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***Connections Between Sensory Sensitivities in Autism; the Importance of Sensory Friendly Environments for Accessibility and Increased Quality of Life for the Neurodivergent Autistic Minority.***

by  
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# **Connections Between Sensory Sensitivities in Autism; the Importance of Sensory Friendly Environments for Accessibility and Increased Quality of Life for the Neurodivergent Autistic Minority.**

By: Heidi Morgan  
Faculty Mentor: Miranda Cunningham

## **Abstract**

Many adults diagnosed with Autism Spectrum Disorder (ASD) experience sensory processing sensitivities. Research shows that 94.4% of adults with ASD report co-occurring sensory differences that impact their daily life in a significant way. These sensitivities can create accessibility challenges for the autistic neurominority, especially for autistic individuals with hypersensitivities. This literature review has two purposes. First, it seeks to better understand how these sensory differences impact the experience of individuals in the neurodivergent autistic minority and the correlations between sensory overload, accessibility, mental, emotional and physical health. Secondly, the epistemology influencing this review is critical in nature and is aligned with the ideals of the Neurodiversity Movement which seeks to promote the "civil rights, equality, respect, and full societal inclusion for the neurodivergent". The articles included in this review provide a better understanding of how these connections are related to experiences of marginalization due to a neurological divergence.

## **Introduction**

The Statistical Manual for Mental Disorders (DSM-V; American Psychiatric Association, 2013) states that Autism Spectrum Diagnosis (ASD) symptoms must be present from an early age and cannot be explained better with an intellectual disability. These symptoms must cause clinically significant impairment in social and occupational functioning and are characterized by challenges in communication, challenges in social interactions across multiple contexts and engaging frequently in restrictive or repetitive patterns of behavior. ASD may also be accompanied by sensory differences that impact the lives of this population in a significant way.

This is a good summary of the criteria needed for a diagnosis, but autism is more than just a collection of deficits or "unusual" behaviors. Autism can be best understood as a neurological difference that impacts the way autistic individuals experience their daily life. This neurological difference also impacts the way that autistic individuals process the events of their lives as well as the way in which they ascribe meaning to these events. Some of the disabling aspects associated with autism may be better understood through a framework of difference rather than deficits. The autistic neurominority is one of many marginalized communities that make up the neurologically divergent population; such as individuals diagnosed with ADHD, Dyslexia, Epilepsy, Downs Syndrome, Bipolar Disorder, and individuals that have suffered a traumatic brain injury (Armstrong, 2018). Many years of study have given us valuable insight into the areas of struggle faced by the autistic neurominority. Most of the research that has been done has focused on the biomedical/physiological or behavioral/psychological aspects of autism (Whyatt & Torres, 2018). Many of studies continue to use a deficit, rather than a neurodivergent paradigm to form their lines of inquiry and interpret the results of their studies. In this literature review I have chosen to use a broader social lens, focusing on the sensory experiences of the autistic neurominority in relationship to their overlapping marginalized statuses which are

characterized by their neurological divergence, their status as members of the disabled community, and any other marginalized memberships based on individual social location.

## A note about language and definitions

It is important to note here that I have chosen to use identity-centered rather than person-centered language to describe this population. This is informed by my connection to and relationship with autistic individuals in my own life and family as well as my interactions with the local and global autistic community in online forums. Many autistic individuals prefer to use identity-centered language to promote their own self-acceptance and to raise awareness in others of their perspectives about autism (Brown, 2011; Ryan, 2019). I have chosen to follow their example while acknowledging that this is a highly personal preference.

Neurodiversity, neurodivergent, neurominority; these words are often used to describe autistic individuals or populations. However, the meanings of these words are not always clear therefore it is important to define them. *Neurodiversity* is a term used to describe the spectrum of neurology that exists in human beings. This includes individuals in the neuromajority and those in the neurodivergent population. *Neurodivergent (ND)* is used to define an individual or a group of individuals whose neurology diverges from the majority. *Neurotypical (NT)* is used to describe individuals that have a neurology that matches most of the population, in sort it is the opposite of neurodivergent. A *neurodivergent minority* is a subset of individuals with a specific set of common experiences of marginalization and a common type of diagnosis i.e. the autistic neurominority. *The neurodiversity paradigm* is a worldview that embraces the diversity of neurology and does not support the idea of one type of neurology as the norm but places neurological diversity in the same category as any other human diversity (race, gender, sexual orientation). *The neurodiversity movement* is a "social justice movement that seeks civil rights, equality, respect, and full societal inclusion for the neurodivergent." (Walker, [web log comment], 2014).

## Methods

The purpose of this review was to better understand the connection between sensory experiences and their impact on the quality of life for the autistic neurominority. I reviewed studies that focused on sensory experiences, mental, emotional and physical health, chronic stress, allostatic overload, marginalization, and accessibility barriers encountered by autistic individuals. I have also included in my review articles published by the self-advocating autistic community and multimedia internet sources to gain a deeper understanding of the impact of marginalization on this population. My analysis was heavily influenced by Feminist Standpoint Theory (Campbell & Wasco, 2000). This epistemological perspective recognizes that oppressed or marginalized groups have a unique perspective as a result of their marginalized status and seeks to center these perspectives in the creation of knowledge and social change. I have chosen the work of bell hooks and Kimberle Crenshaw to inform my analysis as well as the first-hand accounts, personal perspectives, and stories provided by the self-advocating autistic community. Autistic perspectives are vital to broadening our concepts of autism beyond a deficit-focused understanding. It is my assertion that the lived experiences of these individuals are legitimate sources of knowledge equal to any peer reviewed studies published in academic journals; in short, I consider autistic people the experts about their own lives and as such value their perspectives as experts about their own experiences. In addition to Feminist Standpoint theory my analysis was also influenced by Critical Autism studies (Milton, 2016; O'Dell, Bertilsdotter Rosqvist, Brownslow, & Orsini,

2016; Waltz, 2010) which recognize that relationships of power influence the field of autism and seek to create new narratives of autism that explore a critical skills framework. Critical Autism studies also promote the creation of new and inclusive analytical frameworks which include the study of the culture of autism and acknowledge that autistic experience is highly personal and extremely varied.

