

## STUDENTS WITH AUTISM SPECTRUM DISORDER IN HIGHER EDUCATION: ANALYZING INEP DATA

Solange Cristina da Silva <sup>1</sup>; Daniela Ribeiro Schneider <sup>1</sup>; Erikson Kaszubowski <sup>1</sup>; Adriano Henrique Nuernberg <sup>1</sup>

### ABSTRACT

This article aimed to map the socio demographic profile of students with Autism Spectrum Disorder (ASD) enrolled in higher education in 2016 from INEP microdata. With a quantitative approach, it is a survey of descriptive data. The results indicate that there were 546 (no imputation) or 1,217 (with imputation) of self-declared students with ASD (single students), corresponding to 0.01% of the total enrolled students in 2016. These students are predominantly: white (37% without or 51 % with imputation), male (61.5% without or 72.3% with imputation) and residents in the Southeast (33% without imputation) or Northeast (50% with imputation). Data that enable the knowledge of the different characteristics that intersect and help maintain the barriers of access and academic permanence, and bring reflections on the intersectionality of social markers, contributing to the pursuit of improving public policies for this population.

**Keywords:** Accessibility; autism; higher education.

### Estudiantes con trastorno del espectro autista en la enseñanza universitaria: analizando datos del Inep

#### RESUMEN

Este artículo tiene por objetivo el mapeo del perfil sociodemográfico de los estudiantes con Trastorno del Espectro Autista (TEA) matriculados en la enseñanza universitaria en 2016 a partir de los micro-datos del INEP. De abordaje cuantitativo, se configura en una investigación de recopilación de datos de naturaleza descriptiva. Los resultados indican que había 546 (sin imputación) o 1.217 (con imputación) de estudiantes auto-declarados con TEA (alumnos únicos), correspondiendo al 0.01% del total de estudiantes matriculados en 2016. Esos estudiantes son predominantemente: blancos (el 37% sin o el 51% con imputación), del sexo masculino (el 61,5% sin o el 72.3% con imputación) y residentes en el Sudeste (el 33% sin imputación) o Nordeste (el 50% con imputación). Datos que posibilitan el conocimiento de las diferentes características que se cruzan y ayudan en la manutención de las trabas de acceso y permanencia académica, además de traer reflexiones acerca de la interseccionalidad de marcadores sociales, contribuyendo para la búsqueda del perfeccionamiento de políticas públicas para esta población.

**Palabras clave:** Accesibilidad; autismo; enseñanza universitaria.

### Estudantes com transtorno do espectro autista no ensino superior: analisando dados do Inep

#### RESUMO

Este artigo objetiva o mapeamento do perfil sociodemográfico dos estudantes com Transtorno do Espectro Autista (TEA) matriculados no ensino superior em 2016 a partir dos microdados do INEP. De abordagem quantitativa, configura-se numa pesquisa de levantamento de dados de natureza descritiva. Os resultados indicam que havia 546 (sem imputação) ou 1.217 (com imputação) de estudantes autodeclarados com TEA (alunos únicos), correspondendo a 0.01% do total de estudantes matriculados em 2016. Esses estudantes são predominantemente: brancos (37% sem ou 51% com imputação), do sexo masculino (61,5% sem ou 72.3% com imputação) e residentes no Sudeste (33% sem imputação) ou Nordeste (50% com imputação). Dados que possibilitam o conhecimento das diferentes características que se cruzam e ajudam na manutenção das barreiras de acesso e permanência acadêmica, além de trazerem reflexões acerca da interseccionalidade de marcadores sociais, contribuindo para a busca do aprimoramento de políticas públicas para esta população.

**Palavras-chave:** Acessibilidade; autismo; ensino superior.

<sup>1</sup> Universidade do Estado de Santa Catarina – Florianópolis – SC – Brasil; solangecristina66@gmail.com; danischneiderpsi@gmail.com; erikson84@yahoo.com.br; adrianoh@cfh.ufsc.br

## INTRODUCTION

There is a growing number of students with disabilities in higher education, the result of the historical process of fighting for rights and against the concept of the person with disabilities as incapable and deficient from a functional and social point of view. This process of fighting for rights has been materializing since the inclusion policies that emerged in Brazil between the end of the 1980s and the beginning of the 1990s, with the Federal Constitution of 1988 (Brasil, 1988), initially with emphasis on the regular basic education system, a proposal for integration and, later, a proposal for inclusion. Other national documents aim to ensure the right to education such as the LDB - Law of Directives and Bases of Education (Law 9394/96, 1996) -, the National Plan for Education for All (Brasil, 2001) and the *National Policy of Special Education in the Perspective of Inclusive Education* (Brasil, 2008), among others.

