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Experiences of students diagnosed with autism at a Brazilian university

Experiências de estudantes diagnosticados com autismo em uma universidade brasileira

Experiencias de estudiantes diagnosticados con autismo en una universidad brasileña

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ABSTRACT

In recent years, there has been a modest increase in the number of autistic students enrolled in higher education. This is a challenging structure for these individuals, who have different ways of dealing with change, communicating, and interacting. This study, conducted at a Brazilian university, aimed to understand the reasonable adjustments that contribute to their success in higher education. The research, based on Norbert Elias' theoretical and methodological assumptions, investigated the challenges faced by 19 autistic students. The results indicate that most students were diagnosed in adulthood, which generates conflicting feelings of acceptance and identification with the condition of being a student with autism. Knowing that they are autistic has implications for their ways of participating in university life, prompting them to seek support that improves their relationships with professors and classmates. They experience a feeling of relief and self-acceptance of their condition, while at the same time, they fear being stigmatized as incapable. Due to stigmas, stereotypes and prejudices about autism, these students were reluctant to reveal their diagnosis, even though this was a prerequisite for accessing the support and support needed in the structure and organization of higher education. The students made some

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suggestions and criticisms regarding the support they received, highlighting the need for continuous improvement in the support system. Finally, we highlighted the need for research focused on women with autism.

Keywords: Autism; University education; Higher Education.

RESUMO

Nos últimos anos, houve um aumento tímido de matrículas de estudantes autistas no ensino superior, cuja estrutura é desafiadora para essas pessoas que possuem maneiras diversas de lidar com mudanças, de comunicar e de interagir. Este estudo investigou os desafios enfrentados por 19 estudantes autistas em uma universidade brasileira objetivando conhecer os ajustes razoáveis que contribuam para o seu sucesso no ensino superior. A coleta de dados ocorreu por meio de entrevistas semiestruturadas. A análise dos dados assumiu os pressupostos teórico-metodológicos de Norbert Elias como referência. Os resultados apontam que a maioria dos estudantes foram diagnosticados na fase adulta, o que gera sentimentos conflitantes de aceitação e de identificação com a condição de ser estudante com autismo. O conhecimento da condição de autista traz implicações nos seus modos de participar na vida universitária, impelindo a busca por suportes que melhorem as relações com docentes e colegas de classe. Vivenciam o sentimento de alívio e de auto aceitação de sua condição, ao mesmo tempo em que ressentem receio de ser estigmatizado como pessoa incapaz. Por conta dos estigmas, estereótipos e preconceitos sobre o autismo, esses estudantes se mostraram relutantes em revelar o seu diagnóstico, embora esse fosse o pré-requisito para acessar os apoios e suportes necessários na estrutura e modo de organização do ensino superior. Os estudantes anseiam por mais debates e informações sobre o autismo, principalmente na voz de pessoas autistas. Os estudantes fizeram algumas sugestões e críticas em relação aos apoios recebidos. Evidenciamos, finalmente, a necessidade de pesquisas focadas nas mulheres com autismo.

Palavras-chave: Autismo; Universidade; Ensino Superior.

RESUMEN

En los últimos años se ha producido un ligero aumento en la matrícula de estudiantes autistas en la educación superior, cuya estructura resulta desafiante para estas personas que tienen diferentes formas de afrontar los cambios, comunicarse e interactuar. Este estudio investigó los desafíos que enfrentan 19 estudiantes autistas para obtener ajustes razonables en una universidad brasileña que contribuyan a su éxito en la educación superior. La recolección de datos se produjo a través de entrevistas semiestructuradas. El análisis de los datos tomó como referencia los supuestos teórico-metodológicos de Norbert

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Elias. Los resultados indican que la mayoría de los estudiantes fueron diagnosticados en la edad adulta, lo que genera sentimientos encontrados de aceptación e identificación con el autismo. El conocimiento de la condición autista tiene implicaciones en las formas de participar en la vida universitaria, como la búsqueda de apoyo que mejore las relaciones con profesores y compañeros; sentimiento de alivio y autoaceptación de su condición y miedo a ser estigmatizado como persona incapaz. Debido a los estigmas, estereotipos y prejuicios del autismo en la sociedad, los estudiantes se muestran reacios a revelar el diagnóstico, lo que es un requisito previo para acceder al apoyo necesario para afrontar la estructura de la educación superior. Los estudiantes anhelan más debate e información sobre el autismo, especialmente de las voces de las personas autistas. Los estudiantes hicieron algunas sugerencias y críticas respecto al apoyo recibido y quedó clara la necesidad de realizar investigaciones enfocadas en mujeres con autismo.

Palabras clave: Autismo; Universidad; Enseñanza superior.

