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PHIL 199F - Independent Study: Autism and Intersectionality

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**Autism and Intersectionality:
Four Identity Intersections
and Autism's Face**

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Introduction

Autism has a face. It is a face which is seen on billboards, on health websites, and in lectures. It is a face which has materialized along with society's understanding of autism, always coming to mind first when the condition is mentioned. It is more than likely the face you are imagining now. This face is, as is the case with many perceptions in modern Western society, the face of a young, white, and male-presenting individual. The issue is that this face is a facade, a mask drawn out from a single type of autistic experience which the very concept of autism has been conditioned to wear. The reality is that autism has a true face, or rather it has a multitude of true faces which have been obscured by hegemony. In this essay, I will attempt to bring a few of these obscured faces into clear view, and to illustrate that autistic existence is far more complex, and far more variable, than most have ever cared to realize.

A few disclaimers before we continue. Firstly, this paper was originally meant to contain interviews with autistic individuals belonging to each of the groups highlighted throughout the work. For a variety of reasons, I was unable to record more than a single interview. The handwritten transcript of the one interview is provided regardless, as I consider it to be a valuable resource in itself. Just know that the first-person insights gained from this resource are vital, and that in the future I hope to gather those insights with regards to the other groups as well. That all being said, if you yourself are non-autistic and know or know of anyone who falls into the categories described, or into other categories I failed to bring up, I highly recommend that you sit down and have a conversation with them; you may very well learn more than you expect to. Secondly, there are several intersections I did not have the time, space, or knowledge to cover in this work, some examples being the intersections between autism and womanhood, sexual orientation, and specific cultural experiences, among a multitude of others I am sure. I

hope to cover these topics at a later date. Lastly, though it will not be much explored in this essay, it is important to remember when discussing intersectionality through a nexus viewpoint, i.e. focusing on how one identifying trait intermingles with several others, that not only do the various identities affect the experience of the nexus identity, but the nexus identity in turn affects the experience of the varying identities. In other words, if someone is an autistic and transgender person, not only will their being transgender affect their experience of autism, but their being autistic will affect their experience of being transgender. With all of that out of the way, I hope that you enter this paper with an open mind, and come away from it having learned something valuable.

I: Autism and Nationality/Culture Transition

In the introduction, I explained that I did not have the time to cover in-depth how specific cultural existences intersect with autistic experience. True to that statement, this is not what this section covers. This section is devoted to two themes. Firstly, it explores how *general* differences across a variety of national cultures, with brief examples provided, can lead to differing experiences of autism. Secondly, the knowledge gained from that exercise is used to examine the autistic experience of cultural transition, or emigration/immigration.

For the first portion of this section, we will examine two notable culture differences that emerged repeatedly when researching how nationality can affect autistic experience. The first of these is as follows: cultures which place a heavy emphasis on collectivity can enact special harm on autistic people, who tend to stand out in social and communicative spaces, while more individualistic cultures, though problematic in other ways, provide more room for autistic people to deviate from the norm without being paid much attention to. This point bears both clarification and complication. As the above note states, due to the general tendency of autistic individuals to stand out at some point or another as a result of their non-normative behaviors — this is a generalization and by no means true for all autistic individuals — cultures which place a greater emphasis on the good of conformity and smooth social interactions can make life more difficult for many autistic people. To draw from a specific example, author Hyun Uk Kim describes Korean culture as valuing “harmony in family and society, humanity, ethical morality, spirituality, loyalty, respect for elders, and rank, [values which] are manifested in collectivism and authoritarianism.”¹ Though of course not all Koreans hold any or all of these as core values, the general trend in Korean society, at least as of 2012 when this paper was published, is to adhere closely to them. Kim goes on to explain the ways in which this adherence can affect

¹ Hyun Uk Kim, 2012, “Autism Across Cultures: Rethinking Autism,” *Disability & Society*, 27(4), 535-545. 537.

