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The journey of late diagnosis of autism from an autoethnographic, neuroqueer, affective and performative perspective

El viatge de diagnòstic tardà d'autisme des d'una perspectiva autoetnogràfica, neuroqueer, afectiva i performativa

El viaje de diagnóstico tardío de autismo desde una perspectiva autoetnográfica, neuroqueer, afectiva y performativa

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Abstract

In this article, I present my journey of late diagnosis of autism employing autoethnography with video performance, affects and the concept and practice of “neuroqueering”. Within the framework of Performative New Materialism, the neurodiversity paradigm and Critical Autism Studies, I try to respond to the cultural narratives created by non-autistic authoritarian figures, generate a different point of view within Critical Autism Studies by correlating the autistic experience with affects, and give a step forward in changing how the autistic experience is culturally researched, written about and spoken of.

Keywords

Autoethnography; performance; neuroqueer; autism; Affect Theory

Resum

En aquest article presento el recorregut del diagnòstic tardà d'autisme des de l'autoetnografia amb la video performance, els afectes i el concepte i pràctica del “neuroqueering”. A partir dels Nous Materialismes Performatius, el paradigma de la neurodiversitat, els Critical Autism Studies, tracto de respondre a les narratives culturals creades per figures autoritàries no autistes, generar un punt de vista diferent dins dels Critical Autism Studies en correlacionar l'experiència autista amb els afectes, i fer un pas endavant sobre com l'experiència autista és investigada, escrita i parlada culturalment.

Paraules clau

Autoetnografia; performance; neuroqueer; autisme; Teoria dels Afectes

Resumen

En este artículo presento mi recorrido del diagnóstico tardío del autismo desde la autoetnografía con la video performance, los afectos y el concepto y práctica del “neuroqueering”. A partir de los Nuevos Materialismos Performativos, el paradigma de la neurodiversidad y los Critical Autism Studies, trato de responder a las narrativas culturales creadas por figuras autoritarias no autistas, generar un punto de vista diferente dentro de los Critical Autism Studies al correlacionar la experiencia autista con los afectos, y dar un paso adelante sobre cómo la experiencia autista es investigada, escrita y hablada culturalmente.

Palabras clave

Autoetnografía; performance; neuroqueer; autismo; Teoría de los Afectos

Where I stand

The research that I present in this article, explores my personal experience of late diagnosis of autism through the lenses of Affect Theory, the concept of neuroqueer, an autoethnographic and performative methodology. I use a theoretical framework based on Critical Autism Studies, New Materialism, and the neurodiversity paradigm to try to regain agency and to respond to, as Bakved (2022) says, the cultural narratives created by non-autistic authoritative figures.

This article begins by reviewing the list of concepts and theoretical fields that accompany me in my suitcase for the autoethnographic journey while reflecting on the importance of autistic autoethnography. Once the theoretical and methodological framework has been presented, you will find my autoethnographic and performative journey, concluding with some final reflections.

I am mindful of the fact that first-hand autistic experiences are ignored, particularly when they differ from societal expectations. This epistemic injustice is highlighted in research about autism, where autistic people are ostracized and not taken into consideration (Botha, 2021). As Spivak (1998) and Giraldo (2003) mentioned, referring to the subaltern subject, the autistic person speaks, but what they say does not have a dialogical status, since they do not occupy a discursive position from which to speak or respond. This leads me to the question: if the autistic subject can speak and respond, is he/she listened to?

I do not intend to offer the absolute truth about autistic people, nor speak on behalf of all of us. As a researcher, I am aware of my bias, since I will be able to account for certain aspects but not all of them (Liao, 2006 in Gandarias, 2014). I consider that there is no absolute objectivity but strong objectivity (Haraway, 2004) as an alternative to scientific objectivism and as a

way of rejecting the universalizing tendencies of the epistemic authority of the Social Sciences (Harding, 1992). Subjective and situated narratives are essential in research about social matters, where marginalized voices are and must be present (Bakved, 2022).

