, além de comportamentos repetitivos e estereotipados. Nos últimos anos houve um aumento significativo na prevalência do TEA globalmente, impulsionando a criação de políticas públicas voltadas ao suporte e tratamento destas pessoas e suas famílias. O presente trabalho de revisão de literatura tem como objetivo conhecer as principais políticas públicas voltadas ao atendimento de pessoas com Transtorno do Espectro Autista (TEA) em relação ao seu atendimento global, saúde, direitos sociais e educação, no Brasil, nos Estados Unidos e na Europa. Apresenta as principais leis e iniciativas, bem como suas peculiaridades e dificuldades. Evidencia as diferenças entre as realidades, os principais desafios para uma melhor abordagem e assistência, bem como a necessidade de uma uniformização de ações, políticas e acesso aos recursos, possibilitando assim um real avanço nas políticas públicas de atendimento às pessoas com TEA.

DESCRIPTORES: Autismo; Cuidado; Atenção Primária; Saúde; Crianças, Políticas Públicas

ABSTRACT

Autism Spectrum Disorder (ASD) is a condition directly related to neurodevelopment, characterized by difficulties in communication and social interaction, as well as repetitive and stereotypical behaviors. In recent years, there has been a significant increase in the prevalence of ASD globally, driving the creation of public policies aimed at supporting and treating these individuals and their families. This literature review aims to explore the main public policies focused on the care of individuals with Autism Spectrum Disorder (ASD) regarding their global care, health, social rights, and education in Brazil, the United States, and Europe. It presents the main laws and initiatives, as well as their peculiarities and challenges. It highlights the differences between these realities, the primary challenges for better approaches and assistance, and the need for standardization of actions, policies, and access to resources, thereby enabling real progress in public policies for the care of individuals with ASD.

DESCRIPTORS: Autism; Care; Primary Health Care; Children; Public Policies

RESUMEN

El Trastorno del Espectro Autista (TEA) es una condición directamente relacionada con el neurodesarrollo, caracterizada por dificultades en la comunicación e interacción social, además de comportamientos repetitivos y estereotipados. En los últimos años ha habido un aumento significativo en la prevalencia del TEA a nivel mundial, lo que ha impulsado la creación de políticas públicas dirigidas al apoyo y tratamiento de estas personas y sus familias. Este trabajo de revisión de literatura tiene como objetivo conocer las principales políticas públicas orientadas al tratamiento de personas con Trastorno del Espectro Autista (TEA) en relación con su atención global, salud, derechos sociales y educación en Brasil, Estados Unidos y Europa. Presenta las principales leyes e iniciativas, así como sus peculiaridades y dificultades. Destaca las diferencias entre las realidades, los principales desafíos para una mejor atención y asistencia, así como la necesidad de una estandarización de acciones, políticas y acceso a recursos, lo que permitiría un avance real en las políticas públicas de atención a las personas con TEA.

DESCRIPTORES: Autismo; Cuidado; Atención Primaria de Salud; Niños; Políticas Públicas

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INTRODUCTION

According to ICD 11, Autism Spectrum Disorder is defined as a "Neurodevelopmental disorder characterized by persistent difficulties in social interaction and social communication, in addition to restricted, repetitive and inflexible patterns of behavior, interests or activities, which manifest themselves during the developmental period, usually in early childhood."

In recent years, there has been an increase in the number of autism cases in Brazil and worldwide.

In Brazil, around the year 2000, very reliable statistics were not yet available and global statistics were used, mainly American statistics. Considering these numbers, there was an increase from 1 case for every 500-1000 children in 2000 to 1 case for every 150 children after the year 2020 - 0.1- 0.2 to 0.66%. The Centers for Disease Control and Prevention estimated 1 case for every 150 children - 0.66%. (This data is based on the "Autism and Developmental Disabilities Monitoring (ADDM)" monitoring system, which began recording numbers on a large scale in 2000.)