The following three questions describe my lines of inquiry.

1. How does marginalization attribute to the mental, emotional, and physical health disparities seen in this population?
2. What is the current status of the mental, emotional health of this population?
3. How are divergent sensory experiences impacting the quality of life and accessibility of the autistic neurominority?

Articles were collected using the Portland State University online library database including Academic Search Premier, Google Scholar, and Web of Science. Journals most frequently referenced and online resources are listed below. The following search terms provide a basic example of the terms used: "sensory sensitivities/Autistic Spectrum Disorder, trauma and ASD, accessibility/ASD, marginalization/ASD, mental health/ASD, critical autism studies, intersectionality, and allostatic overload, Autism and PTSD, sensory barriers in autism." To gain a deeper insight into autistic perspectives I collected data through a variety of media and online resources such as TEDx, Autistic Self Advocating Network (ASAN, 2019), Reddit, and the Participatory Autism Research Collective (PARC, 2019). This information was collected over the course of two years. After data collection was completed, I used thematic analysis to organize the topics into three broad categories: sensory experiences, health, and marginalization. The articles, books, and media sources included in this review were published or presented between 1999-2019.

Journals most frequently referenced

*Autism*

*Autism Dev Discord*

*Journal of Intellectual Disabilities*

*Neuroscience and Behavioral Reviews*

*Development and Psychopathology*

*Personality and Individual Differences*

*Journal of Autism and Developmental Disorders Journal of Intellectual Disabilities*

*Psychological Trauma: Theory, Research, Practice, and Policy*

*Clinical Psychology: Science and Practice.*

## Multi-media and online references

### YouTube

TED Talks

TEDx

Ask and Autistic (Amethyst Schaber)

Asperger's from the Inside (Paul)

### Online forums, networks, blogs, & collectives

Autistic Self Advocacy Network

The Participatory Autism Research Collective

Wrong Planet discussion forum

Reddit (r/autism)

## Autism as a neurological difference rather than a collection of deficits

In the field of autism the diagnosis is framed as a neurological deficit or a breakdown of normalized developmental patterns rather than a variation of neurology or human development. This framing of autism has limited the scope of research in the field prompting researchers to focus on finding a cure, genetic markers, or behavior modification through intervention (Whyatt, & Torres, 2018). The framing of autism as a neurological difference rather than a collection of deficits allows us to view autism in a new light (O'Dell, Bertilsdotter Rosqvist, Brownslow, & Orsini, 2016). This perspective enables us to ask new types of questions and consider new perspectives. For example, a communication deficit can just as easily be viewed as a different style of communication. Repetitive patterns of behavior become resilient coping mechanisms employed as calming techniques or pleasure-seeking activities. "Unusual" behaviors transform into appropriate responses to unseen experiences. The goal then of intervention and research is not to eradicate this difference by "curing" it or to assist the autistic person to behave in a less autistic manner, but to promote inter-neurological fluency for the researcher, interventionist and the autistic individual. This approach inspires us to celebrate the resiliency of this population opening new possibilities for ethical and equal collaboration in future research efforts. It is important that I take a moment to acknowledge that I recognize autism is a developmental condition with many disabling aspects. However, I submit that autism in its broadest sense can be viewed as a neurological difference that impacts the way in which autistic individuals encounter and experience their world. Some of these experiences are problematic due to the centering of a neurohomogenous majority and the marginalization of the neurologically divergent. As is the case with many marginalized populations, the narratives created by the dominant majority have a powerful impact on the self-perception of those who are marginalized, public opinion, policies affecting these marginalized groups, and the research being conducted in academia (Waltz, 2010).

## The neurological population as a minority

The autistic neurominority is a marginalized group and like many other marginalized communities, the autistic neurominority has cultivated resilience, their own culture, and have continued to navigate a world that is not built for them. I am sure some of my readers may be saying to themselves, "A minority group? Well that seems unwarranted." It would be good of me then to clearly define why it is I consider the autistic population a minority group. Louis Worth (1941) defines a minority group as:

those who because of physical or social and cultural differences receive differential treatment ... who regard themselves as a people apart. Such groups characteristically are held in lower esteem, are debarred from certain opportunities, or are excluded from full participation in our national life. Certain groups within our society occupy not merely a disadvantageous objective position but also tend to develop a conception of themselves as inferiors, as aliens, and as persecuted groups, which significantly affects their roles in the collective enterprises of the nation.

The Autistic Self Advocating Network (2019a) explains the implications of marginalized status on the autistic neurominority stating, "Many of the barriers faced by Autistics and others with disabilities arise not from the condition itself, but from prejudice and stereotypes that have the effect of excluding us from full participation as citizens with equal rights and responsibilities in society... When the message of autism awareness becomes one of stigma, dehumanization, and public hysteria rather than one of civil rights, inclusion, and support, we face a grave threat to our efforts to be recognized as full and equal citizens in our communities."