Introduction

The Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders DSM-5 defines Autism Spectrum Disorder (ASD) as a set of neurodevelopmental disorders characterized by difficulties in social interaction and communication and the presence of repetitive behaviours, activities, and interests and restrictive (APA, 2013).

The term Autism Spectrum Disorder (ASD) is commonly used in the medical field and is most often employed with a diagnostic purpose that emphasizes a person's cognitive and social deficiencies. Other terminologies such as Autism Spectrum Condition (Wright, Spikins, Pearson, 2020), Autistic person, Person on the autism spectrum, and Person with autism are used with a more positive bias about the differences and strengths of people diagnosed with autism (Kenny, 2016).

In recent years, the number of autistic students enrolled in higher education institutions has increased (Kim, Baker, 2022; Camalionte, Kondo; Rocha, 2021; Santos, 2020), which motivates research and reflections on the challenges and tensions experienced by these students at universities.

In 2011, the Brazilian Higher Education Census recorded 6,739,689 enrollments in higher education, of which 23,250 (0.34%) had some disability and

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68 (0.001%) were autistic students. Almost a decade later, there has been a modest increase in autistic students in higher education. The 2020 Census recorded 8,680,354 enrollments, of which 55,829 (0.64%) were students with a disability and 2,974 (0.034%) were students on the autism spectrum.

As of 2021, it is no longer possible to count autistic students based on census data. The National Institute of Educational Studies and Research Anísio Teixeira (INEP) started to adopt the category of Global Developmental Disorder (TGD), which refers to autistic students and students diagnosed with other conditions. In 2022, the Census recorded 9,444,116 enrollments in higher education, of which 79,362 (0.84%) had a disability, and 6,063 (0.064%) were indicated as students with TGD.

The increase in the number of students with disabilities at universities registered in the Census may be related to public policies recently adopted in Brazil. In recent decades, legal provisions have been created to increase the participation of socially disadvantaged groups in higher education, such as students with disabilities. The actions are aimed at public and private institutions. The Financing Fund for Higher Education Students (Fies) and the University for All Program (ProUni) stand out in the private sphere. In the public sphere, the Support Program for Restructuring and Expansion Plans of Federal Universities (Reuni) stands out the National Student Assistance Program (PNAES) and the Quota Law.

The arrival of autistic students at university can cause challenging situations for students, teachers, and the institution (Aguilar, Rauli, 2020). The university is an environment with a less rigid structure compared to primary education schools. The spaces where classes occur may change, and it is not uncommon for periods of idle time between class times, etc. This structural difference gives students more autonomy and requires them to manage their time to complete the tasks needed for the course. Furthermore, the university is a diverse space with many visual and sound stimuli. The characteristics of university can be challenging for autistic people who, in general, need a more structured routine and who have different sensory processing.

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Many factors mark the challenges and difficulties that autistic students face at university and that can contribute to dropping out of higher education, such as feelings of isolation, demotivation, disillusionment caused by frustration with the course or the university, the challenges of navigating social spaces; the lack of proactive support; misinformation about the institutional support offered; the lack of knowledge and understanding of the academic community about autism and the lack of knowledge about the diagnosis of these students when they enter the institution (Cage, Howes, 2020). There is also difficulty in accessing extracurricular activities, the fear of failing subjects, and challenges in regulating emotions (Lei, Russel, 2021).

It is necessary to consider that autistic students have many potentialities contributing to their higher education success. Casement *et al.* (2017) showed they are likelier to disclose their strengths. However, the university still needs to pay more attention to these points. Potentials can be underestimated by difficulties (Gurbuz, Hanley, Riby, 2019). To help autistic students succeed at university, it is essential to provide different types of support that meet the specificities of each student (Macleod *et al.,* 2018).

The creation of universities' accessibility centers was a significant step towards developing institutional actions that ensure the necessary support for the inclusion of people with disabilities. These centers are dedicated to removing physical, pedagogical, communicational, and informational barriers that may hinder the inclusion of students (Brasil, 2013). However, it's important to note that access to support at university is often contingent on disclosing the diagnosis, a process that can be fraught with tension (Macleod *et al.,* 2018).

The main objective of this work is to reflect on the challenges faced by autistic students in obtaining reasonable adjustments that contribute to their success in higher education. This objective leads us to question: **what barriers are faced by Brazilian autistic students in the search for support that promotes their inclusion at university?** Reflection on this issue demands the compression of the network of social relationships that autistic students participate in higher education institutions. This network comprises different

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groupings of people, whose relationships shape dynamic and complex arrangements that cannot be understood in isolation (Elias, 1994).

Understanding this network requires us to delve into the emotions that students experience in relation to their diagnosis, the tensions that arise from disclosing the diagnosis in the university setting, and the access to support that enables students to thrive at university. This understanding is crucial for fostering empathy and creating a supportive environment for these students.

