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## Public Policies and Autism in the Brazilian sociopolitical context

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### Abstract

The terms of the Federal Constitution (BRASIL, 1988) guarantee fundamental rights to all citizens, among which equality, health and education stand out. In recent decades, the growing number of national policy proposals aimed at welcoming and including people with disabilities in schools and social contexts has also questioned a change in society's behavior, highlighting the need to recognize everyone as a subject in history. Before seeing the subject based on their disability and/or specific needs in terms of race, ethnicity, gender, sexuality, religion, culture, class, they are a singular subject involved in their history, however, recognized and respected by it.

**Keywords:** Public Policies, Autism, Brazil, Inclusion, Public Health.

### 1. Introduction

The institution of accessibility as the central route of access to guaranteed individual rights is the result of the Convention on the Rights of Persons with Disabilities, of New York, in 2007, promulgated in Brazil by Decree No. 6,949, of August 25, 2009. In accordance to the Decree, the Brazilian Law for the Inclusion of Persons with Disabilities (Statute of Persons with Disabilities) is established – Law No. 13,146, of July 6, 2015, which aims at social inclusion and citizenship and names the person with disability: is the person who presents long-term impediments of different nature and which, in interaction with one or more barriers, can obstruct their full and effective participation in society on equal terms with other people. (BRAZIL, 2015a, Art. 2º)

At the beginning of the 21st century, the thematic proportion of autism in society called for government initiatives to establish public policies for reception and attention to the mental health of the child and adolescent population, expanding the spheres of care, until then, structured by philanthropic institutions, such as the Pestalozzi Association, the Association of Parents and Friends of Disabled People (APAE) and the Association of Friends of Autistic People (AMA). Briefly, we highlight the creation of the first AMA group in Brazil, in 1983 - São Paulo. According to Mello (2005), AMA-SP sought to exchange experiences and expand knowledge about autism, including seeking knowledge in exchanges with foreign institutions, since the Brazilian State did not equip the public health system with any reception strategy. of children and adolescents with mental suffering, in this way it developed its own assistance fronts even before the SUS.

With the support of professionals from the United States and Denmark, AMA implemented a residential productivity program for autistic people, in order to allow them to socialize and lead a life of autonomy and quality. In this way, he doubled his efforts and, in 1997, founded the Brazilian Autism Association - ABRA, linked to the National Health Council and the CORDE Council - National Coordination for the Integration of People with Disabilities. AMA, even today, continues to have a social identity focused on studies on the topic of autism, with the aim of bringing knowledge to the public with autism and their families, offering assistance services in agreement with the State Department of Education and Health. Historically, Brazilian associations emerged to offer specialized services to people with mental disabilities and through these, expand the development possibilities of these subjects who were, for a long time, excluded from the public education network and did not receive

bonuses in Special Education. In D'Antino (1996), the author states about the difficulties of the 20th century in relation to educational services in the public education network, pointing to a gradual acceptance of the inclusive public, however, restricted to those with physical, hearing, visual and mental disabilities, considering that these deficiencies constitute a mild diagnosis and thus, subject to a potentially educable profile.

This article aims to conduct a comprehensive review of the existing literature on the intersection between public policy and the autism spectrum. We seek to analyze the various government strategies and initiatives implemented in different contexts to support autistic individuals and their families. The review will address not only health policies, but also educational, social and inclusion policies, aiming to understand the impact of these measures on the quality of life, accessibility and social participation of people with autism.

By exploring the gaps and challenges present in public policies aimed at autism, we aim to provide critical insights that can inform future policymaking, identifying best practices and areas for improvement. Furthermore, this article aims to contribute to the development of a more complete and updated understanding of public policies related to autism, encouraging a more integrated approach focused on the individual needs of these individuals.

## 2. Materials and methods

Conducting a literature review on the topic "Public Policies and Autism" required a careful and comprehensive methodology to identify, analyze and synthesize the relevant information available in the scientific literature. The methodology adopted aimed to guarantee quality, objectivity and comprehensiveness in understanding public policies related to autism, as well as the current state of knowledge in this field.

### Source Identification and Selection

Initially, a systematic search was carried out in academic databases, such as PubMed, Scopus and Web of Science, using specific search terms related to public policies and autism.

Articles, books, theses and official documents were considered, prioritizing those that present up-to-date and relevant information for the scope of the review.

### Inclusion and Exclusion Criteria

Clear criteria were established for inclusion and exclusion of studies. Works that directly address public policies related to autism were included, considering different contexts and approaches.

