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Access and permanence of people with disabilities in higher education: participation in the scientific academy as a form of political activism

Acesso e permanência de pessoas com deficiência no ensino superior: participação na academia científica como forma de ativismo político

Acceso y permanencia de personas con discapacidad en la educación superior: la participación en la academia científica como forma de activismo político

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Abstract: Brazilian education for students with disabilities has historically been characterized by an exclusionary process rooted in stigmatizing models of disability. This research aims to analyze the discourse of people with disabilities about their access and permanence in higher education. Employing a qualitative approach, the study utilized narratives interview with 16 participants. The analysis was based on discourse analysis from the historical-cultural psychology perspective. The results point to the presence of barriers to accessing and remaining in undergraduate and particularly, in graduate programs. Additionally, markers of difference, such as race and class, continue to impact university access, emphasizing the necessity for public policies considering these aspects.

Keywords*:* People with disabilities. Public policy. University education. Qualitative research.

Resumo: A educação brasileira para estudantes com deficiência foi marcada por processos de exclusão pautados em modelos estigmatizantes de compreensão da deficiência. O objetivo desta pesquisa foi analisar os discursos de pessoas com deficiência acerca do seu acesso e permanência ao ensino superior. Foi uma pesquisa de abordagem qualitativa. As informações foram obtidas por meio de entrevistas narrativas com 16 participantes e diário de campo e analisadas a partir da análise de discurso na perspectiva da psicologia histórico-cultural. Os resultados apontam para a presença de barreiras no acesso e permanência na graduação e especialmente na pós-graduação e para a intersecção da deficiência com raça e classe como um importante elemento a ser considerado pelas políticas públicas de inclusão.

Palavras-chave*:* Pessoas com deficiência. Políticas públicas. Ensino superior. Pesquisa qualitativa.

Resumen: La educación brasileña para estudiantes con discapacidad la marcó un proceso de exclusión basado en modelos estigmatizantes de comprensión de la discapacidad. El objetivo

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de esta investigación es analizar los discursos de las personas con discapacidad sobre su acceso y permanencia en la enseñanza superior. Una investigación con enfoque cualitativo que utilizó entrevistas narrativas con 16 participantes y un diario de campo y el análisis del discurso desde la perspectiva de la psicología histórico-cultural. Los resultados apuntan a barreras de acceso y permanencia en la graduación y especialmente en el posgrado, y por la intersección de la discapacidad con la raza y la clase como un elemento importante a ser considerado por las políticas públicas de inclusión.

Palabras clave: Personas con discapacidad. Políticas públicas. Enseñanza superior. Investigación cualitativa.

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Introduction

Brazilian education for students with disabilities traces back to the 19th century when initial efforts were made to establish educational opportunities for individuals with disabilities. However, these initiatives were largely influenced by stigmatizing perceptions of disability and were primarily driven by isolated undertakings within Non-Governmental Organizations, philanthropic institutions, as well as segregated classes within psychiatric institutions (JANNUZZI, 1985). These models of understanding disability were rooted in religious, charitable, and medical assumptions, which respectively associated disability with sin, pity, and individual impairment. Consequently, they contributed to perpetuating stigmatizing conceptions of disability. In contrast, the social model of disability acknowledges the interplay between physical impairments and social barriers, attributing the experiences of disability to the societal environment and its hindrances (DINIZ, 2007).

In the 20th century, there was a shift towards adopting less stigmatizing concepts in understanding disability. This shift was accompanied by the implementation of the Law of Guidelines and Bases (LDB), which aimed to facilitate the inclusion of individuals with disabilities in regular classrooms. Additionally, with the enactment of the Brazilian Constitution in 1988, there was a growing movement towards integrating people with disabilities into mainstream schools. The Declaration of Salamanca in 1994 further fueled discussions and efforts to promote genuine inclusion of students with disabilities. As a result, the participation of children with disabilities in regular schools was strengthened. In 2008, with the establishment of the National Policy on Special Education in the Perspective of Inclusive Education (BRAZIL, 2008), inclusive education became a viable possibility.