Methodology

The research is anchored in the theoretical-methodological bases of figurational sociology proposed by German sociologist Norbert Elias. The sociology based on Elias's ideas criticizes exclusively theoretical scientific investigations (Leão, Landini, 2022) as reflections and research on human and social aspects cannot be reduced to static conditions.

The research takes a qualitative approach, as this type of research provides a deeper understanding of the behavior and experiences of autistic people (Bolte, 2014) and in figurational analyzes numbers are important, but "without the use of words as research instruments, the numbers remain silent" (Elias, 2000, p.59).

In the research we had the participation of 19 autistic students enrolled in various undergraduate courses at a federal university in the southeast region of Brazil. The involvement of students was essential to align the study with the emancipatory approach that moves away from the medical conception of disability. In the emancipatory approach, research gives voice to people with disabilities to address their needs, contributing to a more inclusive society (Stone, Priestley, 1996).

Norbert Elias' Sociology is aligned with the social model of disability, which assumes that society is organized in a way that excludes people with disabilities, making it necessary to identify and eradicate social obstacles (Oliver, 2013). In figurational sociology, the inability to live a whole life in society should not be attributed to the individual as he is not a *homo clausus*, that is, a self devoid of us (Elias, 1994).

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The research received ethical approval from the university[i], and all participants signed the Research Consent Form. The interviews took place between December 2022 and March 2023. All students who showed interest in participating in the research were accepted. A group of students preferred to conduct the interviews in person, and another opted for a virtual interview. The face-to-face interviews were carried out at the university, and the non-face-to-face interviews were carried out through Google Meet. The format of the interview was subject to the participant's choice. The interviews lasted an average of 1 hour, with the most extended interview lasting 4 hours and the shortest lasting 30 minutes. The interviews were recorded and transcribed. The transcripts were sent to the participants, who could delete or add excerpts from their statements.

In the interviews, a questionnaire was used containing open questions that addressed demographic aspects, the participants' relationship with the diagnosis, events before entering higher education, and the support provided by institutions. The students' reports contain powerful criticisms that can reverberate actions that contribute to improving the lives of autistic students at university (Chown *et al.,* 2017).

Characterization of participants

The study involved 19 autistic students, 10 men and 9 women, which is a proportion that is far from the prevalence of autism, whose ratio between men and women is close to 3:1 (Loomes, Hull, Mandy, 2017). To guarantee the anonymity of the participants, the identifiers Br1, Br2, and so on were used. Females are Br1, Br3, Br4, Br11, Br12, Br13, Br14, Br17 and Br18 and males are Br2, Br5, Br6, Br7, Br8, Br9, Br10, Br15, Br16 and Br19.

In general, the average age of participants is 24 years old. Male participants are younger, the average age was 22 years old. In the women's group, the average age is 25 years.

The participants in the study represent a diverse range of ethnicities. The majority, 47%, identify as white, while 32% identify as mixed race and 21% as black. These percentages, while not reflective of the general population, provide a rich and varied sample for our study. According to the 2022 Census by the

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Brazilian Institute of Geography and Statistics, 43.5% of the Brazilian population classify themselves as white, 45.3% as mixed race, 10% as black, 0.6% as indigenous, and 0.4% as having oriental traits.

Regarding marital status, all male participants are single. In the group of women, 3 students are married, representing 33% of those interviewed.

When examining the socioeconomic status of the participants, it becomes evident that a significant portion is living in conditions of vulnerability. 37% of the participants have a monthly income of less than 1 minimum wage, 16% have a monthly income of less than 2 minimum wages, 26% have an income of less than 5 minimum wages, 16% have earnings of less than 16 minimum wages, and only 5% have earnings above 16 minimum wages. This data underscores the need for targeted support for these autistic students at Ufes.

Tensions and feelings related to the diagnosis

Early diagnosis of autism, particularly in childhood, opens doors to health services and social benefits that significantly enhance the quality of life and future prospects of the individual. This includes the potential to pursue higher education (Souza *et al.,* 2018). Orrú (2018) strongly advocates for early diagnosis and interventions for autistic individuals, facilitated by multidisciplinary teams, to foster their autonomy. Therefore, if the autistic student receives the diagnosis at a younger age, this diagnosis brings greater well-being and quality of life (Oredipe *et al.,* 2023).

Even when the diagnosis is received in adulthood, it can still have significant positive impacts on the individual's life. This includes the opportunity to reframe the past, construct an autistic identity, and foster a sense of belonging to a community (Lilley *et al.,* 2022).