The process of consolidating public policies aimed at the educational inclusion of people with disabilities was strengthened, mainly, with the promulgation of the International Convention on the Rights of Persons with Disabilities (UN Convention) and its Optional Protocol, ratified as a Constitutional Amendment by means of Legislative Decree 186/2008 (2008) and Decree 6,949/2009 (2009). In this Convention, the term "person with disability" is consolidated, which will be used throughout this text because it is in line with the understanding of disability from the perspective of the social model and in opposition to the medical model, conceiving disability as a historical and perspective construction, the basis of this research.

The list of "people with disabilities" included people with ASD, following the approval of Law 12764/2012 (2012) - National Policy for the Protection of the Rights of People with Autism Spectrum Disorder -, who now have secured all rights aimed at this group.

Inclusion of people with disabilities in Higher Education is strengthened by other legal contributions, such as Ordinance 1679/1999 (1999), which established accessibility requirements for teaching people with disabilities for the authorization and recognition of courses and accreditation of institutions; Decree 3298/1999 (1999), which, in its Art. 27, regulates the duty of higher education institutions (HEIs) to offer adaptations of tests and necessary support to students with disabilities, as well as proposes curricular alterations to include content, items or subjects related to people with disabilities; Decree 5296/2004 (2004), which ensures the inclusion of the universal design and ABNT standards of accessibility in the curricula of professional, technological and higher education institutions in the areas of engineering, architecture and the like, as well as setting standards for establishments to grant authorization to open, operate and renew a

program; Decree 7612/2011 (2011), which institutes the National Plan for the Rights of Persons with Disabilities - *Living without limits*, which advocates "promoting, through the integration and articulation of policies, programs and actions, the full and equitable exercise of the rights of people with disabilities" (n.p.); the National Education Plan (2014-2024), which sets out guidelines, goals and strategies for educational policy for the ten-year period; Law 13005/2014, which in its article 4, recommends public authorities seek to expand the list of research for statistical purposes to provide detailed information on the profile of populations with disabilities from four to seventeen years old.

The recently implemented government policies for access and permanence of people with disabilities in higher education include the University for All Program (ProUni), instituted by Law 11096/2005 (2005), whose objective is to allocate scholarships to people with disabilities in private HEIs (Art. 2) and percentage of scholarships destined to the implementation of affirmative policies for access to higher education for people with disabilities or self-declared indigenous and black people (Art. 7); the Accessibility Program in Higher Education (*Incluir*), Edital *INCLUIR* 04/2008 (MEC, 2008), which proposes actions to guarantee full access for people with disabilities in federal higher education institutions.

Despite the growing commitment to adopting public policies aimed at inclusion and increasing enrollment of people with disabilities, there is a gap in the effectiveness of these policies, demonstrated in the comparison with the general university population enrolled in Higher Education Institutions, in which they represent less than 1% (0.4% in 2015) of the total enrollments (Martins, Leite, & Ciantelli, 2018).

With regard to students with ASD, this number drops considerably, denouncing that there are significant challenges and barriers to access that need to be researched in order to propose changes and expansion of public policies aiming at equal access and the fulfillment of rights already achieved. Therefore, it is necessary to know this public with ASD that enter higher education. This demand was the driving force behind this research on the sociodemographic profile of students with ASD in higher education.

The perspective is that data of this research, aligned with the adopted theoretical matrices, can contribute to the understanding of the profile of students with autism who access higher education and, with that, obtain a reflection tool for the elaboration of public policies that expand the access and permanence of this group in the academic space.

## METHODOLOGY

This was a quantitative survey, with indirect data, as information was collected regarding students with ASD

identified in INEP by the variables “Child Autism” and “Asperger’s Syndrome” (nomenclature referring to DSM-IV) from microdata of the INEP Higher Education Census for the year 2016 (INEP, 2017). The National Institute of Educational Studies and Research Anísio Teixeira - INEP carries out the Higher Education Census, which refers to a “nationwide survey carried out annually by the Directorate of Education Statistics in all Higher Education Institutions, public and private, in the country” (INEP, 2016, p. 3). In the annual document, data are divided into: Higher Education Institution (HEI) Data, Program Data, Student Data and Derived Variables.