The autistic neurominority has experienced oppression that is historically rooted (Silberman, 2015; Thornberry & Olson, 2005) and continues to experience oppression in the form of ableism, paternalism, lack of employment opportunities (Howlin, 2013), reduced personal agency, access to appropriate accommodations in healthcare settings (Raymaker, McDonald, Ashkenazy, Gerrity, Baggs, Kripeki, Hourston, & Nicolaidis, 2017), and violence that continues in educational settings (exclusion and restraint) (Butler, 2009; Harkin, 2014; Phillips, 2012). Autistic individuals are more at risk than the general population for childhood abuse, sexual abuse, and sexual assault (Brown, Vallejo Peña, & Rankin, 2017; Hughes, Robinson-Whelen, Raymaker, Lund, Oschwald, Katz, Starr, Ashkenazy, Powers, Nicolaidis, & Partnering with People with Disabilities to Address Violence Consortium, 2019; Platt, Powers, Leotti, Hughes, Robinson-Whelen, Osburn, Ashkenazy, Beers, Lund, Nicolaidis, & Partnering With People With Disabilities to Address Violence Consortium 2017). These forms of violence have negative impacts on individuals with developmental disabilities, including the autistic population, and are correlated with higher rates of psychiatric conditions.

A literature review examining the prevalence of abuse in this population (Hughes, Lund, Gabrielli, Curry, & Powers, 2011) found that the prevalence of interpersonal violence (IPV) throughout the lifespan of adults with disabilities living in a community setting was 26-90% for women and 28.7-86.7% for men. This IPV happens in relationships with people such as family members, Personal Support Workers (PSWs), intimate partners, medical providers, and strangers. These forms of violence are particularly harmful because they may involve disability-related abuse (destruction of adaptive equipment, denial of needed assistance for daily living tasks, and medication manipulation). Disability-related abuse (Hughes, Robinson-Whelen, Raymaker, Lund, Oschwald, Katz, Starr, Ashkenazy, Powers, Nicolaidis, & Partnering with People with Disabilities to Address Violence Consortium, 2019) is an

additional form of oppression that is unique to the disabled population despite social location and must be factored into any analysis of the disparities that exist for the autistic neurominority. It is important to understand that these forms of violence and discrimination are compounded by a neurology that is divergent and that these events may be interpreted and experienced in a unique way.

The roots of injustice begin with an imbalance of power. One of the ways this power imbalance can be seen is in the definitions assigned to individuals and communities by those in proximity to power. Those who hold a place of power can then use this position to further solidify their status by defining what is considered "normal". This "normalization" of their particular culture, race, sexual preference, gender presentation, religion, body, or neurology provides opportunities to define others who are different from them as less-than, broken, sub-human, or savage. Many of these kinds of definitions have been used to describe marginalized communities (Johnson, 2018; Kirk & Okazawa-Rey, 2018; Tatum, 2018; Wing Sue, 2018). Those who hold little to no power within a society, in this case, the autistic individual, or the autistic neurominority, have often been defined by using terms that describe their differences as deformities of neurology and development (Waltz, 2005). The centering of one type of neurology as "normal" does not allow space for the variation of the human mind. Anyone with a different type of neurology can by these standards be defined as atypical, delayed, broken, or in need of fixing or curing. Elizabeth Janeway states that "the refusal to accept the definition of oneself that is put forth by the powerful" is in fact a form of power (as quoted by bell hooks, 2000, p. 92). This refusal of the definitions often assigned to autistic people can be seen clearly in the self-advocating autistic community. In order to better understand the lived experiences of autistic people, it is important to listen to the way they have chosen to define themselves and what they are saying about their own experiences in the world. Lynda Brown addresses this battle of definitions while talking about the use of identity-centered language stating, "The question of person-first language is definitely important and cannot be disregarded. The way we use language affects those around us -- in our immediate communities and in society at large. Trends of language have the power to transform ideas and attitudes. To dismiss this as "a silly semantics argument" denies the power of language."(Brown, [web log comment], 2011).

The marginalization of the autistic population is unique in that it compounds any additional forms of oppression linked with social location. After all, the autistic population is extremely diverse, including individuals from every race, gender, age, socioeconomic background, nationality, and religion. Depending on where an individual is located in relationship to the center of power in a society drastically changes their lived experience in that society. Those who live on the margins lack the same access to change the society they live in and are therefore forced to choose between conforming to or rebelling against these prescribed norms.

Kimberle Crenshaw (1991) has written extensively about the impact of overlapping marginalized identities, specifically, class, sex, and race; for instance, when speaking about the difficult experience of leaving a domestic violence situation Crenshaw states, "Where systems of race, gender, and class domination converge, as they do in the experiences of battered women of color, intervention strategies based solely on the experiences of women who do not share the same class or race backgrounds will be of limited help to women who because of race and class face different obstacles" (Crenshaw, 1991, p. 1246). She defines this compounding of oppressions as "intersectionality." In relationship to subordinate status within a society she states, "Intersectional subordination need not be intentionally produced; in fact, it is frequently the consequence of the imposition of one burden that interacts with preexisting vulnerabilities to create yet another dimension of disempowerment" (Crenshaw, 1991, p. 1249). Applying the lens of intersectionality to the

autistic neurominority allows us to understand that the marginalization of this population is not uniform but is complicated by additional factors related to social location. Autistic individuals who have multiple preexisting vulnerabilities will be at greater risk mental, emotional, and physical harm.