people with autism and their loved ones. In Korea, a child exhibiting a mental disability, autism included, can be framed as a source of shame, especially for the mother of that child. Much like with Leo Kanner's "refrigerator mothers" in the early days of autism research, a hyper-focus on the social aspects of autism leads to a misjudgment that autism must itself be caused socially, the mother's behavior almost always being where the blame falls.^{2 3} Korean concepts of social status can also produce this effect; Kim states, "When you are married and have a child, you are no longer called by your own first name. You are identified as so-and-so's father or mother, which continues throughout your life. Your child or spouse defines your social stratification."⁴ Effectively, a mother's value is reflected in their child, and if their child has a disability, then they must have done something wrong. Though it is not something we can dive much into here, it is important to recognize that this aspect of the social ramifications of autism is in conversation with the intersection of autism and patriarchal structures. Another element of the collectivity of Korean culture is the keeping up of appearances. Because Korean society generally values social harmony, the avoidance of social disturbance is paramount, meaning that families will often have an incentive to hide their child's disability for fear of social retribution.⁵ Stepping back, it is not difficult to imagine how these factors might affect the early, and even later life of an autistic person in Korea, possibly leading to a great deal of shame and guilt surrounding what is an essential aspect of their being. In effect, a lack of social acceptance of autism can easily lead to a lack of personal acceptance, a phenomenon which is elaborated on in other works.^{6, 7}

² Hyun Uk Kim. 538.

³ Will Bortin, 2022, "Two Stigmas: Infantilization and Roboticization, The Autistic Savant, and the Idiot Genius," *Unpublished*. 2-3.

⁴ Hyun Uk Kim. 537.

⁵ Hyun Uk Kim. 537.

⁶ Edith Cage, Jessica Di Monaco, and Victoria Newell, 2018, "Experiences of Autism Acceptance and Mental Health in Autistic Adults," *Journal of Autism and Developmental Disorders* 48, 473–484.

⁷ Danu B. Anthony, John G. Holmes, and Joanne V. Wood, 2007, "Social Acceptance and Self-Esteem: Tuning the Sociometer to Interpersonal Value," *Journal of Personality and Social Psychology*, 92(6), 1024–1039.

This point is, however, not without further nuance. Starting from the collectivity angle, it is true that there are actually some aspects of a culture of collectivity that can improve the quality of life of an autistic person. Pulling again from Kim's paper, one can see markers of this in the South American country of Nicaragua. As Kim describes, Nicaragua has a culture which, much like Korea, emphasizes collectivity, but expresses it in a different way. In Nicaragua, there is a general notion that, at their core, everyone shares a similar sense of being, and due to this variations among individuals are accepted more readily, and treated as less important. Additionally, there is a notion that the community as a whole is responsible for caring for its members. As Kim puts it, "It seemed as if people in Nicaragua shared the idea that 'everyone is the same,' ... People regardless of their disabilities seemed more embraced by their community than any other cultures that I have experienced."⁸ This example shows that the idea of 'collectivity' is a complex one, and that there can be different forms of cultural collectivity which can be beneficial or detrimental to autistic people.

Moving to the individuality angle, it is also true that aspects of cultures which emphasize the importance of individuality can in turn be detrimental to the quality of life of an autistic person. One manifestation of this, in contrast with Nicaraguan culture, is in the reluctance of society to provide community support to autistic individuals, this stemming from a 'make it by your own merits' sort of attitude towards success or even survival, be it explicit or subconscious, structural or epistemological. This is exemplified by a 2020 study performed in the UK examining dropout rates for university students. This study found that autistic people as a group had a much higher rate of dropping out of university than their 'neurotypical' counterparts, this due to a variety of factors. Most of these factors relate to a lack of community support or understanding, such as "a lack of understanding and appreciation of autistic characteristics," or

⁸ Hyun Uk Kim. 542.

