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Stigma hinders access and permanence of autistic students in

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Ana Gonzalez / 31 de outubro de 2024 / In English

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Inclusion | Autistic spectrum students face obstacles in addressing their needs in the academic environment, and many prefer to hide their diagnosis

*First published February 8, 2024

*Photo: Marcelo Pires/JU

"I am not a burden." This is what Luísa Trevisan, a doctoral student in Human Movement Sciences, has been trying to prove since the beginning of her $extensive\ journey\ in\ the\ academic\ environment.\ Now\ 54\ years\ old,\ Luísa\ is\ a\ physical\ educator,\ artist,\ photographer,\ dancer,\ and\ researcher.$ Additionally, she has been diagnosed with Autism Spectrum Disorder (ASD) since the age of three.

A student at UFRGS since 2011, through graduation, master's, and now ongoing doctoral studies, Luísa reports that difficulties in adapting to the university's methods have permeated her entire academic experience. The work that operates on tight deadlines, long classes without breaks, and the demands of professors and advisors make it difficult for her to stay at the university. She claims that the combination of these factors is damaging to her mental health. "There is a tradition that only the strong survive," she says. "They don't realize it's an environment that makes people sick. It's a pretense that everything is okay, when in reality, it's not."

Mariana, a Social Sciences student who prefers not to be identified, entered UFRGS in 2015, initially in the History undergraduate program, and did not understand why she had so much difficulty studying course contents, unlike her peers. The dense and extensive readings led to sleepless nights and the content of the course of thand generated feelings of frustration and guilt, resulting in poor academic performance. It was only in 2022, at the age of 28, and after an internal transfer to the Social Sciences undergraduate program, that she received the diagnosis that helped her connect the dots and put things into perspective: level 1 autism, which requires the least degree of support. "The diagnosis helped me understand that my way of studying is different; I was able to understand why it had been so difficult before."

The Hidden Part

There is no official count that maps the number of autistic students enrolled in universities, but even if there were, the number might not accurately reflect reality. "Many students choose not to reveal their diagnosis or do not enter the university through disability quotas, so it can be difficult to get an accurate number," explains Adriana Arioli, coordinator of the UFRGS Inclusion and Accessibility Center (Incluir).

The choice not to share this part of themselves with friends, classmates, professors, or even family members is made by some students with ASD for various reasons, but almost all revolve around one factor: the fear of the stigma that the diagnosis carries. Mariana says she opts not to share the information with classmates and professors out of fear of future consequences in the job market. "I know this diagnosis could be used against me in the future," she explains. "That's why I can count on my fingers the people who know."

For Luísa, the decision to keep her ASD diagnosis known only to a few people at the university stems from a need acquired over time to adapt to the environments she is in, a strategy called "masking." This involves the conscious or unconscious effort by some autistic people to camouflage characteristics and behaviors related to their impairments to fit into social situations

"We are trained to adapt ourselves the whole time"

- Luísa Trevisan

While not revealing the ASD diagnosis can serve as a shield against prejudice, this decision can also mean depriving autistic students of their rights within the university. The Brazilian Inclusion Law for People with Disabilities guarantees the right to education for people with ASD and the provision of support professionals for these students at any level of education. However, contacting the support services offered by the university to request assistance related to legally guaranteed educational demands is a decision that must come from each student based on their specific needs. "We pay a very high price, whether we openly identify ourselves or not," notes Luísa.

The Importance of Teacher Preparation

For Mariana, even before knowing her diagnosis, one of the biggest difficulties since entering the university was communicating her support needs to professors and having her requests for help minimized or ignored. She attributes this to a general lack of preparation by teachers to support students who may need individual assistance, whether they are neurotypical or not. The individualistic logic of the academic environment hindered her learning and imposed barriers that made her university journey more challenging. "I need closer monitoring, but I couldn't get that monitoring because I think that's not part of the university structure," she reports. Therefore, she had to adapt to the university learning model alone, gradually, "as well as I could." Over time, the change of undergraduate program and the self-recognition of her learning needs made Mariana's experience more manageable. "In Social Sciences, I study everyday things, so it also helps me understand how other people think so I can understand them and

In the graduate program, Luísa lives under high pressure to prove her good performance and skills to supervisors and classmates, even those who do not know her diagnosis. Her unique creative process, which occurs in intense and spaced-out productivity flows, clashes with the inflexibility of required deadlines. "To do these things, I dive deep. I have a hyperfocus when I'm working on it that, before I know it, much time has passed, and I forgot to eat," she reports. The severe depression she was diagnosed with in 2023 highlights the disastrous effects of being in an environment that rejects atypical behavior.