For example, these preexisting vulnerabilities play a role in the underrepresentation and under diagnosis of autism in people of color as well as young girls and women. In examining the literature it becomes apparent that the male, Caucasian population is overrepresented not only in the rates of diagnosis but in autism research studies as well. An article (Silberman, 2016) examining the history of autism diagnosis in the Black community reported that African Americans have been under diagnosed or repeatedly misdiagnosed with ADHD, behavioral, or other learning disabilities. Silberman (2016) suggests this is due to the origins of the autism diagnosis which was originally thought to only impact upper-middle class prominent White families. This is not the case however; the underrepresentation of people of color in research has led to a delay of ASD diagnosis, particularly in African American families. One study assessed the correlation of race and age in childhood diagnosis of autism and found that many African American children who were later diagnosed with ASD were initially thought to have conduct or adjustment disorders as compared to their White peers who were thought to have developmental delays or learning disabilities (Mandell, Wiggins, Yeargin-Allsopp, Carpenter, Daniels, Thomas, & Kirby. 2009). Mandell and colleagues also found that African American children were diagnosed 1.5 years later than White children. It is important to point out that the stereotypes often placed upon adults in the African American community play a part in influencing the perceptions of African American children as well. These negative stereotypes have the power to influence the perspectives of teachers and medical professionals.

As African American (people who are Black, African American, or a member of the African diaspora) children age into adulthood these stereotypes continue to impact their quality of life, morphing into more visceral forms of oppression. One African American mother shared her concerns about her autistic son and the dangers he would face as a man, particularly when engaging with law enforcement (Martin, 2016). She stated,

"...if an officer stops a young man who is on the spectrum and he asks the man - asks the young man a question and the young man doesn't answer right away - and so of course, the police officer asks again, maybe two or three times. He's getting agitated. The young man gets a little agitated, and then he yells an answer. Immediately, that could, you know, prove to be something detrimental. And I worry about that with my son as he gets older because he - takes time for him to answer questions. And sometimes when he answers, he answers kind of in a loud roar. And he's not angry, but that's what he does."

This is just one example of the kind of intersectionality that Crenshaw (1991) highlights. The preexisting vulnerabilities of being Black and autistic are compounded by systemic forms of racism within the American society. However, the African American community and people of color in general are not the only ones who are underrepresented, or misdiagnosed, young autistic girls and women are often overlooked as well.

Young girls and women tend to have lower rates of ASD diagnosis. Perhaps this is because many of the screening tools used to identify autism have been developed by centering the early signs of autism as they present in young boys. One of the most visible signs of autism in young children, especially young boys is their desire to isolate from their peers and not engage in social play. Many of the social markers in autism, such as playing alone and not

engaging in peer dialogue, are not as obvious in autistic female children. Higher rates of ASD diagnosis in the male population are not necessarily due to the fact that autism affects young boys and men more, but that autism can present quite differently in young girls and women due to gender specific socialization. At a distance, young autistic girls can appear to be engaged in social play. It is only upon closer observation that differences become apparent. For instance, autistic girls struggle to maintain group social norms or as Judith Gould states, "maintain mutual engagement in activities requiring social synchronization" (Gould, 2017, p. 703). Young girls are often socialized to be more active in social peer relationships even if navigating these relationships is challenging. Because of this it is common for autistic girls to mask their autistic differences leading to later diagnosis, or for some, no diagnosis at all.

## The impact of chronic stress on the autistic neurominority

It is important that we look at the cost of navigating the world in a state of chronic stress. Whether this stress is caused by marginalization, sensory divergence, social challenges, communication differences, or any of the other complications associated with autism. Autism literature has quite a few studies that focus on the role of stress in the autistic individual's life. It is quite clear that anxiety is prevalent with this population (Gillott & Standen, 2007, Hirvikoski & Blomqvist, 2014). The impact of these stressors are commonly talked and written about by autistic self-advocates (Baggs, 2007; Beckwith-Fellows, 2017; Botha, 2016; Raymaker, 2017). Analyzing these sources makes it clear that chronic stress is a lifelong experience for the autistic individual. This type of chronic stress can have a deteriorating effect on the mental and emotional health of autistic individuals as well as possible long-term outcomes for physical health tied to allostasis and allostatic overload.

## Mental illness comorbidity

Mental illness is a significant factor impacting the autistic neurominority. For instance, autistic adults are 2.9 times more likely to be diagnosed with depression and 22 times more likely to be diagnosed with schizophrenia as compared to non-autistic individuals (Croen, Zerbo, Qian, Massolo, Rich, Sidney, & Kripke, 2015). Croen and colleagues conducted a survey of medical records to assess mental health disparities among autistic and non-autistic individuals. A higher rate of psychiatric conditions was found in the autistic population as well as a fivefold higher rate of attempted suicide. Of the 1507 autistic individuals included in this review 54% were diagnosed with a psychiatric condition (Anxiety 29%, Bipolar Disorder, 11%, Depression 26%, Obsessive-Compulsive Disorder 8%, Schizophrenia 8%).

This data indicates the prevalence of psychiatric conditions within the autistic neurominority. These conditions tend to arise in adolescents and adulthood suggesting that there may be some correlation between chronic stress and the mental health of this neurominority. One literary review analyzed the prevalence (Hedley & Uljavervic, 2018) of suicide and suicidal ideation in the autistic population. This review summarized the literature published over the last five years relevant to this topic and included studies published from seven different countries (U.S, Japan, Sweden, Australia, Canada, Turkey, and the UK). The findings were alarming. Among the autistic population suicidal ideation was as high as 66%, suicide attempts were as high as 35%, and premature death by suicide was .31% in the autistic population as compared to .04% of the general population.

To clarify these numbers, 66% of autistic individuals are considering or have considered attempting suicide. Thirty-five percent have actually attempted suicide, and .31% unfortunately were successful in their attempts. This is more than a significant disparity, it is a wakeup call. The people most at risk in the autistic neurominority were individuals who were diagnosed with Asperger's Syndrome (now included in the broader spectrum of ASD) and Black or Hispanic autistic men. The authors hypothesized that the higher rate of attempted suicide in individuals with Asperger's may be correlated with the level of awareness of peer exclusion and isolation. It is my hypothesis that the higher rates of attempted suicide in African American and Hispanic autistic men are a direct result of intersectional marginalization.