“difficulties in navigating social spaces at university,” or even the fact that many of the interviewed autistic individuals “did not know *who* could help or *what* could have helped at the time.” It is also notable that many of the interviewed individuals did not know that they were autistic until after they dropped out. This too points to a general failure within more individualistic societies, most commonly Western ones. Support for people with autism is reliant on having a diagnosis, but obtaining such a diagnosis can be a process made more difficult by feelings of shame, doubt, and ‘not being good enough,’ as well as debilitating financial costs. All this leads to a situation where an individual is hesitant to pursue a diagnosis, but has trouble getting the support they need without one, as default support is not provided through a general sense of community, but through bureaucracy and the medical system.⁹

With that all covered, it is now time to examine the second cultural difference which came to my attention during the research process: whether or not autism is a prevalent concept in a culture plays a huge role in how autistic people are treated within that culture. This point requires less explanation, as it is fairly straightforward. In the same work referenced prior, Kim describes services for autistic individuals within the United States and Canada as being far more supportive than in South Korea. This of course comes with the caveat that one already knows themselves or their child to be autistic and has a diagnosis proving such, but the effect is present all the same. This effect is, though not explicitly stated by Kim, likely attributable to autism’s long history within these countries. Autism, for good or ill, is a well-established and studied condition in these places, and therefore support systems for people with the condition have had more time to emerge and improve. This is in contrast to South Korea during the same time, where Autism Spectrum Disorder (ASD) is used interchangeably with the term Reactive Attachment Disorder

⁹ Eilidh Cage and Jack Howes, 2020, “Dropping out and Moving on: A Qualitative Study of Autistic People’s Experiences of University,” *Autism* 24(7), 1664–75. 1667, 1669-70.

(RAD), which is defined as “when a child is neglected and fails to establish normal social interactions.” Because these two conditions are viewed as the same, the stigma surrounding autism colloquially is carried into the medical sphere, and support systems for autistic individuals suffer as a result. Finally, in contrast to these last two examples, autism is only recognized in a very limited sense in Nicaragua, which has upsides and downsides. A positive is that, because autism is not a broadly understood concept, the condition has little to no stigma attached to it. Kim writes of a special education teacher she encountered during her research, “She saw a person with needs, not a disability that incidentally had swallowed up a child.” The flipside of this coin is that there are little to no autism-specific resources present for autistic individuals in the country. A school official told Kim that “autism does exist but the prevalence rate is not known yet and there is not one specialist in autism in León... there are very few pediatricians who can accurately diagnose it.” Additionally, even without the label of autism, stigmas around mental disability do still exist, albeit to a lesser extent, within the country. As the same official described to Kim, “seeing [a psychiatrist] means that you acknowledge and admit your mental instability.”¹⁰ Lastly, a lack of definition for autism can generally have negative effects on autistic individuals, as they can suffer under stigma and oppression, yet not have the language to articulate why this is wrong, or even what it is they are being oppressed for. This concept is generally known, in critical studies including but not limited to autism studies, as hermeneutical injustice, and can be further researched by studying the work of the term’s creator, Miranda Fricker.¹¹

Now that some of the concepts surrounding autism and national culture differences have been examined, we may move on to briefly discuss cultural transition. There are several factors

¹⁰ Hyun Uk Kim. 538, 540, 542.

¹¹ Miranda Fricker, "Hermeneutical Injustice," In *Epistemic Injustice: Power and the Ethics of Knowing*, Oxford, England: Oxford University Press, 2007. 147-175.

which come into play during the process of emigration/immigration that may make the experience more difficult for autistic immigrants. As is discussed in a paper examining the experiences of autistic Somali migrants and their families who traveled to the United States, these factors range from unfruitful job searches, to language barriers, to difficulties with social assimilation, and more. As is also pointed out, traumatic experiences like fleeing a warzone, living in refugee camps, or being mistreated by immigration services can all also have an enhanced impact on autistic individuals.¹²

That all being said, the main focus in this work is on trans-cultural adjustment, and for further insight in this regard we will look to the interview I was able to conduct with Anonymous, a college-age, second-generation, Indian-American woman. Anonymous's status as a second-generation immigrant has led to a wealth of exposure to both American and Indian culture, the former through her public life, and the latter through her family life. She describes an experience of growing up with a sense of unbelonging, similar to many multicultural individuals; she states, "I was too Indian for here, I was too American for there." She also describes how having parents who are not natives to her primarily lived-in culture led to difficulties, stating, "my parents couldn't always help me with social skills in terms of American settings and such." A recurring theme throughout Anonymous's testimony was difficulties with social interaction, and how neurodivergency and differing cultural backgrounds may have compounded to exacerbate certain social situations. Lastly, aspects of American and Indian culture which Anonymous found either helpful or harmful for accommodating her being autistic appeared to reflect general research. She discussed, unprompted, the collectivity of India in opposition to the individuality of America, preferring the latter, but appreciating aspects of both in line with what