Let's pack for the journey: the theoretical frameworks that guided this work and why autoethnography

I imagine this part of the article as the review of a list when you prepare the suitcase for a long journey. Reflecting on the theories that I take with me, I have to start with Critical Disability Studies, a branch of Disability Studies that argues that instead of limiting the analysis of disability to material and economic dimensions (like Disability Studies scholars did) we should try to critically rethink and review the cultural, discursive, and relational aspects of disability experiences (Bakved, 2022). In this context, it is important to acknowledge that by the end of the 90s, Critical Disability Studies focused more on visible disabilities. That is when a large number of autistic people began to get connected, forming a movement that arose in response to a series of prevailing conditions: the discourse and praxis related to autism, which was (and still is) dominated by the pathology paradigm¹, the fact that this paradigm causes many autistic people to be stigmatized, unrepresented, dehumanized, abused, hurt, and traumatized; and the fact that when autistic people tried to address these issues they were met with hostility or violence (Walker, 2021). The majority of the Critical Disability Studies scholars adopted the Social Model of Disability that presents disability not as something inherent in the disabled person but rather in the way society is not adapted to the disabled needs. According to this framework we understand that autistic people are not disabled because there is something inherently wrong with them, but because

¹ The pathology paradigm frames autism as a form of medical pathology or disorder (Walker, 2021).

society disables them (Shakespeare, 2006). Because of these circumstances, autistics began to recognize that they were an oppressed minority and they asked themselves what kind of minority group they were. Judy Singer (1998) answered by creating the term “neurodiversity” and then another important concept was coined by Nick Walker: “neurominority”. The term “neurodivergent” was coined by Kassiane Asasumasu in 2000 (Walker, 2021).

The Autism Rights Movement’s development of terminology introduced the concept of neurodiversity as a framework. This framework views body-mind differences, such as autism, as natural forms of diversity (Mallipeddi and VanDaalen, 2021). It claims that just as humanity is diverse in ethnicity, gender, and other characteristics, it is also diverse in terms of neurocognitive abilities, and autistic individuals are considered a neurominority. It is not just a diversity of the brain; rather, mind, brain, and corporeality are interrelated in a unique and complex system, thus, neurodiversity refers to the functionality of the whole body/mind (Walker, 2021).

Then the concept of the “neurodivergent” was coined to refer to people whose mind functions significantly different from the dominant societal standards of normal. We must avoid viewing neurodiversity through an essentialist lens whereby each individual is neurotypical or neurodivergent because they were born that way (this approach is understood as neuroessentialism) (Walker, 2021). I also find it crucial to explain that neurotypicality is not a biological reality, but a social construct that states what “normal” should be. In the same way that society dictates heteronormativity, it also signals neuronormativity, so neurotypicality does not exist per se. Rather, there are neurotypical people whose neurology resembles more closely the idea of how people should behave (Yergeau, 2018).

Thus, there are opposing points of view regarding the biopsychosocial phenomenon of neurodiversity: the pathology paradigm and

the neurodiversity paradigm. The first one, like I have briefly mentioned, assumes that divergences from dominant sociocultural norms of cognition and embodiment represent a deficit or a pathology, dividing the spectrum of human cognitive/body performativity between the normal and the “other,” with the normal seen as superior and desirable. The second paradigm understands neurodiversity to be part of human diversity, subject to the same social dynamics as ethnicity, gender, and sexual orientation, including dynamics of social power, inequities, privilege, and oppression (Walker, 2021).

These opposing paradigms define autism, so a critical perspective must take their roots into account and shift towards a neurodiversity paradigm. As Audre Lorde (1984, cited in Walker, 2021) put it at a feminist conference: “the master’s tools will never dismantle the master’s house” (p.20). She explained that we are in a system and when we play by the rules of the game, we inevitably reinforce that system, even if we don’t want to. This can be applied to the autistic community and its struggle for empowerment, as the tools of the pathology paradigm will never empower us in the long run.

Furthermore, Critical Autism Studies originated from the need to research the autistic experience, examine, and critique social concerns through the lens of neurodiversity and to challenge deficit-based and pathologizing discourses on autism, within Critical Disability Studies (Roscigno, 2021).