These findings should cause us to pause and consider yet again, that trauma may present differently in this population. Croen (2015) speaks to this issue succinctly by stating, "Of particular concern is the fivefold higher rate of diagnosed suicide attempts we observed among adults with ASD compared to controls. Nearly half of the adults with ASD with a diagnosis of attempted suicide did not also have a diagnosis of depression, suggesting that depression may be underdiagnosed in the autistic population, resulting in lack of needed treatment." (Croen, et al, 2015, p. 819). One of the challenges in addressing mental health issues is a lack of diagnostic tools that are specifically designed to assess mental and emotional health of neurodivergent populations adequately (Hoover, 2015; Taylor & Gotham, 2016; King, 2010; Mehtar, & Motavalli Mukaddes, 2011; Kerns, Renno, Kendall, Wood, & Storch, 2017; Rumball, 2017). In order to improve the quality of life and increase the life expectancy of the autistic neurominority we must reassess our preconceived notions of how trauma may present in this population. The autistic neurominority may be experiencing legitimate traumas that are being overlooked or dismissed as a part of the ASD diagnosis. Therefore, it is important to assess what is currently known about the way in which autistic individuals respond to trauma.

### Physical impact of chronic stress

Stress is more than just a frantic state of mind; in fact, chronic stress throughout the lifespan can lead to negative health outcomes directly connected to stress. The study of chronic illness related to stress is rooted in an understanding of allostasis and allostatic overload. Juster and colleagues introduce the concepts of allostasis and allostatic overload. A study published in 2010 (Juster, McEwen, & Lupien, 2010) describe the concepts of allostasis. This study included the 10 biomarkers that can be found in individuals who experience chronic stress, touching on the impact of allostatic overload throughout the lifespan. Allostatic overload is often triggered by chronic stress and can be caused when there is an imbalance of energy available for the body to use at any given time. For instance, when the energy demanded is less than the energy needed to function, or when the energy present in the body is much more than the body can use. This imbalance can also cause problems for cognitive function, especially when stressful or traumatic events happen at key developmental phases in the lifespan (Gunnar & Cheatham, 2003).

Identifying these biomarkers is an important preventative step for physical and cognitive health. The 10 biomarkers chosen are found in the body as a result of the overactivation of the Hypothalamic Pituitary Adrenal Axis (HPA Axis), the three components of the brain that process stress and fight or flight responses. Long-term exposure to stress causes this overactivation, leading to imbalances in the body. When chronic stress is not addressed it can lead to a breakdown of body systems and create health problems later in life such as

heart disease, hypertension, increased cases of dementia, anxiety & depression, & compromised immune systems.

As noted before, the autistic neurominority experiences higher amounts of stress than the general population. The long-term effects of this stress may be connected to the chronic illnesses reported as the outcome of allostatic overload. Autistic adults not only have a much higher rate of diagnosis for comorbid mental health issues, they also have a higher rate of medical conditions as well (Croen, Zerbo, Qian, Massolo, Rich, Sidney, & Kripke, 2015). Medical conditions that are commonly reported include: immune conditions, gastrointestinal and sleep disorders, seizures, obesity, dyslipidemia, hypertension, and diabetes.

While it's true that there are some correlations between the medical conditions reported by autistic adults and the chronic illness resulting from allostatic overload this correlation may be attributed to other factors that are not stress related such as restrictive diets and lifestyle choices impacting heart health and rates of diabetes and obesity. However, I did not find any studies done to ascertain the correlation of allostatic overload as it pertains to autism. The field of autism research would benefit from studies that assess this possible correlation leading to more targeted health interventions that involve reducing the amount of stress this population experiences. Improved diagnostic tools and research assessing correlations between allostatic overload and chronic illnesses prevalent in this population are not enough. It is also important to consider sensory environments and assess how these environments may be increasing the stress of the neurodivergent population. The experience of navigating the social landscape as an autistic person is challenging enough; however, these social interactions don't happen in a bubble. They take place in sensory environments that may be further complicating and intensifying these challenges. By gaining a better understanding of the way in which the autistic neurominority interacts with their sensory environment, and by understanding the relationship between sensory sensitivities and stress, the repercussions of the lack of sensory safe spaces becomes increasingly evident.

## Sensory differences

Sensory experience impacts every aspect of our lives. Our senses: vision, hearing, olfactory, tactile, vestibular, and proprioceptive are what connect us to the world around us and within us. Our senses alert us to danger and facilitate comfort when it is needed. Our senses are also important when we communicate with others around us. What happens then, if the way in which we experience our sensory world is remarkably different than the majority of the people around us? This is the case for individuals with sensory divergence. Some of the unique aspects of autism may be linked to this difference. It is important to note here that the autistic neurominority is not the only population that has divergent sensory experiences. Individuals diagnosed with ADD, ADHD, Bi-polar Disorder, Schizophrenia, Fibromyalgia, and PTSD have also reported these differences.

Before we can begin to discuss how sensory differences are experienced by the autistic neurominority we must understand hyper/hypo sensitivities (Bogdashina, 2014; Elwin, Schroder, Ek, Wallsten, & Kjellin, 2017; Kern, Travedi, Grannemann, Garver, Johnson, Andrews, Salva, Mehta, & Schroder, 2007; Liss, Mailloux, & Erchull, 2008). Hypersensitivity to sensory input means that the threshold for sensory input is much lower than the general population. Hyposensitivity to sensory input means that the individual has a High Sensory

Threshold (HST) and will be less affected by the external sensory environment requiring more sensory input to register sensory sensations. This hyposensitivity results in less recognition, discrimination, registration of sensory input, and increases the craving for specific types of sensory stimuli. Individuals with hypersensitivities report more reactions to external stimuli, while individuals with hyposensitivities report more reactions to internal, body stimuli; combination of both hyper/hypo is reported by many autistic individuals. (Elwin, Ek, Schroder, & Kjellin, 2012).