As it is attached to the profile of the census available, this documentary survey is configured as a cross-sectional study for the presentation of the variables that have already occurred related to the accessibility phenomenon. Access to the object of study, because it is carried out indirectly, using official electronic documentary sources made available by INEP for public access in the form of statistical records, configures the research as documentary. Documentary research is one whose source is restricted to the collection of data in documents, written or not, that can be accessed at the moment or after the fact or phenomenon occurs (Lakatos & Marconi, 2005). The choice of this document for the research is justified by bringing national data of students with disabilities enrolled in higher education, their profile, form of entry and the characteristics of the institutions accessed.

Variables used to characterize the sociodemographic profile of students with ASD were: Sex, Age of the student, Color/Race and State and Region of the HEI where the student is enrolled. The terms “Color/Race” are used in the INEP document. The use of these will be maintained when referring to INEP data or in citations, otherwise the term “ethnicity” will be used, as it is considered more appropriate and updated.

Identification of students with ASD occurred in two ways. The first was based on the information contained in the census variables that indicate whether the student declared him/herself with Childhood Autism or Asperger’s Syndrome. As these two variables have a lot of missing data, data from the previous years’ censuses were used for imputation, using the last value carried forward filling strategy. All students who identified themselves at least once with Childhood Autism or Asperger’s Syndrome between 2011 and 2016 and who continued with any enrollment situation in 2016, identified or not with ASD in that year, were included in the analysis through this imputation strategy. The crossing between different years is possible due to the identification of students with a unique code among all censuses. This analysis strategy was used because of the weakness in data released by INEP, which is a limitation of the study.

Data of the profile variables were analyzed considering the two data sets: based on the imputation based on previous years and considering only the data from the 2016 census. A descriptive analysis of the profile information was performed using the case count and the frequency relative, summarized in tables, bar graphs and maps.

The research project of which this study is part was sent and approved by the Research Ethics Committee - CEP/CONEP, in a public university located in the state of Santa Catarina and followed all the recommendations established by the National Health Council, through of Resolution 510/2016 and complementary.

## RESULTS

Using only the information contained in the Census for the year 2016, there were 546 students with ASD in higher education, corresponding to a total of 614 enrollments, regardless of the condition of enrollment (enrolled, unlinked, drop-out, deceased, graduated). With the imputation of data from previous years, the number of students with ASD in 2016 increased to 1,217 unique students and 1,368 enrollments. Of the total number of unique students, 73.2% (891 - with imputation) and 52.4% (286 - without imputation) identified themselves with Child Autism; 29.6% (360 - with imputation) and 49.6% (271 - without imputation) identified themselves with Asperger’s Syndrome; and 2.8% (34 - with imputation) and 2.0% (11 - without imputation) were registered with both diagnoses.

Most students with ASD are male, corresponding to 61.5% (748 - with imputation) and 72.3% (395 - without imputation) of the total. Women students correspond to 38.5% (469 - with imputation) and 27.7% (151 - without imputation) of the total students with ASD.

Regarding color/race, referring to the total number of students (unique data), the census indicated the primacy of white color/race, being: Yellow: 151,218 (1.46%); White: 3,769,987 (36.50%); Indigenous: 59,617 (0.58%); Brown: 2,350,409 (22.76%); Black: 592,584 (5.74%); Did not declare: 3,157,436 (30.57%) and Does not have the information: 246,072 (2.38%). This primacy is repeated in the data of students with ASD, being: a) with imputation: Yellow: 154 (13%), White: 454 (37%), Indigenous: 6 (0.49%), Brown: 363 (30%), Black: 140 (12%), Student did not want to declare: 94 (7.7%), Does not have the information: 6 (0.49%); and b) without imputation: Yellow: 6 (1.1%), White: 277 (51%), Indigenous: 1 (0.18%), Brown: 165 (30%), Black: 37 (6.8%), Student did not declare: 57 (10%) and Does not have the information: 3 (0.55%).