Studies that did not present substantial information on specific policies or that were not available in languages accessible to the research team were excluded.

### Data Analysis and Synthesis

Data analysis was carried out systematically, organizing information by key themes, such as legislation, implementation strategies, challenges and impacts of public policies in the context of autism.

The synthesis of results sought to identify patterns, knowledge gaps and divergences in the literature, contributing to a comprehensive understanding of the panorama of public policies for autism.

## Methodological Quality Assessment

A critical assessment of the methodological quality of the included studies was carried out to ensure the robustness of the information obtained.

Studies of high methodological quality were prioritized, while possible limitations were considered when interpreting the results.

## Review Organization

The literature review was structured logically, following a thematic order that allowed a clear presentation of the different dimensions of public policies for autism.

Each section was prepared based on the analysis of the results, providing a comprehensive and in-depth view of the current state of public policies in this field.

The methodology adopted in this article aimed to ensure a rigorous and comprehensive literature review on the topic, contributing to the critical understanding of public policies related to autism and identifying areas for future research and improvements in government practices.

## 3. Results & Discussion

In the 1930s, the Pestalozzi Society of Brazil, founded by Helena Antipoff in Rio de Janeiro, established a structure for specialized pedagogical care for individuals with mental disabilities. Despite lacking government support, it served as an example for visionaries and associations because it focused on the academic learning of children with disabilities. In this context, the lack of government support led to the establishment of the National Federation of APAE (Parents and Friends of Exceptional Children) by the São Paulo School of Medicine on November 10, 1962. Similar to the Pestalozzi Society, APAE believed in the education of children with disabilities and initiated specialized education and health services for individuals with mental, physical, and intellectual disabilities, which continue throughout the country to this day.

It is understood that there is a gap in state power and its public responsibilities in the history of people with disabilities, leading parents, supporters, associations, and organizations to create an institutionalized care model and philanthropic operation aligned with the needs of the population. Recognizing the numerous assistance demands for the rights of the population, Oliveira et al. (2017) highlight an important fact from the 1980s, the Psychiatric Reform Movement. The movement aimed to review the assistance and theoretical circumstances for individuals with mental disorders, replacing the institutionalization-focused model with a community network for freedom-centered care. This movement resulted in the promulgation of Law No. 10,216/01, which protects the rights of individuals with mental disorders and redirects mental health care.

The law establishes the mental health policy for the state along with the organization of the III National Mental Health Conference (CNSM) in 2001. At this point, the need for inclusion in the field of psychosocial care for mental issues in children and adolescents became evident. For decades, these issues were overlooked in the public agenda or relegated to disciplinary, corrective, or normalizing institutions outside the formal mental health system (COUTO, 2004, cited in OLIVEIRA et al., 2017).

Access to health, as expressed in the Unified Health System – SUS (1990b), a public policy based on the principles of

equity and universal access, brings mental health to the forefront of Psychosocial Care. The establishment of Psychosocial Care Centers (CAPS) as key public policies promoting mental health inclusion followed. According to Oliveira et al. (2017), it was from the III National Mental Health Conference (CNSM) that a care network was created for children and adolescents with severe and persistent mental disorders, known as Child and Adolescent Psychosocial Care Centers (CAPSi), ministerial order No. 336/02 (BRAZIL, 2002).

CAPSi are territorial care devices, community-based, with the primary function of providing mental health care for psychotics, autistic individuals, users of alcohol and other drugs, and for any condition involving severe and persistent psychosocial impairments (COUTO et al., 2015, cited in Oliveira et al., 2017).

Due to the difficulties in understanding childhood and adolescent mental health not only as educational issues, these problems gained greater visibility and public investment. This shift occurred when the social and political perspective adjusted to the conception of children and adolescents according to the Child and Adolescent Statute (ECA, 1990a), changing their legal status from "minors" to subjects with full rights. This replaced the notion of "irregular situation" with "comprehensive protection" (Couto et al., 2015, p. 21). In line with this, the International Convention on the Rights of the Child, held by the United Nations (UN, 1989), provides a new legitimizing interpretation of children, recognizing them as subjects and citizens with full rights.