An individual with a Low Sensory Threshold (LST) will be more affected by external sensory experiences and may be sensitive input that would not register with the general population. An example of this which is commonly reported among the autistic individuals is sensitivity to certain kinds of lighting, specifically, fluorescent lighting. Autistic people who experience sensitivities to fluorescent lighting report feeling uncomfortable in environments where this lighting is present. One study that assessed the role of sensory experiences in daily life (Robertson & Simmons, 2015) included reports of the participants about their experiences. When speaking about sensitivity to lighting one participant noted, "my eyes have struggled in sort of like fluorescent light or unnatural light ... that sort of stimulus becomes painful after a while" (p.575). Sensory sensitivities were not limited to visual processing differences however, they also included audio sensitivities (more than one radio playing at a time or volume level) and olfactory sensitivities (hand sanitizer and air fresheners). These examples represent experiences that are not commonly reported among the general population as problematic. Sensory experiences are as unique as the individuals that are having them. It is important to note that the examples provided are not an accurate reflection of all sensory divergent experiences but serve to provide a better understanding of the type of problematic experiences often reported by autistic individuals. Autistic people with hypersensitivities are profoundly impacted by their sensory environment which may make navigating public spaces uniquely challenging for them. There were very few studies in the literature that addressed how these sensory differences may be creating accessibility issues. Future studies would benefit by assessing the correlation of sensory sensitives and accessibility.

### Correlations between sensory experiences, anxiety, and depression in autism

I reviewed studies seeking to assess the relationship between sensory differences in the autistic population and their relationship to stress (Elwin, Schroder, Ek, Wallsten, & Kjellin, 2016; Green & Ben-Sasson, 2010; Horder, Wilson, Mendez, & Murphy, 2014). These studies found correlations between emotional states and sensory experiences, such as anxiety/hypersensitivity and depression/hyposensitivity. Anxiety was reported in the cases of hypersensitivity. Green & Ben-Sasson (2010) noted that autistic children with hypersensitivities tended to be hypervigilant, scanning their environment for unwanted sensory stimuli, noting that anxiety may lead to emotional hyperarousal and a decreased ability to regulate emotion and reaction to sensory stimuli. Associations created by this combination (anxiety, hyperarousal, and hypersensitivity) can lead to the generalizing of environments as unfriendly or dangerous due to context conditioning. Many of the studies published about sensory experiences over the past 30 years have tended to focus on children and adolescents however, increasingly studies are being conducted with autistic adults who can offer valuable insights not available prior to their inclusion.

In 2007 a study found that heightened levels of anxiety in autistic adults impacted their ability to cope with everyday stressors such as: change, anticipation, sensory stimuli and unpleasant events (Gillot & Standen, 2007). The purpose of this study was to evaluate whether elevated levels of anxiety, often reported in autistic children, remain in adulthood

as well as to identify some of the sources of anxiety present for autistic adults and to compare these sensory experiences with the general population. They concluded that heightened generalized anxiety was present for most autistic adults as compared to their peers. However, they determined that although general anxiety levels were present in each of the autistic adult participants, they were present at a lower level than most autistic children. It is important to note that the measures used in this study were modified to reflect the target population by replacing wording as needed (i.e., college instead of daycare center) but these minor revisions were not enough to completely evaluate autistic adult life. These findings suggested that levels of anxiety dissipate as an autistic person ages, either because these symptoms decrease over time or the ability to utilize calming strategies increases with practice. However, a study published two years later presented very different findings (Crane, Goddard, & Pring, 2009). Crane and colleagues assessed the sensory processing in autistic adults using measures that were more appropriate to adult experience and determined 94.4% of the autistic adults surveyed experience significant sensory processing issues. They also confirmed that sensory processing issues persisted throughout the lifespan. Much of the autism research that had been up to this point was conducted with children and adolescents. This is one of the studies that marked a new direction in the field, one that began focusing on the experiences of autistic adults. In conducting this study Crane, Goddard and Pring (2009) happened upon something that the autistic neurominority had known for a long time, that divergent sensory experiences are a daily reality for autistic adults and that they significantly affect the way autistic adults interact with the world around them.

In subsequent studies (Elwin, Schroder, Ek, & Kjellin, 2016; Horder, Wilson, Mendez, & Murphy, 2013) these percentages remain fairly consistent, within the 95-94.4% range representing a majority of the autistic adult population. These divergent sensory experiences create an additional vulnerability that must be considered in our assessment of the of the marginalization of the autistic neurominority. I am not suggesting that these sensory experiences are uniform only that they are widespread and impact many people on the spectrum. The unique way in which each autistic individual experiences their sensory world is specific to them. However, sensory divergence can have a powerful impact on the way in which autistic individuals navigate public spaces such as: educational and healthcare settings, human resource offices, criminal justice and legal offices, modes of public transportation, and grocery stores. These spaces are over- saturated with sensory stimuli. The sensory landscape of these environments may play a part in limiting access to vital centers of public life. However, due to the unseen nature of sensory experience these barriers are often overlooked and often not addressed in the literature.

### Access Barriers in Healthcare settings

Recent research has begun to address some of the accessibility issues that impact this population regarding healthcare. The Academic Autism Spectrum Partnership in Research and Education (AASPIRE) is a collaborative research partnership that involves both the academic community and the autistic adult community. AASIPRE's dedication to the principles of Community Based Participatory Research (CBPR) has resulted in some of the most ground-breaking studies in the field pertaining to accessibility and assessment of the quality of life for the autistic neurominority.