Research by Olivati and Leite (2019) on the inclusion of Brazilian autistic students revealed that late diagnosis can significantly impact the provision of support to students. The absence of this support was found to affect the academic performance and university life of the students in the study during their undergraduate studies. However, becoming aware of autism, even if late, can lead to relief, self-acceptance, and a better understanding of one's place in the

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world (Huang *et al.,* 2020). This awareness can help individuals seek appropriate support and positively impact their postgraduate studies (Olivati, Leite, 2019).

The early diagnosis of autism is strongly linked to the male gender, as the tools used for diagnosis adopt a male pattern (Fusar-poli *et al.,* 2022). This fact results in a barrier for women to be diagnosed early (Lockwood Estrin *et al.,* 2021) leading to late or incorrect diagnosis. Women, when compared to men, are less likely to demonstrate restricted interests (Loomes, Hull, Mandy, 2017) and are more adept at masking their social and communicational difficulties, that is, at using strategies and behaviors to deal with the social world (Cook *et al.,* 2021). Thus, Huang *et al.* (2020) recommend that health professionals, when caring for women, take a more sensitive stance towards atypical autistic traits.

When analyzing the students' statements about access to diagnoses, it was found that 26% were diagnosed in childhood and all those who were diagnosed early were male. Four students reported having received the diagnosis before the age of 10 and they are boys who demonstrated difficulty with eye contact during the interview, stereotyping, more reserved body language and some used language in a very objective way and others in a more elaborate and lengthy way. One student indicated that he received the diagnosis at 12 years of age. He had no difficulty with eye contact, he is very communicative and outgoing, however some stereotypies were noticeable.

The results indicate that 74% of students received the diagnosis as adults. It is possible to separate it into some groups: I) people with comorbid conditions distinct from autism; II) students who discovered that they were autistic people, when a relative was diagnosed; and III) people who have some difficulty related to mental health that led them to seek medical help. Table 1 correlates gender, age and how late the diagnosis was.

Table 1: Late diagnosis

GROUP	IDENTIFICATION	SEX	AGE IN 2022	AGE AT DIAGNOSIS	OBSERVATION
	Br6	Male	26	25	Fragile-X Syndrome

I	Br11	Female	38	38	Intellectual Disability
	Br18	Female	20	18	Epilepsy with seizures
II	Br5	Male	19	18	Son of an autistic woman
	Br14	Female	20	19	Sister of an autistic person and was diagnosed with ADHD since childhood
	Br17	Female	30	30	Mother of an autistic boy and was diagnosed with Bipolar
III	Br1	Female	20	17	Learning difficulties in secondary school
	Br2	Male	18	17	Learning difficulties in achieving the national exam, pre-required to access higher education
	Br13	Female	22	18	Panic attacks related to choosing a higher education course
	Br3	Female	32	31	Sensory Overload: Migraines
	Br4	Female	22	21	Depression
	Br12	Female	22	20	Depression
	Br15	Male	23	20	Depression
	Br16	Male	19	18	Anxiety and stress

Source: Prepared by the author

The mental health conditions or psychiatric disorders that underlie autism can sometimes obscured the process of diagnosing autism (Lai; Baron-cohen,2015); however, in the present study, the opposite occurred. The narratives of the students in group I showed that some mental or psychiatric health conditions covered autism. Students with Fragile-X Syndrome (Br6), Intellectual Disability (Br11), and Epilepsy with seizures (Br18) have been

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monitored by psychiatrists since childhood and were only recently diagnosed with autism.

Student Br18 has epilepsy with recurrent seizures that require frequent medication. The student reported that her mother noticed her autistic traits but attributed them to the chronic use of drugs. The isolation of the pandemic triggered a trip to the psychiatrist, who, after some tests, revealed autism.

Student Br6 has fragile-X syndrome, intellectual disability, and a neurobiological disorder that affects his speech, which characterizes him as a person who stutters. The student was diagnosed with autism due to recurring crises caused by the University's enrollment system that resulted in self-harm. The system used the term rejected enrollment, which was a trigger for the student to self-harm. After the episodes, the University changed the term to rejected enrollment.

Student Br11 also has an intellectual disability and is monitored at the Psychosocial Care Center (CAPS). The student reported that she had recurring anxiety attacks when traveling to the University. This situation was communicated to her psychiatrist, who, after some tests, diagnosed student Br11 with autism.

Students Br6 (Fragile-X Syndrome), Br11 (Intellectual Disability), and Br18 (Epilepsy with seizures) have had access to therapists, psychologists, and psychiatrists since childhood but were not diagnosed as autistic in childhood. One possibility is that the known mental or psychiatric condition was the focus of health professionals, and, in some ways, such conditions may have overshadowed the autistic traits.

Autism can be considered a condition associated with genetic and environmental causes. In genetic terms, it is highly heterogeneous, and heritability is estimated to vary from 40% to 80% (Rylaarsdam, Guemez-Gamboa, 2019). Many adults and their families tend to do extensive research on the internet about autism during the diagnosis process (Lewis, 2016).