In regional terms, Figure 1 illustrates the distribution of students with ASD in the five regions of the country. For this variable, the use of data with imputation indicated a considerable change to the distribution

between the regions, changing the region with the highest number of students with ASD from the Southeast to the Northeast.

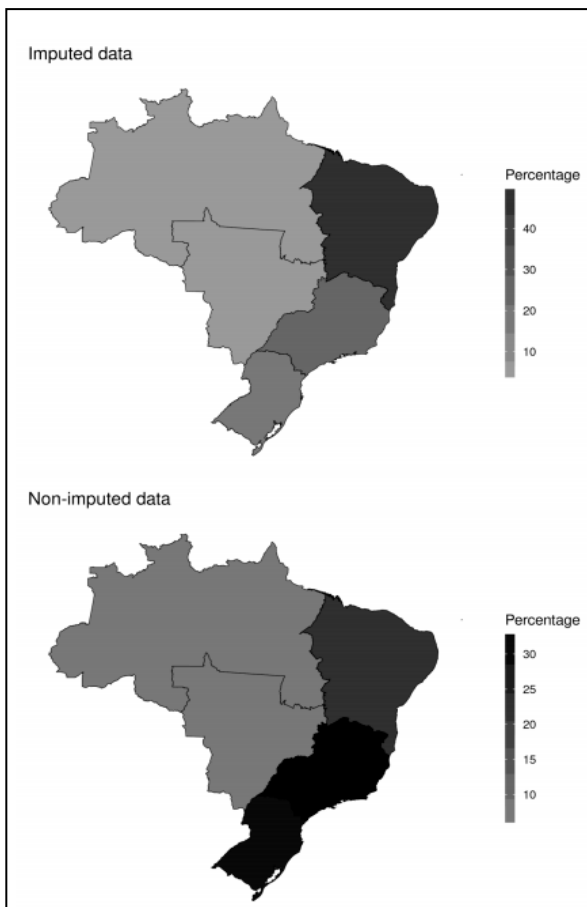
When considering the distribution per State, again the data with imputation were different from data without imputation, as can be seen in Figure 2. With imputation, the largest number of students with ASD was located in Bahia, with 36% of the total (422 students), but this state has only 10 students with ASD (1.8%) in the 2016 census data. Without imputation, the state with the highest proportion of students with ASD was Piauí (81 students, 15%).

The mean age of higher education students enrolled in 2016 is 27.6 years ( $SD = 8.45$ ). For students with ASD, information about age is shown in Figure 3. There was a small difference of two years in the mean age between data with imputation (27 years old) and without imputation (25 years old), accompanied by a small change in standard deviation. The functional form, with positive asymmetry, remained relatively equal between the two sets of data.

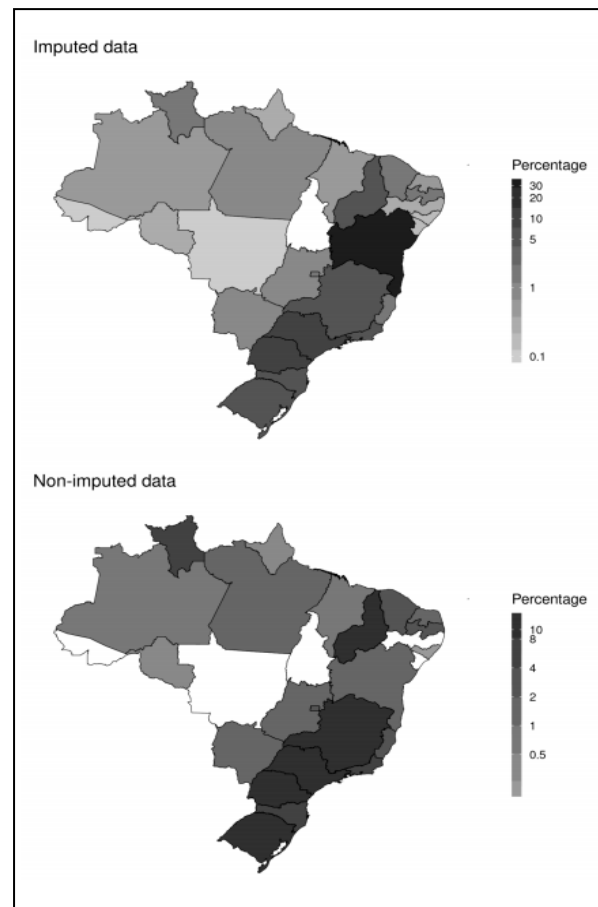
## DISCUSSION

To analyze the research data, we start from the premise that autism is a characteristic of human diversity, not understood as a problem to be solved, but as a characteristic whose intersection with several other bodily, social characteristics, etc., form the subjectivity of the individual. In this sense, it is important to know the different social markers that constitute students with ASD who access higher education and their intersections in the relationship with the environment, which can create or strengthen inequalities and result in barriers in the academic process.