One such study ((Raymaker, McDonald, Ashkenazy, Gerrity, Baggs, Kripeki, Hourston, & Nicolaidis, 2017) evaluated the experiences of autistic adults in healthcare settings. The aim of the study was to identify the barriers experienced by autistic adults as compared to non-disabled individuals and non-autistic disabled individuals. Of 437 participants (173 were non-disabled and non-autistic (NDNA). Fifty-five participants had a disability but were non-

autistic (DNA). And 209 identified as autistic. A clear pattern emerged in the data. Not only did autistic individuals endorse more barriers than the other participants (NDNA 10, DNA 34, autistic 56), the percentage of endorsement was higher and different kinds of barriers were reported which reflect the unique challenges associated with autism. Some of these barriers included challenges with patient-provider communication (inadequate time to talk to and process real-time conversations with their providers), sensory issues caused by the facility, and emotional regulation barriers caused by unexpected changes to routines. This study provides clarity about the kinds of access barriers that are unique to autistic individuals in healthcare settings. It is important to note that a barrier caused by the sensory environment was only endorsed as problematic by autistic individuals. This leads me to question, if sensory environments can create accessibility issues in healthcare settings, what other vital public spaces have similar barriers? I was not able to locate any other studies done to assess the way in which sensory acts a barrier in public spaces. This study led to the development of the AASPIRE Healthcare Toolkit (Nicolaidis, Raymaker, McDonald, Kapp, Weiner, Ashkenazy, Gerrity, Kripke, Platt & Baggs, 2016). This toolkit allows patients to customize their accommodations and share this information with their primary care providers. This resource is outcome of the using the CBPR method. The inclusion of the perspectives and knowledge of the autistic population was vital in the creation of this toolkit that will greatly improve the access of not just the autistic neurominority, but other disabled individuals with similar accommodation needs. The use of CBPR with the autistic community is revolutionizing the field. Dora Raymaker, co-founder of AASPIRE who also identifies as an autistic academic, describes why the use of a CBPR methodology with the autistic population is so important. Dora states, "For me, the main value of this work is the of larger connections between science and broader systems change in that I think that involving people, who have not been given voice in research, and giving them control over research that impacts their own lives creates another feedback loop that changes things" (Han, Nicolaidis, & Raymaker, 2015, p.176). Collaborating with the autistic population in the creation of academic knowledge is not only ethical, it is long overdue.

### Self-advocating autistic perspectives

The autistic community has for many years not been a part of the conversations taking place about them in academic research and at times, in autism advocacy. This becomes evident when we take the time to listen to what the community is saying. One example of this dissonance can be clearly seen in the conflict the community has with Autism Speaks. Autism Speaks is an autism awareness and fundraising non-profit (autismspeaks.org, 2019). This non-profit has met resistance from the autistic community for promoting harmful narratives about autism, exclusion of autistic individuals and perspectives in their non-profit, and using the funds they raise for research that opposes the values of the autistic community such as searching for a cure, the development of behavior modification techniques used to mask autistic traits, and genetic research looking for the autism gene (Semler, 2019). In fact this division is well know and ongoing. Recently Sesame Street experienced a great deal of backlash for promoting Autism Speaks in a public service ad (Wanshel, 2019). The popular children's show sought to raise awareness about autism by creating an autistic character named Julia (Sesame Workshop, 2019). However, the endorsement of Autism Speaks by Sesame Street has led the autistic self-advocacy group Autistic Self Advocacy Network (2019b) to cut ties with the program. ASAN elaborates on this decision by stating,

Too often, parents of autistic children are bombarded with terrifying messages. They are told that their autistic child will destroy their marriage and their nondisabled children's lives. They are told that their child's happiness — and their own — depends on the child "getting better" by hiding their autistic traits, and to work

toward this goal above all else. They are told to grieve for the hypothetical nondisabled child they had imagined, rather than to love and connect to the autistic child in front of them. These messages hurt autistic people, scare our families, and encourage our communities to fear and exclude us. Autism Speaks has played a central role in developing them.

Clearly, there is powerful opposition to Autism Speaks from within the autistic community. This is so common that a well-known phrase has emerged within the community, "Autism Speaks does not speak for me" (Ramos, 2017). Disabled individuals are often the target of benevolent forms of oppression such as speaking for a disabled person without their consent. These microaggressions are demeaning, especially when the individual is capable of speaking for themselves. Arundhati Roy, celebrated author and speaker addresses the myth of voice-lessness stating "There's really no such thing as the 'voiceless'. There are only the deliberately silenced, or the preferably unheard." (Roy, 2004). The autistic community is not voiceless, in fact they have been speaking for many years and what they have to say is vital for the future of the autistic neurominority, and the future of autism research.

### Voices in the community

Temple Grandin, a well-known author and speaker has worked to promote a better understanding of autism and the uniqueness of neurodivergent minds (Grandin, 2012). Her efforts have promoted more awareness and acceptance of autism throughout the world. Grandin is one among many self-advocating adults helping to transform harmful narratives and stereotypes about autism today.

Amanda Baggs, one of the first autistic self-advocates to use YouTube as a platform for raising awareness about autism and autistic experiences. Baggs addresses some of the myths about autistic individuals and their experiences of the world. In her video, *In my own language* (Baggs, 2007) she states, "I find it very interesting...that failure to learn your language is seen as a deficit but failure to learn my language is seen as so natural that people like me are officially described as mysterious and puzzling rather than anyone admitting that it is themselves who are confused not autistic people or other cognitively disabled people...Only when the many shapes of personhood are recognized will justice and human rights be possible." Baggs describes something that resounds throughout the autistic community. The dehumanizing effect of being defined as abnormal instead of different not only has a marginalizing impact on this community, but it solidifies the power and privilege of the neuromajority, concealing it even from those who consider themselves neurotypical.