ISSN 8346
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The Convention on the Rights of Persons with Disabilities (CRPD) in 2009 and, more recently, the Brazilian Inclusion Law (LBI) in 2015, have served as instruments to safeguard the rights of individuals with disabilities, enabling their social participation in various domains, including education. In accordance with the CRPD, people with disabilities are defined as follows:

> those who have long-term bodily impairments of a physical, intellectual, mental, or sensory nature, which, in interaction with various barriers, can hinder their full participation in society on an equal basis with others (BRAZIL, 2009).

This concept was based on the social model of understanding disability and stems from the advocacy and political activism of individuals with disabilities (DINIZ, 2007). Public policies are necessary to ensure that teaching and learning processes occur from an inclusive perspective, with the dissemination of up-to-date and non-stigmatizing knowledge about disability. There is still discrimination against people with disabilities in various spheres, particularly in education, which hinders their full participation in society and is commonly referred to as ableism. Ableism is a

> network of beliefs, processes, and practices that produces a certain type of body (the normative body) that is constructed as perfect, typical of the species, and therefore essential and fully human. Disability is then framed as a diminished state of being human (CAMPBELL, 2001, p. 44).

Ableism underlies the challenges faced by individuals with disabilities in accessing higher education, characterized by a lack of pedagogical resources that support accessibility. In terms of quantitative data, the percentage of the population with disabilities aged 18 and above who have completed a higher education degree is approximately 5.0%, whereas in the population without disabilities, this figure stands at 17.0% (INEP, 2022).

According to data from the National Institute for Educational Studies and Research Anísio Teixeira (INEP), the number of students with disabilities in higher education has been increasing since 2003. Despite this growth, among university students, individuals with disabilities are still few in number. In 2018, the enrollment of students with disabilities represented 0.5% of the total student population in universities (INEP, 2022).

Only a small number of public and private universities have an enrollment of students with disabilities reaching up to 1%. Consequently, the enactment of Law No. 13,409 in 2016, which implemented quotas for individuals with disabilities in federal universities, serves as an important initial step towards addressing this issue (BRASIL, 2016).

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Participation in higher education extends beyond undergraduate students and encompasses graduate students and professors as well. The field of science serves society and holds immense potential for driving significant social transformations, ranging from technological advancements and the development of social indicators to the formulation of public policies.

In light of this context, a crucial question arises: how does access and retention occur in various instances of higher education (undergraduate, stricto sensu postgraduate programs, and faculty positions) for individuals with disabilities who identify themselves as activists? The interest in activists arises from the fact that public policies aimed at people with disabilities have been primarily shaped by the political struggles of disability activists. The context and issue were translated into the objective of analyzing the discourses of individuals with disabilities regarding their access and persistence in higher education.

Method

This is a qualitative research with descriptive-analytical objectives, of a cross-sectional nature, and it utilized the Narrative Interview technique grounded in historical-cultural references (BRUNER, 1991; CAIXETA; BORGES, 2017), aiming to highlight the meanings derived from the understanding of subjectivity as a historical-cultural process that is organized in narratives. Additionally, field notes were employed (CRESWELL, 2011). This article represents a subset of a broader research project focusing on different forms of political participation among individuals with disabilities, with specific data presented regarding participation in higher education. To this end, a theoretical and methodological framework was employed that integrates authors such as Vygotsky (2008) regarding the constitution of meanings and the process of thought and language production, with intersectional studies stemming from black feminism by authors like Kilomba (2018), and feminist disability studies by authors like Campbell (2001), Mello (2016), Moraes (2010), and Diniz (2007). This is an investigation that aligns with the conceptual perspective of the social model of disability, referred to as emancipatory research. Emancipatory research is a way of studying the phenomenon of disability that seeks to highlight the realities of oppression experienced by people with disabilities. Ultimately, it aims to overcome such oppressions by creating ruptures that allow for the transformation of the material and social conditions in which people with disabilities are embedded.

ISSN 8346
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Emancipatory research assumes a collaborative approach with people with disabilities (MORAES, 2010) and is linked to the historical-cultural perspective, aiming to investigate the meanings attributed by individuals with disabilities. It emphasizes that the research process should prioritize the perspective of the participants.

The snowball sampling strategy (BIERNACKI; WALDORF, 1981) was employed to recruit participants, wherein initial participants refer additional participants. The contact with individuals was established through a written message, followed by the provision of an accessible version of the Informed Consent Form (ICF) compatible with screen readers. The interviews were conducted online, employing measures to ensure accessibility.