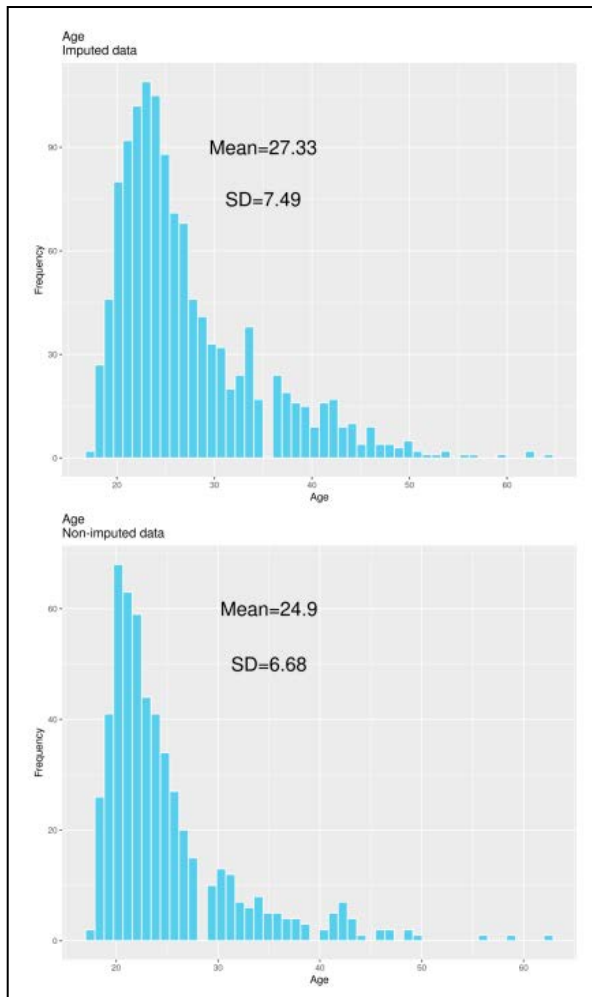
In the data obtained by mapping the profile of students with ASD enrolled in higher education in 2016 through the INEP Census (INEP, 2017), even with all the legal support that determines access for students with disabilities and giftedness to higher education, as mentioned in the introduction to this article, the number of this public in the academy is still low, corresponding to 0.43% of the total students enrolled in 2016, and of these 0.005% self-declared with ASD (INEP, 2017).



**Figure 1.** Map of the Regions of Brazil indicating the proportion of the total students with ASD in each region: (a) with imputation; (b) without imputation.



**Figure 2.** Map of the States of Brazil indicating the proportion of the total students with ASD for each state: (a) with imputation; (b) without attribution.



**Figure 3.** Histograms of the age distribution (with mean and standard deviation) of students with ASD in higher education: (a) with imputation; (b) without imputation.

When considering the imputation method used in data collection, there is a considerable increase in enrolled students, which is not reflected in the percentage of enrollment of these students. It is necessary to clarify that there is a weakness in data worked on in the analysis. The discrepancy of data without imputation in relation to data with imputation does not give evidence for affirmations in relation to the reason that leads to this divergence, but it allows to question that it is necessary a greater control and orientation of HEIs on this filling and improvement in the analysis to obtain more reliable data.

Regarding the entry of students with disabilities in higher education, Silva (2016), when comparing the evolution of enrollments in the university between 2010 and 2014 through the Higher Education Census provided by INEP, noted that, although still incipient (representing 0.43% students in higher education), there was a significant advance in the access of people

with disabilities in higher education, expressed by the increase from 20,287 to 33,377 in five years. This meant an increase of 64.52% compared to the 22.57% increase in the general public that accessed the university during this period. This denotes a gradual insertion of students with disabilities in higher education, but the gap with regard to their university inclusion still stands out, less than 1% general population enrolled in higher education (Silva, 2016). It can be said that this gradual insertion was the result of policies aimed at accessibility, such as the Accessibility Program in Higher Education (MEC, 2008). However, inclusion policies need to be evaluated, improved and expanded.