In Europe, the prevalence ranged from 2 to 5 cases per 10,000 children (0.02% to 0.05%), depending on the country and the diagnostic criteria used. Currently, the prevalence ranges from 0.38% to 1%, with rates varying between countries.

It is important to note that the increase in ASD diagnosis rates can be attributed to a combination of factors, including increased awareness, improved diagnostic methods, and even the actual increase in the number of cases.

With the increase in the number of

cases, there is a need to think not only about greater diagnostic efficiency, but also about public policies to serve this population.

Regarding Autism, which from ICD-11 onwards is now officially better characterized as Autistic Spectrum Disorder 6A02, replacing code F84.0 of ICD-10, it is known that at least in relation to medications, there is no specific treatment for autism, but rather a treatment for "target symptoms", whether or not present at a given moment of the pathology, which may benefit from drug treatment.

On the other hand, there are other effective therapeutic measures, methods of progressive integration and biopsychosocial and school adaptation that significantly improve the social adaptation and prognosis of these individuals.

The main therapeutic and educational approaches currently used for ASD are:

1. Applied Behavior Analysis

(ABA): approach based on behavioral principles that aims to improve specific skills and reduce challenging behaviors, whose main objective is to expand the repertoire of social adaptation.

2. Speech Therapy:

Focused on the development of verbal and non-verbal communication, it helps improve language skills and language comprehension. It is essential for individuals with ASD who have speech delays or difficulties. It does not only aim to improve language itself, but through this, to improve the individual's cognitive-social adaptation.

3. Occupational Therapy: In its

various aspects, aiming to develop better adaptation of fine motor coordination and assist in expanding capacities and daily life activities, also helping in the best response to sensory stimuli.

4. Cognitive Behavioral Therapy

(CBT): Focused on identifying and modifying negative thought and behavior patterns, helping to manage anxiety and various emotional challenges.

5. Animal Assisted Therapy: Still

considered a form of alternative therapy, requiring further studies.

Educational Approaches

1. Structured Teaching: Involves the physical organization of the environment, as well as the organization of content and the ways in which it is administered.

2. Augmentative and Alternative Communication (AAC):

Uses tools and techniques to aid communication, such as symbol boards or electronic devices. Facilitating communication and acquisition of content.

In addition to the resources used for these educational approaches such as **Visual Support and Sensory Support.**

Objectives of this study

To research, evaluate and compare how non-drug therapeutic proposals for the treatment of ASD are being implemented in Brazil, the United States and Europe.

To identify the gains and the main difficulties identified.

METHOD

A literature review was conducted, not only of academic articles, but also of current legislation and public policies, so that it would be possible to understand different realities.

The available legislation is still reasonably old, so laws and articles that supported it were used that were published more than 10 years ago.

RESULTS

United States of America

The USA has several public policies and initiatives aimed at serving people with Autism Spectrum Disorder (ASD). These policies range from education and health to family support, civil rights and social integration, some of these devices being:

1. Americans with Disabilities Act (ADA)

Created in 1990, the ADA is a comprehensive law that protects the civil rights of people with disabilities, including ASD. The law guarantees equal access to public services, education, transportation and workplaces. It requires reasonable accommodations in schools, workplaces and public spaces for individuals with ASD.

2. IDEA - Individuals with Disabilities Education Act

This federal law ensures that children with ASD and other disabilities receive a free and appropriate public education (FAPE) in the least restrictive environment possible. It includes services such as: Special education, Individualized Education Plans (IEPs) and related therapies (occupational, speech, etc.). It covers children and young people aged 3 to 21.

3. Affordable Care Act (ACA)

The Affordable Care Act, created in 2010, expanded access to health insurance, including coverage of services for people with ASD. Under this law, health plans are required to cover diag-

nostic and treatment services, such as ABA (Applied Behavior Analysis) therapy, which is widely used in the treatment of ASD.

4. Autism CARES Act

Created in 2006 and renewed in 2019, this law allocates federal funds for research, early screening, interventions, and services for people with ASD.