Student Br5 is the son of an autistic woman, student Br14 is the sister of an autistic person and Br17 is the mother of an autistic child. The students began

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researching the characteristics of autism and, in the process, identified with the condition. When they sought medical help, they received the diagnosis.

Many adults do not know that they are eligible to receive an autism diagnosis (Robison, 2019). It is possible that, when seeking medical help, health professionals carry out a more holistic investigation and discover the diagnosis. This was the case for the students in group III, who are listed in Table 1.

Students Br1, Br2, and Br13 were finishing high school when they began to have anxiety attacks related to the uncertainty of entering University. The three students sought therapy on the recommendation of a family member. Student Br13 illustrates this moment by saying, "My mother thought I was having some personal issues, and she thought it would be a good idea to go to therapy. I had a lot of anxiety. I never thought I had some kind of diagnosis."

Students Br3, Br4, Br12, Br15, and Br16 underwent similar processes. However, these students were already at University. Student Br3 reported that upon entering University, her headaches became more frequent and intense. In therapy she discovered difficulties with sensory processing. After some time, she was diagnosed with autism.

Students Br4, Br12, and Br15 reported academic, emotional, and sensory overload followed by physical exhaustion, which resulted in depression. Student Br16 reported that:

> I was having a lot of problems, depression, and other things. I ended up having to drop the course in the 2nd semester. I couldn't keep up with my studies. I was no longer studying, I was just doing the minimum [...] In therapy, I discovered that I had always had depression. [...] I'm undergoing treatment (student Br16)

Student Br15 attributes the difficulty of maintaining focus on studies to the pandemic. These difficulties led her to therapy and after a period of investigation, she was diagnosed with autism. The student claims that during remote learning, she was unable to concentrate. She said: "I discovered autism because it was a difficult time for me to stay focused on my studies."

In this study, only five students were diagnosed early, all of whom were male. This aligns with findings from other studies, which suggest that the

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diagnosis of autism in childhood is more common among males, as diagnostic tools are often designed with a male pattern in mind (Fusar-poli *et al.,* 2022).

Students B7, B8, B9, and B10 are boys who fit the stereotypical view of autistic individuals, such as difficulty maintaining eye contact, stereotypies, reserved body language, and objective or verbose verbal language with an unusual tone. The four students received the diagnosis before they were ten years old. Student Br19 was also diagnosed in childhood but has no difficulty maintaining eye contact and has fluid communication, although he presents some stereotypies.

Students Br17 and Br18 spoke about the power of diagnosis in self-understanding and self-compassion. And how the diagnosis brought a feeling of relief and liberation (Lewis, 2016). The students mentioned:

> Discovering autism, a lot of things made sense. All the difficulties I have. Communication problems. Not having friends. It was all very difficult. Everything started to make sense. The diagnosis helped me make sense of my story. (Student Br17)
> The diagnosis came as a liberation [...] I didn't understand why I acted like this, why I was different, why I couldn't do the things that others did. So when my diagnosis came, I freed myself. (Student Br18)

Autism awareness provides coping strategies, as highlighted by student Br3: "The diagnosis helped me manage my crises better" and by student Br15 who stated: "now that I know that my mind is atypical, I started a different approach. [...] I am improving my communication. Now I am aware of this social mask that I wear."

Reframing the past and analyzing the facts and events of your life through the lens of autism can bring, after a specific time, positive feelings; however, at the beginning, there is a feeling of sadness and frustration due to the awareness that many situations experienced could have easily been resolved and understood if the diagnosis was known by the students (Leedham *et al.,* 2020). Student Br14 reported these feelings of sadness and hesitation when discovering autistic people: "It took a while for me to accept it. So far I'm adapting to the idea. So far I haven't accepted it 100%. There are a lot of things I have to discover about myself. There are a lot of things about me that I kept hidden to mask."

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None of the female students in this study received the diagnosis in childhood. The literature explains that many women on the spectrum are not diagnosed early as they are more adept at masking their social and communication difficulties, that is, at using strategies and behaviors to deal with the social world (Cook *et al.,* 2021). In many cases, they receive an incorrect diagnosis (Lockwood Estrin *et al.,* 2021), such as student Br17, who received a diagnosis of bipolarity, and Br3, who received a diagnosis of anxiety, then depression, later bipolarity, and finally, autism.

Social masking is the action, conscious or inconsistent, carried out by any person to hide or alter some aspect of themselves in order to avoid harm (Miller *et al.,* 2021). To mask the person, they need to control their impulses and passions, as demonstrated by Elias (2011) when taking absolutist states as bases in the study of the civilizing process. In the absolutist court, people lived peacefully; they observed and were constantly observed so that their behaviors converged to a specific pattern in the process of policing their own behavior (Brandão, 2009).