The interviews unfolded as narratives triggered by the guiding question, "Tell me your story of political activism." They lasted approximately one hour, were recorded, and transcribed. In total, 16 individuals were interviewed, comprising eight men and eight women[3], que, all identifying as cisgender[4],, with only one person self-identifying as Black. Only one interviewee had completed basic education, while the others had completed or were in the process of completing higher education. Participants came from various regions of the country, excluding the northern region of Brazil. Regarding types of disabilities, there were individuals with physical, visual, intellectual, and autism-related disabilities. All ethical considerations concerning research with human subjects were respected, and this study was approved by the ethics committee under the number 28916720.1.0000.0121. It is important to note that participants chose the names used to refer to them in the text. Following the logic of the article, only selected accounts are presented for discussion. The proposed analysis of the interviews is based on discourse analysis from a historical-cultural perspective of understanding meanings and significances (VYGOTSKY, 2008).

The definition of the analysis categories occurred after the interviews, following their transcription, and involved a process of initial reading with the selection of important excerpts. This was followed by five to ten re-readings and further excerpt selections. Based on the selected excerpts, a framework was constructed with themes and subthemes that interconnected the excerpts, highlighting their emphases on meaning, content, tone, coherence, and incoherence of the narrative throughout the interview, thereby bringing forth the produced discourses within this relationship.

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[3] The equal number of men and women in this sample was coincidental and incidental.
[4] Individuals who have alignment between gender identification and assigned sex at birth.

ISSN 8346
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Results and Discussion

The accounts of university inclusion were characterized d by the fact that the interviewees were either the first or the only person with a disability occupying that educational space, as evidenced by the narratives of Ivan, "I was the only person with a disability in the room, you know?" (Ivan), and also in the account of Priscila, "I was the first visually impaired student in the Law course" (Priscila). The profile of the participants in the study predominantly consists of individuals with a completed higher education, which already sets them apart from a significant portion of the disabled population who do not even have access to higher education (CRESPO, 2009; ANGELUCCI; SANTOS; PEDOTT, 2020). This factor of access is likely related to intersecting factors of class and the critical discourses expressed about the academic environment.

Access to higher education, in some cases, was influenced by financial difficulties and attitudinal barriers, where public policies for access to higher education played a significant role in ensuring the entry into university for some of the interviewees. Arthur recounts, "I ended up taking the entrance exam and I was very close to getting a spot (...). But then I got accepted into the ProUni program and managed to secure a full scholarship to attend a private university" (Arthur). However, admission to the university does not guarantee retention, as university structures are not fully accessible in terms of architecture, programmatic design, and attitudes.

In Priscila's accounts, it is possible to identify the unpreparedness of the university she attended and its administrators in dealing with the situation of vision loss that she experienced after an accident. The university urged her to take a longer leave of absence so that the administration could get organized. Priscila recalls, "After the accident, I went back to the university, talked to the director, and he said, 'Oh, Priscila, suspend the course for a little longer because I still don't know how to deal with you'" (Priscila). However, she did not accept this suggestion and, through her own insistence, returned to the classroom and navigated the new form of learning that she and the professors developed in terms of evaluation parameters. In her own words, "There were professors who scheduled different times, there were professors who assigned different assignments, there were professors who took the exam in the same room with everyone else, but with different questions, you know. Each one evaluated me in their own way" (Priscila), demonstrating that the responsibility for making necessary accommodations for learning falls on the figure of the teacher (CARNEIRO, PEDROSO; SANTOS, 2022). However, these measures should be adopted on a broader scale, as an institutional policy,

ISSN 8346
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as advocated by the LBI (Law for the Inclusion of Persons with Disabilities) and the CDPD (Convention on the Rights of Persons with Disabilities), rather than as occasional adaptations that run the risk of not being implemented to benefit the access, retention, participation, and learning of individuals with disabilities, depending on the individual understanding of each administration or educational professional.