As Sencindiver (2017) defines it, New Materialism is an interdisciplinary, theoretical, and politically committed field of inquiry that emerged as part of the post-constructionist, ontological, or material turn. Coined by authors like Karen Barad, Rosi Braidotti, Elizabeth Grosz, Jane Bennett, Vicki Kirby, and Manuel DeLanda. Cano Abadía (2015) proposes New Materialism as a way to escape the binarisms in which our identities are trapped, by not only showing the cultural mechanisms that are put

into operation to configure them, but also to show that culture and nature are so intertwined that they are not separable realities. Neuronormativity acts in the same way on our body/minds as heteronormativity does, a key concept arises to understand, as we see with the New Materialisms, that the limits between minds, bodies, and material spaces are not as concise as we thought: they are rather neuroqueer. This term was first conceived as a verb (neuroqueering) referring to the practice of “queering” (subverting, challenging, or freeing oneself from) neuronormativity and heteronormativity simultaneously. In other words, examining how socially imposed neuronormativity and heteronormativity interrelate with each other (Walker, 2021).

Affect Theory arose from the realization of how new forms of domination and marginalization resulting from globalization, corresponded more to emotionally-moved drives rather than to rational instrumental ones. It incorporated Foucault's contributions in genealogies and power technologies, gender theory and poststructuralist approaches. The “affective turn”, coined by Tricinetto and Halley (2007), suggested how we could rethink the relation between the social and the subjective. Then, Gregg and Seigworth in *The affect theory reader* (2010) related affects to “the ability to affect and be affected, and to mark the belonging of the subject in a world of encounters and disagreements that they inhabit and that inhabits them at the same time” (Moraña, 2012, p. 318). Affects were defined as a way to describe visceral impulses that are distinguished from conscious ones (Moraña, 2012).

In the search for new ways to narrate myself and to reflect on the autistic experience, I began taking into consideration Affect Theory. By doing so, we can consider how affect is relational and occurs between humans and non-humans, individuals and society, body and culture, organic entities and machines. We affect others and others affect us since affect is always distributed. We feel and are affected

in the relationships we have with others.

From the point of view of neurodiversity and Critical Autism Studies, we can connect autism and New Materialism by understanding the fundamental error of the pathology paradigm in its failing to consider the subjectivity of the observer's point of view. When we engage in knowledge production practices, we always do so as part of a larger material configuration, because we always constitute and are partially constituted by what we observe (Gamble, et al., 2019).

Affect Theory plays a role in how we, as disabled people, interact with the world, how we affect others and how others affect us. For these reasons and for those that I will add later, autism research should be carried out by autistic researchers, abandoning the idea of neurotypical people studying autistic people. If we adopt new ways of approaching and understanding knowledge production concerning autism, we will be able to create new bodies of knowledge about our own experience. As I mentioned earlier, citing Walker (2021) and Lorde (1984), we are not going to dismantle the master's house with his tools: we must look for new words, new horizons and new ways to create autistic knowledge. For this reason, it is vital to understand the theory that Critical Autism Studies draws from, in the same way that we understand intersectionality, bearing in mind the fact that disability in general and neurodiversity in particular, have received very little attention within the intersectional literature. We must keep in mind that autistic individuals are intersected with racism, misogyny, etc. Therefore, intersectionality is crucial to highlight the experiences and needs of marginalized groups within the autistic community (Botha & Gillespie-Lynch, 2022). By incorporating intersectionality into autistic knowledge production and discourse we may allow activists and scholars to examine how contextual factors of oppression may influence individual autistic experiences, neurodiversity, and ableism in society (Mallipeddi &

VanDaalen, 2021).

Autoethnography is a research method that makes use of personal experiences to describe and interpret experiences, beliefs, and practices (Adams, et al., 2017). Thus, the researcher is the subject of research. Because of this, distinctions between personal and social, self and other, are blurred. And, in particular, autoethnographic performance is understood as the confluence of the autobiographical and the ethnographic delineated by movement and critical self-reflexive discourse (Spry, 2001).