According to the author, the civilizing process involves "individual self-regulation of momentary behavior, conditioned by affections and drives, or deviations from these impulses" (ELIAS, 2006, p.21). Self-regulation is an individual's conscious action to hide or change common behaviors, avoiding shame or embarrassment. This policing of one's own behavior reveals itself as social masking. Over time, the awareness of masking ceased to exist, and the custom became so naturalized in the individual's personality that society considered it natural. When masking, standard behavior is reproduced; there is no tension to generate reflection and change. Therefore, social masking, which is the action of reproducing even superficially the dominant neurotypical pattern of behavior (Hull *et al.,* 2020), does not contribute to the construction of an inclusive society that tolerates and respects different ways of being in society.

Huang *et al.* (2020) recommend that health professionals when caring for women, need to be more sensitive to atypical autistic traits. Student Br1 indicates that, since childhood, her friends noticed autistic traits in her, but her diagnosis was only obtained when she was 17 years old. She said "since I was 12 years

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old, my friends were already suspicious. They knew something was strange. They knew I was different. It became an inside joke between us. They said: you are autistic. We laughed. In the end, I was."

Disclosure of the diagnosis

Revealing the diagnosis of autism is a complex decision, imbued with reluctance and caution due to the positive and negative implications that this disclosure can cause (Togher, Jay, 2023).

In the analysis of the student's statements about revealing the diagnosis in this research, it is clear that 11 of the 19 students do not mind revealing the diagnosis, 3 reveal the diagnosis but with some fear, and five prefer to keep the diagnosis secret. Students are more likely to reveal the diagnosis, 7 women reveal the diagnosis to teachers or colleagues, while 7 men have reservations about revealing the diagnosis.

Concealing the diagnosis may be related to negative experiences in the past, fear of discrimination or judgment, the fear of receiving different treatment, and the stigmatization and labeling related to autism (Cai, Richdale, 2016). Participants in this study who prefer to keep the diagnosis confidential claim to be in the process of self-acceptance and understanding of the diagnosis (Br4), declare to have suffered bullying in basic education (Br5), said to have been associated with the stereotype of autistic people who have intellectual disabilities severe (Br7), they show feelings of inadequacy and do not believe they need support (Br13) and they say they have experienced the stigma of being different in a society that marginalizes what is different (Br16). Student Br16 explained:

> I could tell you that I'm not ashamed of being autistic, but that would be a lie. I try to push it away, I try to tell myself: no, I'm not ashamed! Deep down I know I have it. I think it's because of what society imposes. Normal is good. If you're out of the norm, you're strange; because of that, I'm ashamed of being autistic. I think, and I'm pretty sure when I say that, every autistic person wants to appear normal, because it's very uncomfortable not to be normal. It's very uncomfortable to be judged for everything you do. You explain: because I am autistic. And the person moves away from you, because they see you as crazy (Student Br16)

Concealing the autistic identity can cause psychological suffering since "you cannot separate autism from the person, since autism is a way of being, a specific way of functioning of the subject" (Oliveira; Abreu, 2019, p. 82). However, by revealing their autistic identity, the person assumes the "risk of having their uniqueness annihilated or of being seen and understood only based on the biological determinants of their clinical condition, promoting the erasure of multiplicity and individual differences" (Oliveira, Abreu, 2019, p. 82)

In Brazilian studies that discussed the experience of autistic students at university, it is clear that students do not reveal their diagnosis for fear of being evaluated differently than their peers (Costa, Marin, 2017); or due to fear of prejudice involving autism (Silva, Moreira, 2022); or for fear of judgments such as being considered poor or worthy of pity (Olivate, Leite, 2019); or because they did not believe they needed support or help at university (Ferrari, 2016).

The fear of stigma related to the diagnosis can be understood by the asymmetry of power between people and groups in interrelationships. Not infrequently, in the interrelationships between neurotypical people and autistic people, the latter, according to the sociodynamics outlined, take the "place" of outsiders.

The power imbalance between these groups reflects Elias's (2000) concepts of the established-outsider relationship, which explains how dominant groups (the established) hold power over subordinate (the outsiders).

In fact, in societies like ours, in which a specific mode of communication and interaction is consolidated to the point of constituting a reference for what is "acceptable" or "more civilized", guaranteeing them a feeling of belonging and self-recognition as people better, endowed with a group charisma, holders of an ideal of us, the others (outsiders) have a place of resignation, marked by the acceptance of their "lesser" condition and the stigma of outsiders. It is important to note that this stigma produced in this interrelationship imposes itself, penetrating the self-image of the outsider group and making them believe and feel inferior.