¹² Rebecca Houston, 2019, "Children with Autism in the Somali Population: Exploring the Inter-Relatedness of the Somali Immigrant and Refugee Experience Navigating Speech-Language Pathology Resources," *Undergraduate Research and Creative Opportunities (URCO) Grant Program*, Paper 8. 2.

has already been described. There are of course many insights that can be made regarding Anonymous's testimony, but this will do for our purposes in this paper. Before ending this section, I would like to extend a warm thank you to Anonymous. Your insights were incredibly helpful in creating this work, and it was a pleasure to speak with you.¹³

¹³ See Appendix.

II: Autism and Non-Normative Gender Identity

Non-normative gender identity is in itself an incredibly complex topic to even scratch the surface of. Add autism to the mix, and things get exponentially more nuanced very quickly. However, it is this aspect of this intersectionality that I would actually like to focus on the most in this section. I posit that the incredible multitude of labels, attitudes, and experiences which comprise non-normative gender identities, and how that multitude intersects with autistic experience, can provide unprecedented insight into how autistic people, as a general group, interact with, present, and conceive of identity labels.

Before getting into the philosophical weeds of labeling theory, however, there are some unfortunate realities of autistic experience of non-normative gender identity which must be discussed. Firstly is the grim issue of the treatment of these individuals in the medical system. One of the leading contexts through which autism is understood within psychiatry and medicine is that it is a condition representative of a reduced theory of mind.¹⁴ This opinion has been thoroughly discussed and debunked in another of my papers, but its impact is nonetheless very real.¹⁵ In short, doctors often believe that their autistic patients have a reduced ability to comprehend their own minds, which can in turn lead them to dismiss these patients' testimonies. An interviewee from my mentioned earlier paper brought up this exact issue, stating, "I've avoided telling medical professionals that I'm autistic in most cases because any time that I've brought that up it, at least in my perception, has led to them taking me less seriously."¹⁶ Now, note the fact that gender identity is an extremely personal concept, and that the sole arbiter of a person's gender identity is and should always be that individual, and it is not difficult to see

¹⁴ Simon Baron-Cohen, 1990, "Autism: A specific cognitive disorder of 'mindblindness,'" *International Review of Psychiatry*, 2, 81–90.

¹⁵ Will Bortin. 3-5.

¹⁶ Will Bortin. 73.

where problems begin to arise. To explain, if an autistic individual is claiming to have a non-normative gender identity, but their doctor, among others, assumes that they have a reduced theory of mind, then there is a good chance that this individual's chosen identity will be dismissed, which can have serious emotional or even physical consequences. Additionally, autistic individuals may be more hesitant to advocate for their chosen gender due to already existing stigmas surrounding autism. These concerns have proven true in what few studies have been performed surrounding transgender autistic experience.¹⁷ Secondly, and relatedly, is the pathologization of both autism and non-normative gender identity, particularly transgenderism. Academic and colloquial discourse has long centered around, when not outright treating autism and transgenderism as illnesses to be cured, medicalizing transgenderism and autism in a way that minimizes social, cultural, and personality factors that all, in reality, contribute heavily to both of these experiences. Suffice it to say that this can lead to discrimination, medical malpractice, and other horrors. The history of this issue in particular is examined in a research paper by Shahar Shapira and Leeat Granek.¹⁸

Now it is time to discuss how autistic people interact with gender labels, and the possible wider implications of what such an examination reveals. As a starting point, it is well-documented, though has not always been so done with the greatest understanding nor purest of intentions, that rates of gender nonconformity are significantly higher within the autistic population than the 'neurotypical' population.¹⁹ Most examinations as to why this is tend to focus on hormones, brain chemistry, and other biological factors. While insights gained from this

¹⁷ John F. Strang, Meredith D. Powers, and Megan Knauss *et al*, 2018, "'They Thought It Was an Obsession': Trajectories and Perspectives of Autistic Transgender and Gender-Diverse Adolescents," *Journal of Autism and Developmental Disorders* 48, 4039–4055.