The phenomenon of autism was first recognized and named in the 1940s, not by Kanner but by a woman, Sukhareva (Manouilenko & Bejerot, 2015), up to the present day, there have been disciplinary discourses on autism that have been dominated by an epistemological viewpoint that ignores the subjectivity and experiences of autistic people. All of this has led to a point where the body of autism theory is constructed from a misguided collection of stereotypical concepts that dehumanize autistics and indicate that they lack the capacity for symbolic thinking and imagining, and that therefore, the experiences of autistic people should not be considered valid. As Yergeau (2018) puts it:

What is at stake here is who explains my story and roughly speaking who explains the story of people like me. What is important is who is the author of our individual and collective identities, who determines whether we are narrative creatures, whether we are living beings in rhetorical bodies, whether we can call ourselves human (p. 21).

According to the pathology paradigm then, autistic voices are disregarded, and as autistic

researchers we can recover our agency by seeking new methodologies. We need methodologies like autoethnography to make our voices heard. When we connect theory with our personal experiences, we can see how these cannot be separated from each other. In the same way that we can't separate the brain from the body, I can't separate the way my mind processes things from the way my body interacts with the material world. Autistic stories told in our own voices have the potential to be powerful forms of resistance and, like other marginalized communities, we can find in autoethnography, a way not only to explain our stories but also contextualize them (Yergeau, 2018). Autoethnography is therefore a way of recovering the space for autistic stories and experiences, told by autistic subjects, with a cultural voice, capable of complex rhetoric (Barkved, 2019). In the context of the autistic experience, autoethnography offers us the opportunity to connect our autobiographical narratives with reflections and interpretations of those narratives (Walker, 2019).

My journey

The autoethnographic part of this research focuses on a selection of my own experiences, which are relevant to autistic ways of being, and offers new insights into what the autistic experience is, while at the same time keeping in mind that this work is based solely on my subjective experiences and does not attempt to be fully representative of the experiences of others. Inspired by Amanda Baggs' video performance titled "In my language" (Baggs, 2017), I assembled a seven-minute video performance titled "Undoing the mask"² by placing layers of clay on my face and then removing them and cleansing them with water.

If I had to describe my time between elementary and middle school in two words these would be: loneliness and confusion. As social interactions in elementary school

² Which you can view at:
<https://www.youtube.com/watch?v=3AaX7PZoFxU>

became more complex and demanding, my sense of being different increased and I kept feeling that my classmates had been given a manual to help them navigate the world but, on the very day it had been handed out, I had stayed home. I felt that we had nothing in common, that for them playing and interacting seemed to come naturally, and every time I tried to approach them I sounded forced and robotic. Just as I became aware of my bonding difficulties, my classmates were also aware of these differences and soon the bullying started. No classmate would talk to me, no one wanted to pick me for group work, and during every recess I was left in a corner by myself. As the school years went by, I began to normalize it, thinking that it was normal while I was “defective”. I didn’t understand them nor did I have anything in common with them, but I wanted to be like them, I didn’t want to be always alone. Understanding neurotypical ways of socializing did not come naturally to me, but trying to “look normal” was a matter of survival. These performative actions that many autistic people do to try to fit into neurotypical standards are known as “masking” in the autistic community. Reflecting on this painful part of the journey, I can’t help but understand these performative actions, where you first mask what you really are to later undertake actions to fit in, as if moved by affects. It was about reconfiguring how your body moves, how it interacts with the surrounding material world. At this point, it becomes indispensable to remember what Preciado (2004) indicates when talking about how the performative action can become the narration of one’s own experience, that appears as a theatricalization. It was after realizing the performative character not only of my gender but also of neuronormativity, as constructs and not as essences, that I decided to interweave this autoethnography with a video performance on the creation and dismantling of this performative mask. In adopting the autoethnographic methodology and, performative autoethnography I not only recalled my journey and connected it with the sociocultural context or reflected on the affects

that accompany it, but also experienced the body situated in time, history, and place (Sughrua, 2019).