It is important to note that the established-outsider relationship is not static; there may be changes as a result of tensions and conflicts between the two

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groups, which may contribute to changes in the balance of power between them (Elias, 2000). In particular, the neurodiversity movement has defended the respect and guarantee of social rights for people who do not have neurodevelopment, which is considered typical in our recent societies (Dwyer, 2022).

The group of students who revealed the diagnosis with reservations reported that they are indifferent to the diagnosis (Br2), seek sensitive, welcoming, and helpful people to reveal the diagnosis (Br18), or are looking for some type of support (Br19). Student Br18 explained:

> I tell some teachers that I am autistic. The ones that I feel will be more accepting or, for example, when I have a lot of difficulty with noise in class, then I need to use my headphones. Generally they accept. They just don't ask if there is anything they could do to help me in the classroom. With colleagues, sometimes I say that I am autistic. There are people who say that I don't look autistic. As if autistic people have any face, right! (Student Br18)

Autistic university students are more susceptible to social exclusion when compared to other neurotypical students, as communication and social interaction take on striking peculiarities (Matthews, Goldberg, 2015). When the clinical label is known by students, they are more tolerant of the atypical behavior of autistic subjects (Brosnan, Mills, 2016). The diagnosis serves as a label, and its presence can reduce stigmatization by peers (Matthews, Goldberg, 2015).

In the speeches of students Br9, Br10, and Br11 about revealing autism, there is no emphasis, neither positive nor negative. Autism is treated neutrally as a characteristic that does not define them but that they possess, such as hair color (Botha *et al.,* 2020). Students Br9 and Br10 are already used to the support they received since basic education, and Br11 indicated that the disclosure of autism occurred as something bureaucratic when she entered the university, as her CAPS psychologist contacted the university to inform them.

Student Br1 is very friendly and expressive. All of her speeches are marked by good humor and positivity. She said she prefers to expose the diagnosis to avoid any discomfort in communication or interaction. Revealing the diagnosis can bring more acceptance and tolerance to the group in the face of

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communication and interaction barriers and also instigate changes in teachers' pedagogical practices (Fischer,2019).

Self-esteem is the characteristic that student Br6 conveys about himself in his speeches. He spoke with a tone of pride and resilience: "I am the first intellectually autistic person in the history of the course. I say that I am. I say that I am intellectually disabled and autistic." The student shows a feeling of belonging to both groups: autistic people and people who have intellectual disabilities. He makes it clear that the diagnosis is not incompatible with the ability to prosper in higher education, that is, to meet the expectations of society, which is mostly neurotypical (Botha *et al.,* 2020).

At university, revealing the diagnosis can be beneficial as peers' awareness of the diagnosis results in more positive responses to the peculiarities of the autistic student (Brosnan, Mills, 2016). In Fischer's work (2019), the autistic student revealed his diagnosis to the class, and this brought more acceptance and tolerance from the group in the face of the communication and interaction barriers he presented. Also, the disclosure of the diagnosis generated changes in the pedagogical practices of the teachers who worked in the class.

In several Brazilian studies involving autistic university students, the exposure of the diagnosis occurred to a group of specific people, such as teams from accessibility centers or centers and to some teachers (Olivate, Leite, 2017; Donati, Capeli, 2018; Aguilar, Rauli, 2020; Silva, Moreira, 2022). The motivation for making the autism diagnosis public was access to university support (Silveira *et al.,* 2020; Leonel *et al.,* 2022; Oliveira *et al.,* 2022) or the creation of emotional bonds after some time (Oliveira, Abreu, 2019).

Access to support at the University

It is important to consider that access to assistance offered by support centers and units for people with disabilities at universities is carried out when the diagnosis is formally revealed through the report (Cai, Richdale, 2016).

To enter a Brazilian public university, autistic students must participate in the National High School Exam (Enem), a nationwide test that takes place annually at the end of the year. When registering for Enem, the student can request some adjustments, such as additional time, a special room, reading assistance, among others.

Student Br2 highlighted that Enem influenced him to seek the report and declare his autism to obtain the adaptations to which autistic students are entitled, however student Br2 realized that the adaptations did not help him, as much as he had imagined.

> I got the diagnosis last year to take the Enem. I got the diagnosis to have 1 hour more in Enem. [...] I want to have this convenience of having 1 extra hour. I took the test. Damn! I realized that I need more time to do some things that other people do in less time. [....] The Enem test is an extremely exhaustive test. A test that borders on unhealthy. [...] I didn't use the additional time I had. [...] What would really help in terms of testing, in the case of Enem, would be a test done with questions prepared in a different way. More objective questions. (Student Br2)

Students Br12 and Br13 also struggled to gain admission to University on their first attempt at the Enem. Similarly, Student Br10 mentioned that he was unable to enter the University the first time he took the Enem test. One of the student who has an intellectual disability shared: "I had to take the Enem test several times. The test is torturous, not because of the questions but because the test is very long. The people who were with me supported me. I had good support, but the test lasted more than 6 hours. So it's very tiring for me."