"I don't accept being convinced that I am a hindrance or that I am holding a vacancy"

Although there are courses and training for higher education teachers to prepare them to deal with the needs of students with disabilities, including autistic students, these are not mandatory. The lack of formal and qualified preparation translates into an inability to handle situations that deviate $from \ the \ neurotypical \ and \ often \ ableist \ norm \ of \ university \ teaching. "It's \ a \ hermetic \ box, \ where \ this \ is \ how \ teaching \ is \ done, \ and \ those \ who \ can't$ keep up will have to leave," observes Luísa.

At UFRGS, Incluir, in partnership with the School of Development (EDUFRGS), offers free training programs for teachers and staff to foster a more inclusive environment in all university fields and spaces for people with disabilities. "It's a way to eliminate barriers, especially those related to people's lack of knowledge on the subject," explains Adriana.

The Change Must Be Collective

The inclusion of autistic students in the university involves multiple and complex paths, but the link between a beneficial and quality university experience for autistic students and the efficient preparation of teachers to meet these students' needs is clear and needs to be recognized and reinforced. For Clarissa Haas, a professor at the UFRGS School of Education and a researcher at the Center for Studies on Inclusion Policies in Education (NEPIE), it is essential to remember that all autistic people are different and have unique demands that do not fit into a single label and go beyond the diagnosis. "As education professionals, we cannot assume the profile of students with autism as a general profile. We must pay attention to the unique way each person experiences the condition of autism," she points out.

"It is the role of teaching valuing the unique expression strategies used by ASD students, legitimizing their own forms of communication through pedagogical action"

— Clarissa Haas

Furthermore, the responsibility for the inclusion of people with ASD in the academic environment in all its complexity falls on all parts of the university and cannot be reserved exclusively for directly responsible bodies. "It's a shared responsibility," Adriana reminds us.

Support projects for autistic students at the University, such as Incluir and the UFRGS Coletivo Autista, try to mitigate the harmful effects caused by the universal lack of preparation in higher education to support neurodiverse students. While the pretense mentioned by Luísa continues to exist, this invisible segment of the university population waits for the rest of the academic community, including faculty members, students, and staff, to be empathic towards them and accommodate their most basic needs and demands. 'The university should be a place of acceptance and support, not only theoretically but also so that you can become a competent professional and human being. It should be the last place for this kind of prejudice,"

Translated into English by Gustavo Flores Ramos, undergraduate student enrolled in the course "Supervised Translation Training I (English)" of the $Undergraduate\ Program\ in\ Language\ and\ Literature,\ under\ the\ supervision\ and\ translation\ revision\ of\ Professor\ Elizamari\ R.\ Becker\ (P.h.D.)-line and\ translation\ revision\ of\ Professor\ Elizamari\ R.\ Becker\ (P.h.D.)-line and\ translation\ revision\ of\ Professor\ Elizamari\ R.\ Becker\ (P.h.D.)-line and\ translation\ revision\ of\ Professor\ Elizamari\ R.\ Becker\ (P.h.D.)-line and\ translation\ revision\ of\ Professor\ Elizamari\ R.\ Becker\ (P.h.D.)-line and\ translation\ revision\ of\ Professor\ Elizamari\ R.\ Becker\ (P.h.D.)-line and\ translation\ revision\ of\ Professor\ Elizamari\ R.\ Becker\ (P.h.D.)-line and\ translation\ revision\ of\ Professor\ Elizamari\ R.\ Becker\ (P.h.D.)-line and\ translation\ revision\ of\ Professor\ Elizamari\ R.\ Becker\ (P.h.D.)-line and\ translation\ revision\ of\ Professor\ Elizamari\ R.\ Becker\ (P.h.D.)-line and\ translation\ revision\ of\ Professor\ Elizamari\ R.\ Becker\ (P.h.D.)-line and\ translation\ revision\ of\ Professor\ Elizamari\ R.\ Becker\ (P.h.D.)-line and\ translation\ revision\ of\ Professor\ Elizamari\ R.\ Becker\ (P.h.D.)-line and\ translation\ revision\ of\ Professor\ Elizamari\ R.\ Becker\ (P.h.D.)-line and\ translation\ revision\ revis$

:: Read in portuguese

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Secretaria de Comunicação Social/UFRGS ISSN 2966-4675

Av. Paulo Gama, 110 | Reitoria - 8.andar | Câmpus Centro |

Bairro Farroupilha | Porto Alegre | Rio Grande do Sul | CEP: 90040-060 jornal@ufrgs.br

ufrgs.jornal

@ufrgs.jornal

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