

AUTISM, NEURODIVERSITY AND STIGMA: POLITICAL AND INCLUSIVE PERSPECTIVES

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ABSTRACT

Movements of people with Autism Spectrum Disorder (ASD) and their families have been increasing and gaining strength in Brazil and worldwide. The neurodiversity movement understands that autism is part of a person's personality, not a disease that must be cured. The study addresses the neurodiversity movement in the context of ASD, discussing its relations with scientific evidence. From a theoretical study, we saw that the medical model still seems to be the most adopted in Brazilian research about inclusion, which may influence stigma and negative and distorted views about the differences presented by people with ASD. Among other aspects, the importance of the participation of people with ASD and/or their family members in the development of research related to them is highlighted, seeking to promote scientific and academic practices that listen, respect and be inspired by neurodiversity.

Keywords: autism; neurodiversity; stigma

Autismo, neurodiversidad y estigma: perspectivas políticas y de inclusión

RESUMEN

Los movimientos de personas con Trastorno del Espectro Autista (TEA) y de sus familiares vienen aumentando y ganando fuerza en Brasil y en el mundo. El movimiento de la neurodiversidad entiende que el autismo forma parte de la personalidad de la persona, no tratándose de una enfermedad que debe ser sanada. El estudio aborda el movimiento de la neurodiversidad en el contexto del TEA, discutiéndose sus relaciones con las evidencias científicas. A partir de un estudio teórico, se percibe que el modelo médico parece ser aun el más adoptado en investigaciones brasileñas sobre la inclusión, pudiendo influenciar en el estigma y en las visiones negativas y distorsionadas sobre las diferencias presentadas por las personas con TEA. Entre otros aspectos, se demarca la importancia de la participación de personas con TEA y/o de sus familiares en el desarrollo de investigaciones relacionadas a ellas, buscando la promoción de prácticas científicas y académicas que escuchen, respeten y se inspiren en la neurodiversidad.

Palabras clave: autismo; neurodiversidad; estigma

Autismo, neurodiversidade e estigma: perspectivas políticas e de inclusão

RESUMO

Os movimentos de pessoas com Transtorno do Espectro Autista (TEA) e de seus familiares vêm aumentando e ganhando força no Brasil e no mundo. O movimento da neurodiversidade entende que o autismo é parte da personalidade da pessoa, não se tratando de uma doença que deve ser curada. O estudo aborda o movimento da neurodiversidade no contexto do TEA, discutindo as suas relações com as evidências científicas. A partir de um estudo teórico, vimos que o modelo médico parece ser ainda o mais adotado em pesquisas brasileiras sobre a inclusão, podendo influenciar no estigma e nas visões negativas e distorcidas sobre as diferenças apresentadas pelas pessoas com TEA. Entre outros aspectos, demarca-se a importância da participação de pessoas com TEA e/ou de seus familiares no desenvolvimento de pesquisas relacionadas a elas, buscando a promoção de práticas científicas e acadêmicas que escutem, respeitem e se inspirem na neurodiversidade.

Palavras-chave: autismo; neurodiversidade; estigma

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INTRODUCTION

The estimated prevalence of Autism Spectrum Disorder (ASD) is one in every 54 births (18.5 in 1,000), according to a multicenter study carried out in the United States of America (USA), with data collected in 11 areas of the country (Centers for Disease Control and Prevention [CDCP], 2020). In Brazil, the only epidemiological research carried out was a pilot study in 2011 and developed in a neighborhood of just 20 thousand inhabitants in the city of Atibaia, in the interior of São Paulo, which resulted in 1 autistic child for every 367 children (Paula, Ribeiro, Fombonne, & Mercadante, 2011). The causes of autism are multifactorial, involving the interaction of neurobiological and environmental aspects, to which individuals are exposed during the peri- and prenatal periods, with strong evidence of genetic causes (Júlio-Costa & Antunes, 2017).