Regarding the age of entry of students with ASD, it is notable that they access higher education later than neurotypical students<sup>1</sup>. The fact of facing barriers to school entry since basic education is reflected in the postponement of entry to higher education, in addition to this, entry barriers as inadequate tests and environment.

Regarding the sex of students, the proportion of men and women enrolled in higher education in 2016 (unique data) corresponds to 56.09% (5,792,709) females and 43.91% (4,534,614) males, contrary to the proportionality of students diagnosed with ASD enrolled in the same year, since the majority are male. This data agrees with the records that indicate that boys with ASD are the majority. Data recorded by APA (2014) bring the information that the proportionality of gender prevalence in people with ASD is 1: 4, that is, one girl for every four boys with ASD. However, data presented in this research differ from the 1: 4 ratio, since, when considering the data with imputation of students with ASD enrolled in higher education in 2016, the ratio is 1: 1.59 (1 female student for every 1.59 male) and the data without imputation is 1: 2.6 (1 female student for every 2.6 male).

Although in research results, the majority of men are found in the population with ASD, this is questioned by other studies that point to a tendency to ignore the diagnosis or a mistaken diagnosis when referring to the female sex. An example is the study by Dworzynski, Ronald, Bolton and Happé (2012, p. 792), in which they state that “in the absence of additional intellectual or behavioral problems, girls are less likely than boys to meet diagnostic criteria for ASD with equivalently high levels of autism traits”, and this fact can bring “genuinely better gender bias in diagnosis or adaptation/compensation in girls”. Dean, Harwood and Kasari (2017), in research on social behaviors in children with ASD related to gender, reported that girls are prone

<sup>1</sup> Neurotypical (NT) is the person who has “a neurocognitive functioning that fits the dominant ‘normal’ social patterns” (Walker, 2014. n.p.).

to “camouflage” their ASD symptoms, imitating social behaviors to face challenges. Although the camouflage seems protective at first, it makes the diagnosis and therefore support for the intervention difficult.

Saxe (2017, p. 157) understands that, in a qualitatively different experience from men, women with disabilities are at a disadvantage because of the following issues: extremely low rates of employment, domestic violence, sexual assault, among others, and that women with developmental disabilities “are often victims of unspeakable abuse”. The author argues that women with ASD have three identities, which contribute to the experience of barriers: 1) being female, a gender that faces more obstacles and subjugation; 2) have disabilities, in a world where most people do not have and live in an asymmetrical power relationship with their peers, thus facing several obstacles to be fully included in their communities; 3) being women with autism, since they are the minority in research, in research-based practices and the community of people with ASD, to a large extent, focuses on males. This causes women with ASD to be triple oppressed.

A large part of social policies for the promotion of equality, which mention socially discriminated categories such as gender, do not include disability in the debate and crossing with other categories. In accordance with this finding, Cerchiarri and Paganelli (2018) report that the UN Committee on the Rights of Persons with Disabilities (CRPD) when considering that, in general, policies for women do not mention disability and policies aimed at disability have the same stance on the issue of gender and recognizing the low impact of Article 6 of the Convention on the Rights of Persons with Disabilities, which deals with the rights of girls and women with disabilities, launched in 2016, a complementary document entitled *General comment No. 3 (2016), Article 6: Women and girls with disabilities*” (UN, CRPD, 2016). This document aims to provide guidelines for reviewing and providing support for the establishment of policies and practices to guarantee the rights of girls and women with disabilities (Cerchiarri & Paganelli, 2018).

Thus, in terms of gender and disability, there was a greater number of male students compared to female students who access higher education. The reason that leads to this male primacy, we can hypothesize some explanations with that of considering the existence of an underreporting of women with ASD; or the historical-social dimension that gives more value to the education of boys than girls, consequently few are able to access higher education; or, still, for the character of greater vulnerability of women, so that they are not encouraged to occupy social spaces such as the University, etc. Further research focusing on this nuance would be necessary to clarify the reasons for this male primacy.