¹⁸ Shahar Shapira and Leeat Granek, 2019, "Negotiating Psychiatric Cisgenderism-Ableism in the Transgender-Autism Nexus," *Feminism & Psychology* 29(4), 494–513.

¹⁹ Rita George and Mark A Stokes, 2017, "Gender Identity and Sexual Orientation in Autism Spectrum Disorder," *Autism* 22(8), 970–82.

research can be valuable, it is equally important to go to the source, and hear from gender nonconforming autistic individuals themselves. For this we will rely on the book *Gender Identity, Sexuality, and Autism* authored by Eva A. Mendes and Meredith R. Maroney.²⁰

Several general insights can be gleaned from the accounts described in this book, and the most important of these, for the purposes of this work, relates to the specific ways in which these participants choose to label their gender. Out of the fifteen autistic individuals interviewed, eight were gender nonconforming, and seven were Queer. Of those seven, three were agender, and three identified with multiple labels, one of these being Phoenix, who identified as agender, non-binary, and transgender. Even one of the two people who identified simply as transgender, Yaeli, expressed only doing so in order to make social interactions go by smoother. In their words, “It’s easier to tell people I’m a transgender woman rather than going into complicated feelings.”²¹ This is of course a small sample size, but even these limited accounts may outline a partial explanation for why gender nonconformity rates are so high within the autistic population. Simply put, it is possible that autistic people, as a general group, find it especially difficult to identify cleanly with any specific gender label, be it normative or nonconforming, and therefore must deviate more so than the general population in order to feel comfortable. If this is indeed true, there are a multitude of possible explanations, the space for only some of which can be made here. One of these argues that autistic people, for various reasons relating to how autism affects socialization, generally feel a weaker social affiliation, and less positive social and personal association, referred to as “gender self-esteem,” with their given or chosen gender group, and therefore are less likely to feel at home identifying with that gender.²² Another

²⁰ Eva A. Mendes and Meredith R. Maroney, *Gender Identity, Sexuality and Autism: Voices from Across the Spectrum*, London, England: Jessica Kingsley Publishers, 2019.

²¹ Mendes and Maroney. 81.

²² Kate Cooper, Laura G. E. Smith, and Ailsa J. Russell, 2018, “Gender Identity in Autism: Sex Differences in Social Affiliation with Gender Groups,” *Journal of Autism and Developmental Disorders* 48, 3995–4006.

explanation argues that the hyper-systematizing aspects of autism lead autistic individuals to fixate on specific details regarding gender identity, and therefore find it difficult to identify under a label that does not suit them perfectly (the particular paper cited here makes a mildly questionable distinction between “gender confusion” and “cross-gender roles,” but the main point still stands).²³ To double back for just a moment, the tendency for autistic individuals to have a longer and more complicated gender questioning process than the general public, as well as the other factors already described, puts them at greater risk for medical discrimination, as gender questioning has long been pathologized by the medical system, being an extension of gender dysphoria which is itself viewed as a neurological illness to be cured.

As much as these or other explanations might be true, it is arguable that there is a more fundamental driver causing this effect, representative of how autistic people relate to the very concept of labeling. To elaborate, it is entirely possible that the differences in conceptualization caused by autism naturally lead those with autism to develop a sort of resistance to identity labeling. On the surface this seems far fetched, as one would imagine that people who are generally prone to systematization would readily embrace categorizing labels. However, the evidence, at least with regards to gender identity, implies otherwise. In addition, it may be that identity labels in particular are the ones which tend to not fit. If autistic people do indeed tend to systematize and break things down with regards to choosing their identity, it would make sense for them to refuse to settle on a label until every detail of that label is in line with how they feel internally, a process which may require a lot more searching and switching than it would for an average ‘neurotypical’ person. This is all speculation, of course, though further research in the near future delving into proving or disproving it definitely would certainly be welcome.