Over the last few years we have seen an increasing curve of people being diagnosed with ASD, a phenomenon that has become known as the “autism epidemic” (Rios, Ortega, Zorzanelli, & Nascimento, 2015). The fact of the increase in registered cases of ASD, according to Rios et al. (2015), is not only due to the growth in the number of people with the disorder, but due to the greater visibility given to it, in addition to the new way adopted by psychiatry to classify and describe its symptoms in the fifth edition Diagnostic and Statistical Manual of Mental Disorders (DSM-5, American Psychiatric Association [APA], 2013). Proportional to the increase in the number of cases diagnosed with ASD worldwide, we have also seen the growth of organizations, groups and movements of people with this diagnosis and their families, presenting different purposes.

In this study, we intend to specifically address the neurodiversity movement in the context of ASD and discuss its relations with scientific evidence, especially those that seek to reduce this population’s stigma. Furthermore, we intend to raise issues related to neurodiversity in the Brazilian school context, presenting findings from international research and formulating questions that can be addressed for future studies about the topic in Brazil. This is a theoretical study, which will be divided into two parts: 1) *Autism: historical and social constructions* and 2) *Neurodiversity, stigma and implications for the school context*.

DEVELOPMENT

Autism: historical constructions and social constructions

The term Autism was first used by Eugen Bleuler, in 1911, to describe a type of schizophrenia that caused the individual to dissociate from reality (Ferreira, 2018). The condition began to be considered as a specific clinical type in 1943, with Leo Kanner, who established, from a study involving the analysis of 11 cases of children who presented common difficulties, the differentiation

between autism and schizophrenia, highlighting the beginning precocious of the first (Kanner, 1943/1997). In fact, it is known that it is possible to detect ASD early in individuals up to 24 months of age, when they present characteristic signs of the disorder (Júlio-Costa & Antunes, 2017), which is not possible in cases of schizophrenia (APA, 2013). In 1944, while Kanner was carrying out his research about this new “mental illness”, Hans Asperger published his thesis about “autistic personalities”, which included the description of cases similar to Kanner’s (Asperger, 1944/1991). Asperger followed children who were able to compensate for their difficulties due to their high level of thinking, language and intelligence, a condition that later became known as Asperger Syndrome (Ferreira, 2018). It is worth noting that Kanner’s work, as it was written in English, was quickly disseminated, while Asperger’s was restricted to German and Dutch readers for decades, probably due to the Second World War. In this context, it was Lorna Wing, researcher and mother of a child with ASD, who was responsible for disseminating Asperger’s thesis in the scientific world and for its association with Kanner’s autism, who also coined the idea of autism as a *spectrum* of conditions, marked by a triad of disturbances (Wing, 1991).

Over time, different nomenclatures and descriptions were adopted to cover the clinical picture of Autism. Since the publication of the fifth edition of the DSM-5 (APA, 2013), the diagnostic categories Autistic Disorder, Asperger’s Disorder, Degenerative Childhood Disorder and Pervasive Developmental Disorders Not Otherwise Specified began to be classified solely as Autism Spectrum Disorder (ASD). As a result, and in line with theories and evidence in the area, the hitherto known “diagnostic triad” (language, communication and behavior) began to consider only two domains: socio-communicative development and behavioral patterns (Júlio-Costa & Antunes, 2017; APA, 2013).

Throughout their lives, people with ASD and their families often face challenges and difficulties related to the disorder. One of these major challenges is dealing with the consequences caused by “being autistic” in a society that is sometimes unaware of its characteristics and differences (Kapp, Gillespie-Lynch, Sherman, & Hutman, 2013). “Being different” from the majority can generate feelings of loneliness and not belonging on the part of people with ASD and their families, which often ends up mobilizing the search for a cure for their condition. On the other hand, there are policies and movements in favor of inclusion, which cover all areas of a society, the problematization of what it means to be “different” and the search for social transformations (Júlio-Costa & Antunes, 2017). In contrast, to understand what it means to be “different” and the consequences of this condition, it is necessary to first understand the historical constructions of the “social normalization” concept.