However, even in the minority, female students should be considered in their specificity and uniqueness. It must also be considered that discrimination in relation to women is a fact and can generate or intensify barriers in their access and permanence in the academic space.

Amanda Paschoal, artist, person with autism and activist on the agenda of the rights of people with autism, published on August 31, 2018 a lecture on YouTube, in which she questions the male primacy of autism at 1: 4 and discusses the invisibility of female autism. She warns about the lack of inclusion of women in research on autism and how this issue brought limited criteria for the diagnosis of autism, not considering the difference in the characteristics of women in relation to men, consequently the difficulty of diagnosing female people.

With regard to ethnicity/race, the research points out the primacy of white ethnicity/race of students in higher education, both of students with ASD and students in general enrolled in 2016 (INEP, 2017). This fact, verified in the research, is in line with the historical trajectory of oppression, discrimination and subjugation to which the Afro-descendant population is subjected, resulting in underreporting of ASD due to the difficulty of accessing health and barriers or impediments to access to higher education, among others. Junqueira (2007, p. 18) states that the university is “constituted as a space for training professionals with an overwhelming non-black majority, in a society that, historically, insisted on valuing a single civilizing component - simultaneously, white, male and heterosexual”. In this oppressive social context, “Affirmative Action Policies emerge as an instrument of historical reparation and promotion of racial equality for the population of black origin and who declare themselves as belonging to such a group” (Santos, 2007, p. 106). The primacy of entry of white ethnic students, denotes that even with the implementation of Law 12711/2012, known as the “Quota Law”, the result of an affirmative action movement that tries to correct the inequality of opportunities, still the inequality remains for the “non-whites”, deserving greater investment in this agenda.

Regarding the distribution of students with ASD per region, when relating to the Brazilian regional population (IBGE, 2017), the largest number of students with ASD enrolled is not concentrated in the most populous region (Southeast), but in the second region with the greatest number of inhabitants (Northeast).

Discrimination in terms of ethnicity and regionality is present in various social sectors, as observed by Paschoalino Silva and Santos (2017, p. 52), who claim that “being white and living in the Southeast (to the detriment of being black and living in the Northeast) increases the salary of both genders”. However, the “average hourly wage of men is higher than that of

women and the total difference between genders is 13%, favoring men”.

All these social markers of difference such as gender, class, ethnicity, among others, in the intertwining with the disability, provoke a unique experience for the person who lives in a discriminatory and oppressive society. This crossing of different social markers of difference with disability, which puts people at a social disadvantage, also impacts on the educational level, in the construction of subjectivities of students with disabilities. Liasidou (2013, p. 1.) states that “disablism forms part of an intricate web of social conditions that subjugate certain forms of ‘student-subjects’ and create compounding forms of oppression and exclusion that need to be addressed through relevant education policy and practice”.

In order to fill the gap still existing with regard to the university inclusion of students with autism, it is necessary, in addition to government and institutional actions, to monitor and evaluate the fulfillment of access and permanence policies, enabling higher education a space that welcomes all students.

### FINAL CONSIDERATIONS

Inclusion as a consequence of the process started in Basic Education becomes a political banner in the legislation and in the policy of affirmative actions, expressed in decrees, ordinances and laws to guarantee the access and permanence of people with disabilities in Higher Education institutions. Brazil, a country that stands out for the number of legal contributions that guarantee the right of people in situations of vulnerability, lives the contradiction of failure to enforce basic rights for, among other reasons, financial cuts in health, education and other sectors responsible for ensuring compliance with these rights. In this context, conservatism, both political and social, promotes prejudiced, homophobic, racist, ableist attitudes and makes them something natural and in the struggle with resistance groups, several of which with the protagonism of people with disabilities, black women, women with disabilities; activists fight for the Human Rights agenda.

It is important to point out that government laws and actions are constituted in accordance with the current political culture and the degree of organization of civil society, and thus, there may be advances or setbacks in guaranteeing the rights of people with disabilities.

When mapping the profile of students with ASD in higher education, there is a weakness in the official data available. This leads to the reflection on the commitment, the process and the control in data construction. Although with this limitation, the research consistently brings the characteristics of the sociodemographic profile of students with ASD, which

at its intersection may produce situations of inequality to a greater or lesser degree and barriers of access and permanence in higher education. These aspects should be considered when thinking about public policies and affirmative actions, as well as actions aimed at including these students.

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