Given this historical context, the importance of the entire journey under the framework of human rights is evident. From this perspective, there is a significant gain in policies for individuals: caring for the psychic, social, subjective, and linguistic conditions of subjects filled with individual experiences and crossed by the enigmas of existence. In the words of Couto et al. (2015), for the sake of human condition and history, these are subjects who suffer, whose structures are disrupted, and who can express their disorder, discomfort, or suffering in different ways. They are complete subjects who can develop, socialize, learn, but also be affected by the enigmas and subjective vicissitudes inherent in their human condition. They are beings susceptible to suffering and mental illness, with the right to be cared for when suffering becomes unbearable or hinders the construction or maintenance of social bonds without reducing this care to correction, normalization, or adaptation of behaviors (COUTO et al., 2015, p. 22).

From this discourse, yes, public policies on disabilities and autism permeated discussions in all areas on a large scale (families, professionals, medicine, academics, schools, and autistic individuals themselves). However, with the establishment of the National Policy for the Protection of the Rights of Persons with Autism Spectrum Disorders (BRAZIL, 2012), autistic individuals are guaranteed the right to a dignified life, physical and moral integrity, free development of personality, security, and leisure. Access to actions and health services is ensured for comprehensive attention to their health needs. The subject is given the conditions to structure themselves in the face of the disorder through the need for early diagnosis, multiprofessional care, proper nutrition and nutritional therapy, medication and information, as well as access to education, vocational training, the job market, social

security, and social assistance.

In the public documentary perspective on autism, it is important to highlight the consequences of the Guidelines for the Rehabilitation of Individuals with Autism Spectrum Disorder that emerged in 2014 (BRAZIL, 2014), and the document titled Care Line for the Attention to Individuals with Autism Spectrum Disorders and their Families in the Psychosocial Care Network of the Unified Health System, in 2015 (BRAZIL, 2015). Both reveal a historical-political context of differences and positions in the psychosocial care area regarding rehabilitation and associations of autistic families. Oliveira et al. (2017), in their documentary analysis approach, expose the evident differences and similarities:

"The Guideline emphasizes the genetic, neurobiological, and psychosocial factors associated, without, however, developing a deeper reflection on the subject. Its text gives more weight to concepts from classical psychiatry and neurology (with emphasis on Kanner and Asperger), while the Care Line proposes a broader, contextual approach, more comprehensively reconstructing the history of concepts attributed to autism and investigating how these relate in contemporary times" (Oliveira et al., 2017, p. 717).

Regarding the diagnostic process in the face of suspected autism spectrum disorder (ASD), the same research by this author portrays an analysis of the processes that identify both. The Guideline emphasizes the observation of behavioral and risk indicators, while the Care Line uses descriptions, diagnostic categories, and the exposition of cultural, ethical, and political vectors involved in this process. The Care Line consists of psychoanalysis and, in this context, addresses issues such as the risk of reducing an individual to their diagnosis, criticism of the trivialization of psychiatric diagnosis, and therefore discusses the ethical and political dimensions involved in the diagnostic process, as they can produce both social disadvantages and stigmas as well as benefits supported by public policies and rights of individuals with ASD.

In both publications, the convergences emphasize the importance of early detection measures (linked to the Basic Care Network) and differential diagnosis; the participatory inclusion of family members throughout the diagnostic process; the importance and use of screening tools such as IRDI (Clinical Indicators of Risk for Child Development) and M-Chat (Modified Checklist for Autism in Toddlers); the use of the International Classification of Diseases and Related Health Problems (ICD-10) and the International Classification of Functioning, Disability, and Health (ICF) as reference classification systems; attention to possible clinical comorbidities; and collaboration with multidisciplinary clinical teams.

In light of these facts, the policies and actions outlined call for comprehensive attention to individuals with ASD and their families in the Basic Care Network. In this process, the perspective of many professionals involves identifying parents' awareness of abnormalities in certain areas of the child's development. The weaving together of interconnected points in search of a coherent narrative provides the individual with better conditions for developing cognitively, socially, linguistically, and motorically. In Brazil, there is considerable fragility in the working relationships of professionals, leading to immediate challenges in implementing and monitoring

mental health services, particularly for individuals with autism. The hiring of professionals is often delegated to third parties on the front line, subject to low salaries and a lack of guarantees regarding continued employment in the healthcare system.

This aspect produces astonishment and immense dissatisfaction with what is proposed for the developing child. The early years of a child's life are crucial for a quality life, as experiences shape the child's psyche subjectively from birth, characterizing appropriate development for each stage of life or the presence of a child whose behavior raises unknown questions for parents. Later, we will discuss this relationship between the baby and subjective constitution. However, a baby showing a deficit in relating to others is at risk of autism or another developmental disorder. Well-structured public health inferences can address the needs of the mother and baby, assess the child at risk, and provide diagnosis and intervention in these relationships, potentially preventing social disadvantages and stigma and promoting benefits through public policies and ASD rights.