In addition to the challenges of accessing and remaining in higher education, having an undergraduate degree does not guarantee employment, especially for individuals with disabilities who face barriers to formal employment (PAIVA, 2014). For this reason, the interviewees express a desire to deepen their knowledge through participation in a stricto sensu graduate program. Interviewees Priscila, Ricardo, Amarílis, Denise, Cacto, Frida, and Arthur demonstrate an interest in pursuing a stricto sensu graduate program, but their motivations vary. Priscila spoke about her interest in achieving financial stability through public tender (a career in the public sector) Therefore, it appears that the motivation for pursuing a master's degree stems from the perspective of improving salary and/or enhancing their qualifications.

Considering the Brazilian context, it is understandable why Priscila and others express a desire for further education, as since 2014 the number of graduates occupying positions of lower qualification has been increasing, and nearly half of young people with degrees are working outside their field of expertise (IPEA, 2018). Therefore, the need for further education leads individuals to perceive academia as a means to pursue professional development and strive for improved salary prospects.

Access and permanence of students with disabilities in higher education

The educational attainment levels of individuals with disabilities are notably lower in comparison to those without disabilities (INEP, 2022). This highlights the urgent need for policies that aim to eliminate barriers and promote equitable access to higher education. Amarílis shares a case concerning a student who uses a wheelchair at the university where she was employed:

> This student was a wheelchair user and when she entered the campus it was quite difficult (...) And the campus had no architectural accessibility. She was very restricted to the classroom because she had no way to circulate in the university spaces. Until one day we mobilized ourselves, (...) we went to the Public Ministry. And, based on this complaint, she was able to finish the course (Amarilis).

The student's full inclusion and ability to navigate the campus freely, was only possible after involving the Public Prosecutor's Office. The Convention on the Rights of Persons with Disabilities ensured that State Parties committed to ensuring an inclusive educational system at all levels of education (BRASIL, 2009). There is still limited programmatic knowledge within public agencies regarding the necessary measures to guarantee accessibility. The Incluir Program, focused on Federal Higher Education Institutions (IFES), emerged in 2005 with the aim of promoting the creation and consolidation of accessibility centers to support students with "Special Educational Needs." This program has been of great importance for individuals with disabilities to receive support within higher education institutions (MELO; ARAÚJO, 2018).

The entire ableist structure in which universities themselves are embedded, lacking the necessary accessibility apparatus, presents constant barriers to the inclusion of individuals with disabilities (MELLO, 2016). Access to the scientific academy itself is influenced by factors of race, gender, and class (KILOMBA, 2018). For instance, Ricardo feels discredited and faces additional obstacles when applying for a master's degree due to having attended a private college. He explains this as follows:

> The public university, as much as it has quota spots, and there are many people from low-income and social minorities getting in, it is still a micro portion of the population. The rest are those people who spent their whole lives studying in private schools, did [the selection process] and got in (Ricardo).

For Ricardo, entering the scientific academia is closely tied to gaining admission to a public university, and this makes sense, considering that over 95% of research publications in Brazil originate from public universities at the federal and state levels (MOURA, 2019). Similarly, according to INEP (2022), the percentage of students entering higher education after completing high school in the public education system is 36%, compared to 79.2% of graduates from private schools (INEP, 2022), and the majority of students in private universities come from public schools. These data justify Ricardo's account, as he further discusses the low academic credentials of students from private undergraduate programs. Considering that most private universities lack a research tradition and that the criteria for evaluating academic resumes for admission to master's programs already assume prior research experience, this poses a challenge for students who have not had research initiation opportunities.

ISSN 8346
DOI: https://doi.org/10.14393/REPOD-v12n3a2023-68502

The scientific academia remains a ableist space.

Several interviewees were striving to pursue an academic career, as they understood that entering this field could provide greater opportunities for financial advancement, social power, and identity formation, which emerge in contrast to other more ableist scenarios.

> They [private companies] only want to fulfill the quotas of the quota law, and in one of the selection processes, I [at 25 years old] was treated like a child. After that, it was when I started wanting to transition to the academic field (...), I know it's difficult, largely because of the productivity demand that is required (Ricardo).

Ricardo's reflection both reinforces academia as a possible place in the face of difficulties accessing employment in private companies and also demonstrates the existence of barriers regarding academic productivity, aligning with findings from research on the ableist rigidity of certain university processes (MELLO, 2016; MOZZI, 2020) and what is considered within the predetermined ideal time of production (ISAACS, 2020).