Other self-advocates have followed in the footsteps of Amanda Baggs and have chosen to create YouTube channels and blogs to promote neurodiversity and educate non-autistic people about autistic experiences or support individuals in the autistic community (Asperger's from the inside, 2019; Queen of the Drowned, 2019; Schaber, 2019). The self-advocacy of the autistic neurominority extends beyond blogs and YouTube channels. In fact there are many organizations that promote the wellbeing and the rights of the autistic community who are led by self-advocates such as Pittsburgh Center for Autistic Advocacy (PCAA, 2019), Autistic Self Advocacy Network (ASAN, 2019a), Autistic Women & Nonbinary Network (AWN, 2019), & Self Advocates United as 1 (SAU1, 2019).

## Partnership in research

Self-advocacy is also changing the way research is being conducted. Partnerships between the academic world and the autistic community are beginning to form. This collaboration is revolutionary for both the field of autism research and autistic community. For instance The Theorizing Autism Project (Greenstein, 2014) conducted one-day seminars in 2014 to facilitate ethical collaboration between the autistic community members and academic researchers. The topics were presented by autistic individuals and covered a variety of issues such as the misaligned goals of research and the needs of the autistic community, negative cultural perceptions of autism in the media and research. This seminar conducted participatory workshops to strengthen collaborative partnerships and improve the CBPR process. These workshops lead to the creation of other similarly aligned organizations. The Participatory Autism Research Collective (PARC, 2019) based in the U.K. and the Academic Autism Spectrum Partnership in Research and Education (AASPIRE, 2019) based in the United States.

AASPIRE has been partnering with autistic community since 2008 and has published multiple studies that have focused on barriers in healthcare and intimate partner violence. They are currently in the process of publishing a study about autistic burnout, the first of its kind in academia, and finishing a pilot study assessing successful interventions in employment settings. This pilot study will be used to develop a model of intervention to improve professional outcomes for autistic individuals. Utilizing the CBPR method with the autistic community is one of the best ways to ensure the studies being done are ethical and will address the needs of the community.

## Gaps in research

The autistic neurominority is a resilient but misunderstood community. The struggles of this marginalized group are often hidden behind the veil of disability. The neurodiversity paradigm allows us to pull this veil back and consider the possibilities resulting from ethical allyship, inter-neurological fluency, and collaboration with this community in future research efforts. This review was done to evaluate the factors that are impacting the quality of life for autistic individuals. There have been some positive breakthroughs in recent years, but there is still much work to be done. The following is an examination of some of the gaps that still exist in the field.

The autistic community is extraordinarily diverse. We must recognize that social location plays a significant role in the complex marginalization of autistic individuals. To disregard the impact of intersectional oppression is not just remiss it is an act of compliance, helping to construct the very systems that create these disparities. Using the framework of intersectionality will provide us with a more accurate picture of the challenges that exist for this population within a broader social context.

The amount of stress frequently experienced by this population, exhibited in the pervasive anxiety that has been reported in the literature, may be correlated with multiple forms of marginalization. The high number of psychiatric diagnosis in this population in conjunction with high rates of suicide and suicidal ideation require us to pause and reconsider what we know about the nature of autistic trauma. The tools we currently use to assess trauma, and our present understanding of what constitutes a traumatic event for this population need to be reconsidered as well.

The possible correlations between chronic stress and chronic illnesses resulting from allostatic overload are under studied at this time. To improve the health of this population it is important to verify if any correlations exist.

Stress and its relationship with sensory sensitivities have been qualified in the literature. However, what is largely absent is the way in which these sensitivities interact with public spaces resulting in accessibility issues. Future studies would benefit from research addressing sensory experience as a barrier.

Finally, a reassessment of standard ways in which autism presents, specifically in young girls and women is needed to address the occurrence of late diagnosis in autistic females. Rethinking methodologies and addressing the negative stigma that exists between researchers and communities of color will help to increase participation in future studies, leading to earlier rates of diagnosis for these populations.

## Limitations

In line with the ethics of power sharing and self disclosure championed by feminist theory and the ideals of critical autism studies I acknowledge that I have many forms of privilege, some of which may distort or inform my perspectives. I identify as a White, non-autistic, queer woman. I am aware in some part of the liberties I have because of my social location. For instance I have been granted the privilege of writing the review you are currently reading. I acknowledge that this has given me a voice and the power to speak about the autistic neurominority, when others who may have much more insight to provide have not been given this opportunity. I acknowledge the blind spots that I have due to my race and social conditioning. I may not be aware of racist concepts or language I use in speaking about racial inequality and identity. In addressing intersectionality as it pertains to race, I acknowledge that the literature I highlighted for this review focuses primarily on the African American community. Many people of color experience similar disparities regarding late diagnosis and misdiagnosis. Finally, this review was informed by the articles I have read to date. I acknowledge that there many more studies I did not review that may have expanded my perspectives or influenced my conclusions.

## Conclusion

Improving the quality of life for the autistic neurominority begins with listening to the autistic community which has been speaking plainly about their needs for many years. The way forward has already been pioneered by researchers who actively include this population in their research efforts by utilizing a CBPR methodology. The outcome of these collaborations has resulted in the improved quality of life of autistic individuals by uncovering what can only be seen through autistic eyes. Many people in the field of autism research are looking for solutions to improve the quality of life for autistic people. Attempting to correct the problems experienced by autistic individuals using only the perspectives of the neuromajority is akin to trying to unlock the right door with the wrong key. It is my strong assertion that the key we have been looking for can be found in the perspectives of the autistic neurominority. And that this door can be opened by ethical collaboration with the autistic community.

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