The word “normal” was coined as a medical term by Augusto Comte, in 1820, with the aim of describing normal laws to the organism, facilitating their description. As pointed out by Singer (2017), normal emerged from the use of statistics as a government tool, which established the idea of the “average man”, as well as the idea of “average morality” and defined what we today call the middle class. Along the same lines, the process of normalization of society, according to Miskolci (2003), caused typical patterns (i.e., those that appeared in most people) to be associated with the ideal, with this process being both a medical and social movement. History points out that the fear of “abnormality” strengthened the discourse of what we call “eugenics” during the rise of bourgeois society, bringing with it the discourse of degenerates (disabled people, black people, prostitutes, etc.) and the fear of their reproduction, being the practice of isolating these people considered common during the 19th century. As stated by Miskolci (2003), it is important to emphasize that in this case, the degenerate was not the “sick person”, but rather the one who had an inherited and definitive abnormal condition.

Eugenics emerged at the end of the 19th century as a genetic science that aimed at racial improvement (Moura & Crochík, 2016). Today, with the birth of genetic engineering and scientific discoveries, the biological adaptation of the subject becomes possible, which, through embryonic or post-birth interference, creates the ideal individual. These new technologies can culminate in the disappearance of conditions considered imperfect such as deafness, blindness or even Down Syndrome (Moura & Crochík, 2016). For some autistic people, parents of autistic people and allies, finding the genetic cause or cure for the disorder can represent a search for its disappearance. As a result, they fear that offering this “screening” for ASD during prenatal care could lead to abortions of babies who would have this “genetic flaw”. In this sense, it is in this context that autistic movements that combat negative thoughts about ASD emerge, as is the case of neurodiversity (Silva, Gesser, & Nuernberg, 2019; Ortega, 2009).

Neurodiversity stigma and implications for the school context

The neurodiversity movement, which began at the end of the 20th century and beginning of the 21st century, emerged as a counter-proposal to the ideology of division between normal and abnormal or pathological, going against the medical model and the eugenics discourse in force until then. In the case of ASD, the neurodiversity paradigm takes its particularities as characteristics that are inseparable from the identity of these subjects (Kapp et al., 2013). Neurodiversity also marked the migration of conceptions about the etiology of autism, moving from the psychogenic hypothesis (primarily based on psychoanalytic conceptions, and

mostly with the negative view of parental figures) to areas related to biology and brain sciences (Ortega, 2009). This movement emerged together with the birth of computers and the information processing approach, which contributed to the explanation of the brain functioning of people with ASD (Singer, 2017). Furthermore, during this period, biographies of autistic people, such as Temple Grandin and Donna Williams, began to be published, presenting the perception of reality based on the peculiarities of autism and showing that not all people with ASD have the comorbidity of ASD intellectual disability, many of which are “high functioning” (Singer, 2017).

The term “neurodiversity” (translated as *neurodiversidade* in Brazil) was first adopted by Judy Singer, in 1998, with the aim of creating a different perspective about the ASD. In the work entitled “NeuroDiversity: The Birth of an Idea”, Singer (2017) talks about what it was like to be raised by a mother with ASD and to have a daughter who, during the first years of her life, presented a development pattern that deviated from normality. Furthermore, she reports her experience of finding herself “within the spectrum”, a nomenclature used by the author to describe people with restricted interests, some difficulties in relating to peers, but who do not meet the criteria for the diagnosis of ASD, currently called autism extended phenotype (Endres, Sbicigo, Sales, & Bosa, 2020).

Currently, neurodiversity encompasses a heterogeneous group of neurodevelopmental and neurological disorders, not limited to just the movement of people with ASD. Bipolar disorder, attention deficit hyperactivity disorder, Tourette Syndrome, dyslexia, epilepsy and childhood apraxia syndrome, as they are associated with distinct neurological patterns, illustrate disorders that are also part of the neurodiversity movement (Baker, 2011). As a social movement, neurodiversity allows people with ASD, parents of people with ASD, and allies to advocate for understanding that we should not seek a cure for autism, in the same way that we should not seek a cure for homosexuality, ethnicity, left-handedness, among others (Ortega, 2009). However, like any social movement, neurodiversity encounters challenges and conflicts in its struggle (Singer, 2017). For example, she receives criticism from parents of severely autistic people, for having “high-functioning” autistic people as her voice, that is, those who border on “normality” (Ortega, 2009), and who do not represent the majority of the population that understands the diagnosis. This criticism is countered by neurodiversity activists pointing out that movements that seek the cause and cure of autism have high-functioning autistic people, highlighting that the neurodiversity movement also includes non-verbal autistic people in its cause (Silva et al., 2019).