Given the increased demand for risk during the period from 1999 to 2008, the research group (National Research Group) initiated a Multicenter Research on Clinical Indicators of Risk for Child Development that developed the IRDI instrument as a basis for ASD screening. The instrument consists of 31 indicators with predictive value for later developmental problems, including 15 indicators refining prediction for the baby's psychological risk. According to Kupfer et al. (2009), the indicators were gathered for pediatricians to use IRDIs to assess the presence of psychological risk in the baby's development and, above all, to facilitate early intervention and increase the chances of favorable development. That is, they are indicators of a provisional psychopathological position whose realization depends on the evolutionary course, verified under the change of the "protocol that establishes standards for the assessment of risks to the psychological development of children" (BRAZIL, 2017).

Clinical investigation of the psychic constitution palpated through the appropriation of IRDIs in the first 18 months of life can determine the presence or absence of conditions for the proper development of a psychic structure, considering bodily, affective, and symbolic relationships involved in the relationship between the baby and its mother. It is based on observation and questions directed at the mother (or caregiver), and the prominent discourse produces in listening the demand for risk for perceived development in the absence of developmental characteristics described in the items, indicating early on the existence of autism risk and the need for early interventions. In addition to pediatricians, the instrument is accessible to all healthcare professionals in basic care and can benefit many children, although it is still unknown.

The theory of Rehabilitation Care Guidelines (BRAZIL, 2014) allows the use of rapid instruments such as M-Chat in anticipating ASD risk screening. The quick test consists of 23 questions directed at parents of children from 18 to 24 months, and the content of the questions is calculated based on the quantity of "yes" or "no" regarding the child's behavior. From the strategic perspective of the Guidelines, the care and rehabilitation of individuals with ASD begin with the presence of signs of developmental problems, undergo diagnostic assessment and behavior examination,

subjecting them to a hypothetical diagnostic classification (ICD-10). The initial diagnostic configuration provides support for outlining the Singular Therapeutic Project (PTS) and referring the child to appropriate interventions to illustrate the precise diagnosis. During the rehabilitation and treatment process, the individual is also assessed for their health needs.

Therefore, the Rehabilitation Care Guidelines (BRAZIL, 2014) establish evaluation as the establishment of diagnosis, identification of individual potentials, checking with the "teams what they have expertise in their respective fields of activity, while each area interacts with the other" (p. 40). Legitimizing the diagnosis of ASD creates an arrangement to consider and identify "qualitative deviations in development (especially in the field of social interaction and language)" (idem, p. 40). The child undergoes team care, including psychiatrists, neurologists, pediatricians, psychologists, and speech therapists, all aiming to identify both potentials and impairments and bring such observations to medical assessment.

On the other hand, according to the Care Line for ASD attention (BRAZIL, 2015), the discourse revolves around the symbolic subject, one that can enrich the psychic apparatus and structure itself in the face of early intervention in risk observation. This diagnostic process highlights the singular person, with their unique history and characteristics, taking into account the context to understand the suffering or mental disorder of the individual with ASD and their family. The history, context, and experiences of the individual with ASD and their family guide the diagnostic process. The construction of the Singular Therapeutic Project (PTS) is proposed with activities that seek to know the child and make interventions to minimize developmental problems.

In this case, some characteristics, although not specific for identifying ASD risk, should also be considered and investigated, either due to their frequency or the difficulty they generate in management. Especially considering the imminent risk in the first symptoms perceived by the family, well-placed in the Care Line for ASD attention (BRAZIL, 2015), since not all families are informed about the signs of autism spectrum disorders that manifest and are already noticed before the age of 3. Although this age is indicated for precise diagnosis, with lower risks of misidentification, known as "false positives" (p. 51).

In this process, it implies the knowledge of a team not concerned with finalizing the diagnosis but discussing the child's developments in conjunction with the family. The involvement and consistency of family members throughout the diagnostic process are crucial; otherwise, there is a risk of falling into diagnostic reductionism and exacerbating the problems that parents bring, prompting them to create symptoms. Interventions consist of listening, parents appropriating children's issues, recognizing their knowledge about their child, not based on a superior, academic, medical knowledge. In many cases, the symptom not recognized in listening by professionals becomes inherent to the structure of the individual.