5. Medicaid and State Programs

Medicaid provides health coverage for low-income individuals, including people with ASD. In many states, specific programs have been created to cover therapies and interventions related to ASD. It allows access to treatments, such as behavioral therapy and community services.

6. Autism Support Centers

States have specialized government-funded centers that provide early diagnosis, treatment, support for families and caregivers, and training for professionals.

7. Employment First Initiative

State and federal policies that promote the employment of people with disabilities, including ASD, prioritizing integrated work in the competitive labor market.

Remaining Challenges:

Although there are several public policies in place, challenges remain, including:

- Unequal access: Services can vary significantly across states.
- High cost: Therapies such as ABA can be expensive, even with partial insurance coverage.
- Lack of qualified professionals: The demand for specialists exceeds the supply in many areas.

Europe

Several European countries also implement public policies for the

treatment and support of people with Autism Spectrum Disorder (ASD). Although there is no single, standardized policy at European level, there is an attempt to promote more standardized guidelines through the European Autism Action Plan.

The European Union and many of its member countries have specific strategies and actions aimed at ASD.

Here are some examples:

1. National Strategies for Addressing Autism.

As the main citation, we have France: In 2018, France launched the Quatrième Plan Autisme (Fourth Autism Plan), focusing on early diagnosis, support for families, school inclusion and research.

2. European Guidelines

The European Union promotes general guidelines to support member states in developing policies related to ASD, based on human rights and equitable access to health and education services, citing the following as its main initiatives:

The European Autism Action Plan, (already mentioned) approved by the European Parliament, recommends that countries implement policies to improve early detection and access to specialized services.

The UN Convention on the Rights of Persons with Disabilities (CRPD), ratified by the European Union, protects the rights of people with ASD in areas such as health, education and work.

3. Health Services and Early Diagnosis

Most European countries offer early diagnosis and interventions for children with ASD through public health systems, often funded by the state, notably the United Kingdom, where the National Health System (NHS) provides free diagnosis, early intervention (such as occupational and behavioral

therapy) and ongoing support services.

4. Inclusive Education.

Many European countries have adopted inclusive education policies that ensure that children with ASD have access to regular schools with specialized support. For example, Spain has Specialized Education Classes for Autism (Autism Specialized Education Classes) within regular schools, offering individualized support.

5. Employment Programs.

In Germany, companies receive tax incentives to hire people with disabilities, including ASD.

6. Funding and Support for Families.

In Sweden, families have access to financial subsidies to pay for therapies and the government offers intensive support through public services.

The main challenges in Europe are:

Inequality of services and resources between countries: Services and policies vary widely between member states.

Lack of resources: In some countries, there is a shortage of trained professionals and long waiting lists for diagnosis and treatment.

Limited social and work integration: Despite supportive policies, many people with ASD face difficulties in integrating fully into society.

Brazil

There are public policies aimed at the treatment and support of people with Autism Spectrum Disorder (ASD),

The main ones being:

1. Brazilian Inclusion Law (LBI) - Statute of Persons with Disabilities (Law No. 13,146/2015)

Guarantees the rights of people with disabilities, including those with ASD, to access education, health, transportation and work with the necessary adaptations.

2. National Policy for the Protection of the Rights of People with Autism Spectrum Disorder (Law No. 12,764/2012)

Known as the "Berenice Piana Law", it recognizes people with ASD as people with disabilities, guaranteeing access to essential rights and services such as comprehensive care in the SUS (Unified Health System), inclusion in regular schools, Continuous Benefit Payment for low-income families, and policies to support inclusion in the labor market.

3. Regarding Health Care - SUS (Unified Health System)

The SUS, through its principles of comprehensiveness and universality, the right and access, offers free services for people with ASD, including early diagnosis, therapeutic interventions (occupational, psychological and speech therapy) and treatment:

Psychosocial Care Centers (CAPS):

CAPS are specialized services for people with mental disorders, and their services may include ASD care.