There are stigmas concerning the academic incapacity of individuals with disabilities that exist prior to the exploration of their potentials. Even though the standard time frame for writing and research production is difficult to accommodate and follow for many individuals, the presence of a disability characteristic presupposes academic unfeasibility (ISAACS, 2020; MOZZI, 2020), and for this reason, many people choose not to disclose such a characteristic if they can avoid it. Ricardo mentions that some autistic individuals within academia "don't disclose their autism precisely because there may be some kind of reprisal" (Ricardo). Such "reprisal" seems to be related to a potential change in attitude towards individuals with disabilities, and Mozzi's research (2020) revealed that students with disabilities tended to try to perform ability (overcoming barriers instead of requesting their removal) likely to avoid social stigmas. Similarly, when the disability is apparent, barriers can become factors that hinder participation in the academic sphere, as Amarílis recounts about her advisor, also a person with a disability, who left graduate school because "the university didn't provide the necessary conditions for him to participate in graduate studies (...), barriers of all kinds, including attitudinal barriers" (Amarílis).

Only recently have the official notices and calls for graduate program admissions begun to consider disability and other markers of difference in their selection processes, as a result of the struggle and presence of individuals with disabilities and their allies in academic spaces guided by the legal provisions of the Brazilian Inclusion Law (LBI) and the UN

ISSN 8346
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Convention on the Rights of Persons with Disabilities (CDPD). Crespo's research (2009) identified the difficulty in finding researchers with disabilities, highlighting the disparity in access for individuals with disabilities to postgraduate research (CRESPO, 2009).

Academic-scientific participation as a possibility for political engagement.

In light of the considerable critique surrounding the academia and its ableist processes, how can scientific inquiry be an emancipatory form of life beyond ensuring the mere sustenance of individuals with disabilities? Despite the presence of ableism within academia, it remains one of the few places of power that offers some opportunities for full participation for individuals with disabilities. This participation is influenced by passability[5] (GUERRA, 2021), and bodies with complex dependencies experience more barriers in fully engaging in academic spheres (GESSER; ZIRBEL; LUIZ, 2023), in conjunction with an intersectional framework (GESSER; BLOCK; MELLO, 2020) encompassing race, class, and gender. This incongruity of a primarily ableist space, which simultaneously offers a potential for full social participation, highlights the oppressive nature of various realms of social engagement.

Denise talks about the issue of women with disabilities in science, and according to her: "It is still difficult for a woman with a disability to carve out a space outside academia, I'm telling you. Academia is a different story." (Denise). In Denise's perception, academia appears to be one of the few possible spaces for women with disabilities to occupy. However, she also highlights the barriers that exist within these spaces, where there is a competition of oratory skills (ISAACS, 2020) and bodies that are considered ideal for knowledge transmission. Nevertheless, where there is the possibility of being present, there is also the possibility of engaging politically, as Ricardo states:

> So, I believe that activism, in addition to what I mentioned about its mere existence being a kind of political movement, we have to consider that activism encompasses various issues related to the theme, including promoting public policies, developing legislative projects, and engaging in academic debates, as some are beginning to do at this moment. Therefore, I believe that within the disability rights movement, something very similar is happening, since within the autistic movement, there is a lot of academic material produced by non-disabled individuals, as if autistic individuals were some kind of zoo animal. It's reminiscent of the anthropological study model from the last century, which we are now striving to address within academia, even if it's gradually, by encouraging autistic individuals to conduct research about autism (Ricardo).

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[5] Passability is a term used to designate bodies that are able to "pass" unnoticed in terms of their disability characteristics.

ISSN 8346
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For Ricardo, engaging in this space of power, occupying the role of a researcher rather than being the object of research, seems to change the status of disability, transforming it into a subject who, among many other characteristics, is a researcher (CRESPO, 2009). In this sense, participating in academia aligns with the very motto of the disability rights movement, which states: "nothing about us without us" (BRASIL, 2010).

The researchers Angelucci, Santos, and Pedott (2020) assert that in addition to the importance of having researchers with disabilities, it is crucial to consider the provision of accessibility resources both in conducting research and in dissemination. It is necessary to produce scientific knowledge that is accessible to all individuals, and in this regard, Ivan shares: "I see that this type of content [scientific article] is not accessible to people with disabilities" (Ivan). There is a discrepancy between what is produced in academia and how this information reaches those who need that knowledge; it is necessary to transform academic language into accessible information.