As we have seen with the concept of neuroqueer, neuronormativity and its effects on affects are similar to those of heteronormativity. This became clear after reflecting on how gender expectations were not natural for me, but seemed rather to be a performative construction. We should stop here to remember that autism discourse has been intertwined with (male) gender since Kanner’s foundational case studies in 1943, Wing’s 1981 epidemiological study, or Baron-Cohen’s “extremely male brain” concept. Because of this, autistic experience has been stereotyped as masculine, as have current diagnostic methods (which are based on the stereotype of seeing autism as a “male condition”) (Moore et al., 2022). This explains how people socialized as women, who are told to inhabit space on the margins and be quiet, have less chances of being detected than people socialized as men (Millan Lopez, 2021).

In society in general, not only within the autistic community, women are pressured to be more social than men, and if the individual is autistic, these social pressures are amplified (Milner et al., 2019). In *Gender Trouble*, Butler (2007) problematizes assumptions that gender precedes behavior, explaining how this is performatively constituted from stylized and repetitive acts, such as gestures, movement, and clothing. These acts have been recognized as male or female, discursively produced within a heterosexual matrix that gives rise to a hierarchical binarism of male dominance. In this context, not performing gender well and doing gender badly implies being punished (Moore et al., 2022). At the same time, when autistic people mask, they start a performance in the way they speak, move, dress, to “pass as normal”. Because not performing yourself as “normal” means you are “othered” by the neurotypical hegemonic standard.

Figure 1

Video performance frame

In my video performance the actions taking place are understood as a way of positioning the body in narration. A way of understanding that, in the action of masking, mind and body are interconnected. The first step is constructing a mask with clay that represents the work in modifying my actions and movements to pass as neurotypical: to be seen as normal. Implying that this was a process of many years and not always a conscious one. In doing so, I am not only constructing my neuronormativity mask, but also constantly constructing my heteronormativity mask, and making visible my gender performativity. As such, there is a similarity between the construction of autistic femininity and the mask (masking) and gender performativity, in that many autistics perform consciously and in a very studied way the behaviors that are attributed to their gender, constructing a mask that is difficult to see, because it connects with the feminine artifice (Moore et al., 2022).

The next part of this journey took place when I started college. I remember this time as a set of memories between depressive episodes and suicidal ideations, between antidepressants and anxiolytics, modifying that mask that accompanied me to try to mitigate my flaws: not understanding social conventions, not being able to maintain lasting friendships, putting myself in dangerous situations for not understanding social signals, getting in and out of abusive relationships, and continuing to feel different without knowing why.

I took a Master's degree for secondary school teachers and then a second Master studies. In the middle of the latter, I signed up for a course for teachers on autism. Before this, being autistic merely crossed my mind, and when it did, it was followed by the thought: "it is impossible for me to be autistic because I have

empathy, and autistic people are known for not having empathy". As I started the autism course, and began to read suggested readings, I felt it spoke to me and my life experiences. It ended up turning my whole life upside down. Suddenly, my mind wanted to gather all the information, trying to remember all the cues that were evident but somehow missed by everybody. I remember that I was shaking, as if my body, all my being, knew I just stumbled upon something that was about to change my life.

If we pause for a second in this journey to reflect again on the video performance, we can see how I tried to express this moment of realization, a moment I felt with all my being as a decisive point, a point of no turning back. This will later take me to realize all the ways in which I was performing.





Figure 2
Video performance frame II

I had not been officially diagnosed yet, but I knew it, and I began what I can only describe as a grieving process. I was first hit with great sadness when thinking about my pre-diagnosis self. And as it happens to many autistic women with a late diagnosis, I had a great sense of guilt (“how come I didn’t find out sooner?”) (Millan Lopez, 2021).

One of the disabling situations that we face is the difficulty of access to a diagnosis, since it not only excludes the person from the services he/she should receive in his/her environment, but also keeps him/her uninformed. In the terms of the Social Model of Disability, autism is not a disability by itself, but we, autistic people, are disabled by the barriers of a disabling society (Walker, 2021). One of the main reasons why many autistic women are diagnosed as adults is that they become aware of it themselves (e.g. through a college class) and then seek formal validation (Mallipeddi & VanDaalen, 2021). Not fitting within the autistic stereotype of an “extreme male brain” (Baron-Cohen, 2002, cited in Mallipeddi & VanDaalen, 2021) puts you in a place of vulnerability: you do not have easy access to a diagnosis for socioeconomic reasons, you may find out you are autistic in your mid-twenties, you may not be white or cis, etc.