Specialized Rehabilitation Centers (CERs)

SUS spaces that offer diagnosis, treatment and rehabilitation for people with disabilities, including ASD. They offer Occupational Therapy, Speech Therapy and Psychology services.

4. Inclusive Education

Law No. 9,394/1996 (Law of Guidelines and Bases for National Education):

Guarantees the right to enroll children with ASD in regular schools, with specialized support.

Multifunctional Resource Room:

Many public schools offer rooms equipped to serve students with ASD.

School Support Professionals:

Students with ASD can count on caregivers or school mediators.

5. Social Protection - Continuous

Benefit Payment (BPC - Benefício de Prestação Continuada) – Provides financial support to families with incomes of less than 255 times the minimum wage per person.

6. National Plan for the Rights of Persons with Disabilities (Living Without Limits)

Created in 2011, this federal plan aims to promote inclusion and accessibility for people with disabilities, including ASD, by expanding access to inclusive education and strengthening health services. (Project that integrates multisectoral actions in Health, Education and Social Protection).

Challenges and Limitations of Implementing and Operating These Initiatives in Brazil:

Lack of specialized professionals: There is a shortage of trained therapists in many regions of Brazil.

Regional disparities: Access to public services is unequal, being more limited in rural areas, and in the states of the North and Northeast, even in urban areas.

Long waiting lists: Many families report difficulties in obtaining early diagnoses and accessing therapies in the SUS.

Poorly implemented inclusive education, with reports that most schools are prepared to adequately serve students with ASD.

Lack of integration between health, education and social assistance

Insufficient benefits and support.

Low awareness and prejudice

Deficiencies in monitoring and evaluating policies.

Reliance on private initiatives.

Lack of policies focused on adult life.

CONCLUSION

Analyzing the data presented in the literature, it was concluded that there

has been a global increase in the number of ASD diagnoses, including in Brazil, the United States, and the European Union. This may be due to more reliable statistics, more sensitive methods and professional eyes at the time of assessment, and/or also due to the real increase in the number of cases.

With this increase, there is a need to consider public policies that guarantee treatment and the rights to education and citizenship for people with ASD.

Both the United States and the European Union have social, educational, and health policies to address and guarantee the rights of people with ASD. However, they have difficulties in standardizing the resources offered among their states and countries, noting that accessible and effective therapeutic approaches for ASD depend on multidisciplinary teams, involving large financial expenditures.

In Brazil, we also have important laws to guarantee the rights and treatment of the population with ASD, but we face many challenges. Most Brazilian laws speak of guaranteeing rights,

but do not specify exactly how this right will be exercised.

It is recommended that care be provided through the Psychosocial Care Network (RAPS), which includes Psychosocial Care Centers (CAPS) and Specialized Rehabilitation Centers (CERs). Regular schools offer Multifunctional Resource Rooms and Specialized Educational Care (AEE). However, regional inequalities, waiting lists and a lack of trained professionals persist.

Inclusive education is discussed, but there is a lack of policies to implement and train professionals.

We are guaranteed treatment by the SUS, but there is a shortage of trained professionals and a need for more professionals and places to provide care.

There are still difficulties, such as little oversight of the implementation of resources and services, and little focus on work on ASD in adult life. Consequently, many places depend on private initiatives for treatment.

Making a comparison between Brazil, the USA and Europe, while the

USA and Europe have robust systems for early diagnosis, Brazil faces difficulties in implementation and the number of trained professionals.

Access to treatment is broader in the US and Europe, while in Brazil there are limitations in the provision of specialized therapies.

Regarding inclusion, Brazilian legislation is advanced, but it lacks the structure to guarantee full inclusion in schools and the job market.

Brazil is stronger in its social policies and in guaranteeing rights than in relation to health and education itself. There is a good specification of “what” to guarantee, but there is a lack of explanation about strategies for “how to provide it”.

Even in the most advanced centers, it is necessary to expand studies and proposals thinking about better access to treatment and guaranteeing rights to the population with ASD.

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