One of the objectives of neurodiversity is to promote the pride of people with ASD as a social minority,

intertwining movement activists and the community. This movement denies autism as a disease, fearing that genetic tests could lead to an attempt to extinguish people with ASD. In other words, as previously stated, movement activists fear that identification through prenatal care could lead to abortion by parents fearful of the possibility of their child being born with ASD (Kapp et al., 2013; Ortega, 2009). Furthermore, neurodiversity suggests a fight for inclusion and the universal rights of people that the movement embraces (Baker, 2011). It is, therefore, a movement that also defends and fights for public policies aimed at people with disabilities, such as school inclusion.

In Brazil, the National Policy on Special Education from the Perspective of Inclusive Education (PNEE; Ministry of Education [MEC], 2008) legitimized access and retention for all students, and the school (context and people) must adapt to include students with different conditions. The new PNEE (MEC, 2020) prioritizes Special Education in the regular education network, in accordance with the National Education Guidelines and Bases Law (LDB), but does not exclude the possibility of assistance in specialized schools, aiming to cover all stages and educational modalities. According to this policy, the decision on whether to enroll in a regular inclusive or specialized school is the responsibility of the student or their family. The aforementioned policies strengthen the neurodiversity movement by emphasizing the value of neurobiological diversity and the inclusion of individuals with different characteristics. The inclusion of students with disabilities in regular education encourages the adaptation of schools to meet diverse needs. Furthermore, the new PNEE (MEC, 2020), by allowing students and their families to choose between inclusive or specialized schools, encourages respect for individuality and diversity of needs, in line with the principles of neurodiversity.

However, it is important to highlight that the neurodiversity movement is still not widespread in Brazil. A literature review study, carried out by Wuo, Yeadau and Wayszceyk (2019), whose objective was to analyze research about ASD developed in postgraduate studies in Education in Brazil between the years 2008 and 2018, in a brief survey, found only five articles that combined the terms "neurodiversity" and "autism" as research descriptors, all of which focused on the health area. When carrying out deeper research on the topic, the authors found 22 productions in the area of education, which combined broader descriptors (i.e. *autism, autistic and education; school inclusion, educational inclusion, schooling, inclusive education, inclusion*). In these, specifically on neurodiversity and autism, a psychoanalytic thesis was found in Brazilian research in the Education area, which brought together the trajectory of ASD and its social movements (Furtado, 2011). In the article, the authors criticize the way research describes

autism, stating that it can generate stigma about it and thus promote exclusion rather than inclusion (Wuo et al., 2019). In this study, research focused on autism within the Brazilian context was divided into what researchers Wuo et al. (2019) called it the medical model and the critical model. The authors defined the medical model as research that adopts the definition of ASD as described in the DSM-5 (APA, 2013) and the critical model is that which describes ASD criticizing the medical model, that is, research that seeks other ways of seeing ASD without being guided by the biomedical model, which focuses on its deficits and difficulties; from the 22 productions analyzed, the majority of them (i.e. 17) referred to the medical model (Wuo et al., 2019). Regarding this aspect, it is worth mentioning that neurodiversity corresponds to what is understood as the biopsychosocial model, distancing itself from the purely biomedical or social model (Gillespie-Lynch et al., 2017). The neurodiversity movement understands the neurobiological and behavioral bases of ASD, but understands such changes as part of the personality, thus seeking interventions in the social sphere.