People with disabilities participating in university teaching, research, and outreach programs not only shape the world around them but also undergo transformative experiences. This fosters the construction of a social identity that extends beyond stigmas and engenders a sense of social belonging (GESSER; BLOCK; MELLO, 2020). As Cacto further specifies:

> I say that the university has shaped me not only as a social worker but primarily as a person who knows his rights, knows his duties as a citizen (...), today I am Cacto, an activist, today I am Cacto the social worker. Cacto, who is recognized for creating my own identity (Cacto).

The identity that Cacto associates with herself is much broader than her individual experience; it is the result of lived interactions and subjective self-construction over time, involving the construction of meanings and significances (Vygotsky, 2008) for her own individual and collective identity. In addition to identity formation, the academic space facilitates critical exchange, where one can encounter diverse individuals. Access to technical knowledge and academic education itself strengthens disability activism. Frida reinforces this argument: "I also feel the need to qualify myself technically and politically for debates because I feel, I perceive, that this issue of disability (...), it requires us to have technical, qualified, and informed stances" (Frida).

This theoretical academic knowledge, when employed in activist action, is referred to as expertise power, serving as an important tool for disability activism. Conversely, when the experience of activism informs academic studies and theoretical development, it is known as referential power (MELLO; FERNANDES; GROSSI, 2013).

In order to achieve this referential power in the field of disability, it is important to have researchers with disabilities, and historically, there have been few professors with disabilities in the university (PAIVA, 2014). However, there has been a shift in the processes of public university hiring, and quotas for Black and Brown individuals and people with disabilities have begun to be implemented, which is a gain for these groups. It is still necessary to consider that university centers are centralized in the capitals, but there has been a decentralization starting from the National Program of Education in Agrarian Reform (PRONERA) in 1998, a program that enabled the education and training (from basic to postgraduate) of settled workers (SANTOS; SANTOS NETO; BEZERRA NETO, 2022), and more recently, through the Program of Support for Restructuring and Expansion Plans of Federal Universities, known as Reuni, created in 2007 (CARMARGO; ARAÚJO, 2017).

Academia, in this sense, is a space of struggle in which individuals with disabilities are still engaged, striving to ensure that their entry and presence in universities are shaped by their own decisions and choices. To broaden the notions of who can be part of academia, we need to create fissures within this still deeply ableist space (GUERRA, 2021).

Conclusions

The aim of this article was to analyze the discourses of individuals with disabilities regarding their access to and persistence in higher education. The accounts of their overall experiences in higher education are marked by the encounter of barriers, the influence of public policies, and the increasing entry of individuals with disabilities into higher education. The importance of this inclusion for the process of learning and the development of citizens was also highlighted. Furthermore, the discourses revealed that institutions still lack preparedness and show a lack of interest in modifying their structures to accommodate students with disabilities. The responsibility for the teaching and learning process falls on the shoulders of the professors, even though they have not received adequate training for this purpose.

The access of individuals with disabilities to higher education is still permeated by barriers, both at the undergraduate and postgraduate levels. The issue of persistence in higher education is still being addressed, necessitating specific public policies to ensure it. The academia, like other spaces of power, is a site of contention where intersections of race, class, gender, and disability play a significant role in determining who holds more power and who holds less in the social hierarchy. While there are individuals with disabilities who have attained master's and doctoral degrees, few occupy positions as professors/researchers in universities (CRESPO, 2009). These findings reinforce the results of Paiva's (2014) study, which indicate that quotas often prioritize technical administrative positions, while positions in high-level management and leadership roles are not given priority under quota systems.

To disrupt the fissures of ableism in academia, it is necessary to conduct research and professional practices that challenge the hegemonic knowledge surrounding disability, enabling individuals with disabilities to occupy the position of subjects rather than mere objects of research. This study aimed to provide insights into issues related to the access and persistence of individuals with disabilities in higher education, serving as a foundation for the development of affirmative policies. However, there are limitations to qualitative research in this field, and it is important to consider other studies that specifically focus on professors with disabilities, different types of disabilities concerning access to higher education, mapping of selection processes for admission to postgraduate programs, and the accessibility of academic journals in producing accessible content.

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