When autistic students are informed of their condition at the time of enrollment, the University's Accessibility Center is informed about the student's presence at the institution, and a welcome meeting is held so that the University is aware of the demands for support and adjustments that the student needs.

Student Br2 stated that Enem influenced him to seek the report and declare his autism with a view to obtaining the adaptations to which autistic students are entitled. According to student Br2:

> An email arrived about reception [...]. I went there. They told me: when you want something, show up. It was an individual conversation. They talked about the core, about what I can have. They said that if I needed anything, I should get in touch. They said they would contact the course coordinator, and the course coordinator would communicate with the teachers about autism. They talk about the right to extension of tests, work, deadlines [...] (Student Br1)

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Students Br2, Br7, Br15, and Br16 mentioned that they are aware of the center's but have never visited it. Students Br5, Br11, Br17, and Br18 did not know about the existence of the nucleus. Student Br13 complained about the lack of publicity about the center at the University: "it needs to be widely publicized. I only found out about the nucleus now. I'm in seventh period. It's only now that I've been informed [...]".

Students also indicated the need for architectural and behavioral changes to occur at the University to improve their experience in space. Student Br12 asked that public servants take a closer look at people with disabilities:

> Everyone who works in a public institution has to understand how to treat people with disabilities. It's a question of empathy, of trying to put yourself in someone else's shoes and seeing that some situations are complicated. They need to have a different look at people with disabilities. I think training is important. Training of professionals. (Student Br12)

Students Br8 and Br14 suggested increasing investments in the accessibility center in order to optimize the support and services offered, making the space more powerful. She mentioned that it is necessary to have specialized people. People who know the specificities of autism:

> I was in class. I had an anxiety attack. I left class and went straight to the core. It was late at night but it was still open. The person who helped me didn't know the basics about autism. The psychologist did not know how to deal with the situation. The psychologist said she needed to leave. I was frustrated. I went home and it got worse (Student Br14)

Student Br3, Br17 said that she would like institutional actions to be less bureaucratic. Student Br13 suggested that the coordinators publicize the existence of the nucleus from the first period. And student Br4 highlighted that it is important to control dropout rates among autistic students. For her, the center could monitor the academic situation of autistic students more closely.

Students Br6, Br9, and Br10 mentioned that the accessibility center provides monitors to support them during classes. Student Br10 said: “I have had two monitors since I joined [...] They are good, they are excellent. Support is significant because it makes a difference to us. It is not moral support, it is more concrete support, support that makes a difference. It's the help we need.”

Student Br4 expressed the desire for the university to promote actions that encourage dialogue about autism.

> I wish there was more dialogue about autism. There are few people talking about autism at university. [...] I don't see any autistic person talking about autism. I wish there was more dialogue about this too. I think students need this. (Student Br4)

University students enrolled in public institutions can request student assistance, which is an assistance action aimed at students in situations of socioeconomic vulnerability, including students with disabilities (Assis, 2013).

Student assistance is typically takes the form of financial support to help students stay enrolled, including free tuition, access to university dining services, teaching material, language courses, and childcare support for student with young children. Students Br5, Br6, Br8, Br9, Br10, Br11, Br12, Br17, Br18 and Br19 receive various forms of assistance due to their socioeconomic vulnerability.

Final Considerations

This article offers a unique perspective by exploring the experiences of 19 autistic students enrolled in a Brazilian federal university. The article examines the processes of acceptance and disclosure of the autism diagnosis, as well as access to support at the university. Notably, the student profile differs from previous research, with the number of women almost equal to the number of men.

Most students received their diagnosis in adulthood, often triggered by events that caused psychological distress and prompted them to seek medical help. They disclose their diagnosis to address communication challenges, improve social interactions, and gain access to university support and benefits. A smaller group of students do not disclose their diagnosis due to fear of stigmatization and prejudice.

Regarding university support, some students are aware of their rights and make use of available resources, while the majority choose not to. Those who do utilize support highlight the usefulness of monitors, psychological assistance, deadline flexibility, and alternative assessment methods.

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The students expressed a strong desire for increased dissemination of autism-related information at the university. They suggested that having autistic individuals openly discuss their experiences would be particularly beneficial. Additionally, a group of students, facing social vulnerability, reported challenges in accessing social benefits, that could potentially help them remain at the university for longer.

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Notes

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[i] Process number 5744322 (Número do parecer) can be verified on the website https://plataformabrasil.saude.gov.br/login.jsf;jsessionid=VFiL8WdLKibxbpScRh1e+tYK