Although research is scarce, when we consider all together, the recent movements that defend neurodiversity and questions about the education of people with ASD, the relevance of preparing professionals and society for an inclusion that understands and respects the point of view of these movements. According to Ortega (2009), the traditional model of education focused on curing, repairing, repairing, or improving the child's "deficits". On the other hand, it is known that good inclusion is built with knowledge of the particularities of each student, considering their potential and difficulties, which is not restricted to the assessment of their cognitive abilities (Kapp et al., 2013). In the case of ASD, it is essential to understand the different ways of processing environmental stimuli and expressing/communicating, considering how their changes mark the subject's relationships with people and the environment/world.

Regarding this aspect, it is worth mentioning the study carried out by Jones, Hawn and Beck (2013) involving nine people with ASD, which presented their report that people called neurotypical (non-autistic) generally do not understand behaviors used as means of self-regulation, such as repetitive behaviors as a way of dealing with the atypical sensory difficulties of people with ASD. Thus, it is common for people who are not part of the spectrum to characterize ASD based on the disorder's social impairments, failing to recognize other particularities, such as hyper- or hyposensitivity. For this reason, it is understood that knowledge and sensitivity to identify and interpret the behaviors presented by someone with ASD is fundamental to improving inclusive practices.

The change in knowledge about ASD is constant, in line

with current research findings and the implementation of new technologies (Gillespie-Lynch et al., 2015). Scholars on the subject understand that specific and accurate knowledge about a given population, generated from contact with a group of minorities, can reduce prejudice against that same group (Allport, Clark, & Pettigrew, 1954; Foster, Elishberger, & Hill, 2018). On the other hand, when knowledge is exposed in an erroneous or distorted way, as sometimes occurs in the media, it can cause harm to the group that presents the disorder and/or condition (Allport et al., 1954; Foster et al., 2018). It is worth noting that the media is one of the main sources of information about ASD for the public who have no contact with people with the disorder (Obeid et al., 2015).

From the perspective of ASD, we find studies that prove that the greater the knowledge about the diagnosis, the less stigma about the disorder on the part of neurotypical individuals; however, these two factors do not always appear to be correlated (Feldman & Crandall, 2007; Obeid et al., 2015). Here it is important to reinforce that the neurodiversity paradigm brings with it the construction of an “autistic” identity (Kapp et al., 2013). As exemplified previously, there is a discussion between the pro-cure and pro-neurodiversity movements (Silva et al., 2019; Ortega, 2009; Singer, 2017), which can generate internal conflicts in individuals with ASD about their identity, which also can be the target of stigma (Goffman, 1981; Obeid, et al., 2015), as the conflicts of a stigmatized person can influence the perception of their identity (Goffman, 1981).

Goffman (1981) defines stigma as “the situation of the individual who is incapable of full social acceptance” (p. 2). In other words, stigma is seen as evidence of a derogatory attribute characteristic of an individual. From the moment an attribute becomes stigmatizing in one person, it can define normality in another (i.e. a stigmatized view of autistic people is linked to a view of normality in non-autistic people). Within what we call mental illnesses, Fernandes and Li (2006) present the fear of the unknown and erroneous beliefs as the biggest providers of stigma. People who have some type of mental disorder can be classified with negative descriptions about themselves, in addition to presenting discrimination and social harm, with the term “mental disorder” being full of mistaken thoughts on the part of individuals who do not have a mental disorder, who refer to the aggressiveness and unpredictable behaviors of people who carry this label (Foster et al., 2018).

Feldman and Crandall (2007) state that mental illness, or mental disorder, brings with it rejection. For the authors, mental illness is a double-edged sword: on the one hand there are all its differentiated cognitive processes, its limitations, its dysfunctional behaviors (sensitive, emotional, affectionate); and on the other, the social stigma that is carried by these individuals.

Studies show that stigma may be related to the little experience/coexistence that a group has with the stigmatized group, and the opposite also occurs (Feldman & Crandall, 2007). In this context, it is considered that rejection is linked to current social norms, since before a person is stigmatized, what is different is collectively conceptualized by society, and this phenomenon is also observed in cases of ASD (Feldman & Crandall, 2007; Goffman, 1981). With these questions we return to the conception that normality was created by man in order to define what would be expected for a subject based on social determinants (Miskolci, 2003).