Having my diagnosis did not end my confusion: on the one hand, I felt that I had been provided with a frame of reference for learning and improving my well-being, feeling hope, strength and pride in the diagnosis. On the other hand, however, I fell into an identity crisis. If I am not my mask, then who am I? Am I something more than all these symptoms? I did not want to stick to the symptomatic classifications of the diagnosis or the DSM-5, as I needed to find new ways to narrate myself. I wanted to connect with the autistic community as a way to start building on new grounds. This need – to connect with those who are similar to you – is grounded in affect. I can describe it as being home after a long journey far away (mine was twenty-four years long), and meeting your people again.

It was then when I found the way in which many autistic women, diagnosed as adults, narrate themselves through the neurodiversity paradigm: I felt that I had found narratives with which I could thrive. These stories empowered me, not in the sense that they changed my autistic behaviour, as the pathology paradigm and most common therapies would wish, but to see myself ready to accept my differences.

This shift is present in the video performance when I begin to take off the mask and cleanse it with water in order to dismantle it. This was one of the great affective movements of the journey: If I’m not only my mask and my “symptoms”, I will have to find new ways to narrate myself from the perspective of growth

and acceptance. But another question arose: if I leave my mask behind, will I be heard, will I be taken seriously, how will I cope with possibly being othered by people?

Figure 3

Video performance frame III

However, I comprehended how important it is to make autistic voices heard, as Milton's (2012) theory of dual empathy proposes: one group of people will always find it difficult to put themselves in the place of another group's experiences, because they have different experiences. Therefore, they will always find it difficult to empathize with each other. When we think about it through the lens of autism, we see how autistic people experience and express emotions, communicate, interact with others, form relationships, embody, and experience the world around them in very different ways than non-autistic people do. This is not to say that autistic people do not have emotions or empathy, these are just expressed and experienced differently. These divergences can make it difficult for non-autistic people to recognize what emotions and empathy look like in autistic people, because they experience them differently which often causes them to interpret autistics incorrectly.

At the same time, autistic people have little knowledge of non-autistic culture and its social communication, as it is just as difficult for autistic people to empathize with, and understand, non-autistic people, as it is for non-autistic people to understand autistics. This mutual lack of knowledge creates an empathy gap, which is a problem for both groups. Non-autistic ways of communicating

and empathizing are seen as typical, expected, and accepted as normal and correct. In contrast, atypical and unexpected forms of autistic communication and empathy are rejected as different or incorrect; they are pathologized. Although the gap is experienced by both groups, there is an inequity in the level of impact it has on them both (Milton, 2012).

We, as autistic, are applauded when we show "no signs of being autistic", but at no time are non-autistic people expected to understand, accept, or adopt autistic perspectives or culture. The problem of dual empathy highlights the lack of empathy of non-autistic people for autistic people, their experiences, and their culture (and the other way around). This lack of empathy from the majority of society leads to the marginalization and stigmatization of autistic people. Society defines itself as inclusive, but often basic services are denied and natural autistic behaviours are pathologized (Milton, 2012).

It should be highlighted that currently, autistic people are the ones who make the effort to understand non-autistic people (Milton, 2012). As Sinclair (1992) indicates:

(...) don't try to change me to fit into your world. Don't try to confine me to some tiny part of the world that you may have changed to fit me in. Grant me the dignity of knowing me on my own terms: recognize that we are equally strange to each other, that my way of being is not merely a damaged version of yours. Question your assumptions. Define your terms. Work with me to build more bridges between us (p. 12).

How vulnerable it may be to unmask and stop pretending, when you are the minority and when embodying as a "normal" person is expected? But after all these fears, there is hope and bravery: to not stand in a victimizing point of view, but in one of change. As we reflected earlier with the new materialist turn,

and as Haraway (1988) anticipated, we can embody our autistic selves as we are, and as we do, in the way that thinks the material, the body, the flesh, and the discursive together. By being as I am, I am also doing. I am deconstructing neuronormativity and constructing a new autistic discourse, and performing-contemplating the material-discursive practices of adapting my body to my needs and surroundings (e.g. by wearing sunglasses to protect myself from light and ear defenders).