In summary, a qualified listening of the family and the person in question is necessary, including: their life history (data on pregnancy, birth, the first years of life, developmental milestones); family configuration (who lives in the house, family ties, relationships with friends, who primarily takes care); daily routine (daycare, school or

social group, day-to-day, autonomy); clinical history (health issues, hospitalizations); the interests of the individual and the family in general; the complaint of the individual and/or the family (BRAZIL, 2015, p. 44).

The instrument based on this logic comes from the psychoanalytic perspective to assess child development (BRAZIL, 2015), supporting a diagnostic process in which a multidisciplinary team with clinical experience does not limit itself to the application of tests and exams, permeated by the plurality of etiological hypotheses without conclusive consensus and the variety of clinical forms and/or comorbidities that can affect individuals with ASD. The encounter of diverse disciplines allows the composition of intertwined knowledge and prevents professionals from limiting themselves to initial impressions.

The purpose of the work conducted by a multidisciplinary team implies being with the child in different situations: individual sessions, family sessions, free activities, and group spaces, where the interplay of actions sustains the place of each in the relationship, of the child, the family, the therapist in observation and intervention, to evaluate the established relationship between the subjects of this relationship, whether through language, touch, etc., or to assess the need for neurological, metabolic, and genetic exams that can complement the diagnostic process. There is a hidden knowledge within a family in treatment, whose pleasure in being parents and passing on their cultural and social heritage to the child does not apply and gives way to deep anguish, as it is necessary to be attentive to ensure that the structuring of the individual is not compromised.

Clearly, public policies present theoretical and practical divergences in the proposal for rehabilitation and psychosocial care, with a conflict of epistemological and clinical knowledge. Besides differences in the initial management of a child at risk or with autism, there are also differences in understanding the individual and their uniqueness. From the perspective of the Guidelines (BRAZIL, 2014), care is surrounded by medical and other professionals; according to the Care Line (BRAZIL, 2015b), recognizing the integral subject within a care network seeks to organize and respond comprehensively to the diversity of demands, devaluing fragmented knowledge production and the segmentation of actions and services, which consequently promotes segregation and exclusion of the population in question.

The reflection focuses on the relationships and various interactions related to those involved in the front lines of action, such as health, social assistance, public safety, defense, and guarantee of rights, and intra- and inter-sectoral articulations. Although they deal with active public mental health policies for the population, according to the Care Line (BRAZIL, 2015b), there is a need for the institutional body to approach and share responsibility among services and professionals providing care, considering different roles and specificities, sharing principles focused on immediate reception and the provision of appropriate services.

Therefore, the organization of care networks requires coordination between health systems, not forgetting to meet the needs of the individual, even though the existing dichotomy between both policies is supported by different fronts. Outlining each of them, there is a disparity in access to services as in the operating matrix. The Rehabilitation

Care Guidelines (BRAZIL, 2014), linked to the Disability Care Network, rely on habilitation/rehabilitation actions, providing mental and medical health services, with specialized care at the core, offering services known as Specialized Rehabilitation Centers - CER (which unfold into physical, mental rehabilitation, etc.), Intellectual Rehabilitation and Autism Services, and Psychosocial Care Centers - CAPS.

#### 4. Conclusions

The Care Line approach (BRAZIL, 2015b), linked to the Psychosocial Care Network (RAPS), calls upon professionals from different services (child care, neuropsychomotor development, early intervention, psychosocial care, rehabilitation, and crisis health care) to form a large network of expanded care. This network focuses on bringing individuals with Autism Spectrum Disorder (ASD) and their families closer together through their knowledge and specific actions. It collaborates with Social Assistance and Education, emphasizing the need to clearly outline intersectoral relationships, naming habilitation/rehabilitation services for individuals with functional impairments and the care networks of the Unified Health System (SUS), such as the Care Network for People with Disabilities.

In brief, it is worth noting other legal landmarks that alter the reality of individuals with Autism Spectrum Disorder, aiming to facilitate access to basic and essential rights, such as the creation of the Identification Card for Individuals with Autism Spectrum Disorder – CIPTEA, Law No. 13,977 (BRAZIL, 2020). Through basic specific measures like this, it provides actions and rights that reduce suffering for individuals in certain circumstances, such as requiring preferential treatment in a hostile environment. The issuance of the card by state, district, and municipal agencies for free, the Continuous Benefit Program (BPC), free public transportation, etc., allow for the planning of public policies and modulations designed to integrate new concepts and practices into social inscription. There is still much to achieve; however, among other welfare rights as provided by the Federal Constitution (Brazil, 1988), one can observe the growing organization of care policies and the guarantee of citizen rights.

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