In the United States of America, studies such as that by Gillespie-Lynch et al. (2015), among others, sought to analyze the perception, knowledge, acceptance and stigma of university students towards their peers with ASD. The results of the study carried out by Gillespie-Lynch et al. (2015) showed that university students’ knowledge about ASD, acquired from online training developed by people with ASD, can reduce stigma about it. This study was replicated by Obeid et al. (2015), in 2015 in Lebanon, and the researchers found similar results to those of Gillespie-Lynch et al. (2015), however, cultural particularities were observed in the findings. Regarding this aspect, Obeid et al. (2015) highlight that, depending on the country in which the person lives, they will have a different conception and knowledge of ASD. This statement corroborates Siqueira and Cardoso (2011) when they state that stigma is a social construction that is shaped by the culture and historical period in which “different” people find themselves, and these are stigmatized only in a cultural context.

Studies about stigma in Brazil are not scarce, with some initiatives are found, they are related to the topics of mental illness, disabilities, addicts, ethnic stigma, etc. (e.g. Fernandes & Li, 2006). However, the stigma surrounding ASD, which is a common disorder worldwide and the second largest demand for Special Education in regular education (INEP, 2022), appears not to have yet been explored in the Brazilian context.

FINAL CONSIDERATIONS

In this text, we saw that the medical model is still the most adopted to describe ASD in Brazilian research on education and inclusion (as found by Wu et al., 2019), which can influence stigma and negative views and distorted about the differences presented by these people. Furthermore, we saw that stigma is marked by cultural and historical issues, being linked to socially established norms and standards, with the lack of coexistence with neurodivergent people being a factor that can contribute to the establishment and maintenance of stigmatizing practices. From these understandings, some implications and questions emerge, which can be addressed and debated in future researches.

The importance of including people with ASD and/or their families in the development of research related to them is highlighted, seeking to promote scientific and academic practices that listen, respect and are inspired by neurodiversity. For Gillespie-Lynch et al. (2017), people with ASD should be considered experts on the disorder, as they can explain what autism is and what difficulties they face as autistic, bringing a discourse that is not stigmatized to neurotypical people.

With regard to the school context and, in particular, teacher training in Brazil, it is necessary to evaluate and develop strategies that contribute to the advancement of teaching knowledge about ASD, working with their beliefs and possible stigmas in relation to people with this diagnosis. Knowledge about existing pro-cure and pro-neurodiversity movements is also important for teachers and undergraduate students, and can help in understanding the identities of their students with ASD. The guidelines for initial teacher training (Conselho Nacional de Educação [CNE], 2015) provide for critical reflection on different social movements, in addition to promoting diversity, whatever it may be. The neurodiversity movement seeks to change thinking about what autism is, trying to extinguish the belief that ASD only brings difficulties to people who have it, and that these people should be treated and normalized, being exalted by activists and allies of the movement the positive aspects of the disorder (Gillespie-Lynch et al., 2017). Few neurotypicals know about the neurodiversity movement, which is best known by people with ASD (Gillespie-Lynch et al., 2017)).

Finally, it is highlighted that the model focused on healing must be rethought and modified to a model that takes into account the facilities, difficulties and abilities of each person with ASD (Kapp et. al., 2013). Only in this way, by adapting processes and covering the entire school community, can we make inclusion viable. Always highlighting that regular schools must adapt to the demands of students with special educational needs, in addition to providing an educational environment that combats discrimination, understanding the diverse public that comprises it and guaranteeing effective education for all.

The growing neurodiversity movement, the increased diagnosis of children and adults with ASD, in addition to the high enrollment rate of these individuals in regular education, highlight the importance of research and interventions regarding the conceptions of teachers and future teachers about autism. In this context, it is believed that training, qualifications and training about ASD and that actively include people with ASD and their families in their development, thus supporting the neurodiversity movement, can be powerful tools for changing the conception and increasing knowledge about the disorder. Such factors, in turn, may represent a fight against the pathologization of ASD and a search for

more understanding and inclusive attitudes, respecting human diversity.

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