All of this is not just about accepting our differences and demanding to be accepted. It is not only about taking off the mask to make my neurodiversity visible, not only about fighting for equality as a minority, or about enjoying the diversity of our bodies/minds, but also about finding ways to increase this neurodiversity and explore its full potential. I realized the power in neuroqueering my identity when I examined my internalized ableism and found how I had consciously performed my gender. I saw how fighting internalized heteronormativity was quite similar to fighting internalized ableism and how if you are “weird” to society (because you are autistic, for example) you are weird in relation to heteronormativity (because heteronormativity dictates the right and wrong ways to be). Both heteronormativity and neuronormativity tell us that there are right ways to embody your body/mind, right ways to talk or walk “like a woman”, etc. They impose rigid standards on the ways we embody ourselves (Walker, 2021).

As women are taught submission and are not allowed to occupy space or put barriers in their own personal space (which are embodied practices), men are taught that they have to occupy as much space as possible all the time (which cuts off their possibilities for tenderness, etc.). I quickly understood that, since these standards are so rigid and absolute, I cannot deviate from one without deviating from the other. If I start moving and freely living as my autistic self, I will also deviate from conventional feminine ways of

embodiment. If I act as it is natural for me, I am challenging heteronormativity. When I give myself permission to move as I like I recognize that the autistic mask was also the mask performing as a cis woman. So, in being autistic, in neuroqueering, I liberate myself from imposed neuronormative and heteronormative styles of cognition, consciousness, and embodiment (liberating the psyche and the way it is embodied).

I find power in not considering myself “broken” because of my lack of ability to relate appropriately to the world around me or, in the way that is expected. So, if I leave the mask behind, it is not only to try to survive without it, but to be able to move forward and thrive. Instead of being distressed by my hypersensitive sensory perceptions, I cover my ears with ear defenders; if I need to rock myself back and forth in public to regulate myself, I will do it, and I do not need to force myself anymore to look into people’s eyes while in a conversation. In doing so, I am learning to value and nurture my body/mind by trying to do what it needs to do, what it is, instead of forcing appearances of normalcy. Neuroqueering is about being able to access a wider range of options of what your body/mind can do and about reclaiming and exploring your embodiment and affects with the world that surrounds you.

Walker (2021) claims that the current state of autism-related discourses, theory, and praxis in academic and professional spheres is deplorable and reflects a level of ignorance that would be shocking in most academic circles today if it involved any other historically oppressed group. In academia, the autism discourse is dominated by non-autistic voices based on the pathology paradigm. Whereas substantial change for the better will only come if the pathology paradigm is abandoned and a shift is made towards the neurodiversity paradigm. Autism should be written and researched by autistic authors and researchers, since to speak of autism is to

speak of autistics and therefore, we should not be left out.

New Horizons

There is potential in individual experiences that become political – when performative artistic practices transform the limits between private and public spaces (Preciado, 2004). Reflecting on the experience of making this autoethnographic piece, I find engaging with alternative methodologies a powerful way to create new spaces for non-represented voices (not only autistic ones) in a more open way. I understand performing my autistic self as the creation of a political space. A place to stand and invite other autistic (or non-autistic non-represented voices) people to embody themselves as they need. A place of compassion and community. But I do not want you, the possibly non-autistic reader, that went on this journey with me, to leave feeling that I hold resentment against neurotypical people. I would rather like you to feel that there is

possibility in change. There is power in the possibilities that can happen if you think critically about the hegemonic autistic discourse present in the majority of media releases about autism, or in the majority of studies on autism. Do ask yourself: is the professor that gives the lecture on autism autistic? From which paradigm is s/he speaking? If the autistic character of a movie or TV show is not played by an autistic actor, what kind of unidirectional view on autism are they portraying? I ask you, as I ask myself, to root in the never-ending possibilities of human-non-human diversity. I ask you to listen to autistic voices and experiences and to take part in the construction of a bridge between all kinds of neurodiversities.

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