Regardless of the truth or falsity of this specific theory, however, it seems that there is still much

²³ George and Stokes. 978.

to be learned about how autistic people relate to identity labels, and one of the best ways to engage in this specific learning is to try and understand, through study, conversation, and even representation in the research room, the experiences of autistic individuals who embrace non-normative gender identities.

III: Autism and Race

When it comes to autism and race, there are two main throughlines to be considered. One of these is how exposure to differing race-based cultures affects a person's autistic experience. To get an important clarification out of the way: race, while having great impacts on how people live within society, is not a biological reality, and races are socially constructed for various reasons, including by colonizers and the wealthy in order to further oppression. In other words, the relationship between race and culture, while having real social ramifications, is itself socially constructed, and should therefore not be used as a reason to make judgements about a person's or group's inherent qualities. Moving on, one of the main ways in which racial culture intersects with autism is in how it can affect modes of autistic expression. Although the specific reasons are not fully understood, it has been proven that race frequently plays a role in how autistic people express themselves, leading to differences in things like facial expression/recognition, preferred amount of eye contact, and other behaviors.²⁴ For instance, studies within the United States have found that Black autistic people tend to exhibit a greater range and frequency of emotional facial expressions than White autistic people.²⁵ The other throughline to be considered is race-based discrimination, or racism, be it subconscious or explicit bigotry. This is fairly self-explanatory; due to racism, people of minority race encounter confrontations, humiliations, and harassment at much higher rates than people of a majority race, and social difficulties exacerbated by autism can make these situations especially difficult to deal with, especially if things turn hostile. This is not to mention how racism can create another level of external and internalized stigma experienced by minority autistic individuals, on top of the autistic stigma many already face.

²⁴ Ashley J. Harrison, Kristin A. Long, and Douglas C. Tommet *et al*, 2017, "Examining the Role of Race, Ethnicity, and Gender on Social and Behavioral Ratings Within the Autism Diagnostic Observation Schedule," *Journal of Autism and Developmental Disorders* 47, 2770–2782.

²⁵ Harrison, Long, and Tommet *et al*. 2772.

The most notable result of both of these throughlines can be found in the autism diagnosis process. A 2013 study performed in the United States examining past autism diagnosis rates found that rates for minority ethnic groups, specifically Black, Hispanic, and Native American, were far lower than among White people. They found that, in 2006, when using rates of diagnosis for White people as a control at 1.0, rates of diagnosis for Black people sat at 0.7, rates for Hispanic people sat at 0.467, and rates for Native American people sat at 0.45. The one exception to this rule was the Asian and Pacific Islander group, whose rates were about equal with the White control, which may in and of itself be indicative of American stereotypes of AAPI people.²⁶ While these figures are indeed old, the consensus seems to be that this issue has not been fixed in the years since. On the cultural side, these disparities may arise from a variety of factors. There is a well-documented, and justified, distrust among minority communities, especially Black communities, of medical professionals given the way these groups have been medically abused and mistreated in the past. Macho or machismo conceptions of masculinity may also lead men within minority cultures which exhibit those conceptions to hesitate in getting a diagnosis. In any case, intra-cultural reasons for these disparities are culture-specific and highly complex, and therefore should, beyond what has been touched on, be left for a different discussion. What can be discussed more broadly, however, are the effects of (1) ignorance of differing autism expressions between racial cultures on the part of medical practitioners, and (2) racism and how it complicates the autism diagnosis process. First is the general conception of autism as a White condition. As Nathan Mallipeddi and Rachel VanDaalen write, “Disability essentialism, which postulates that there is a defining essence to disability experience and

²⁶ Jason C. Travers, Matt Tincani, and Michael P. Krezmien, 2013, “A Multiyear National Profile of Racial Disparity in Autism Identification,” *The Journal of Special Education* 47(1), 41–49. 45.

inequality, has historically assumed a White racial identity.”²⁷ This default to Whiteness can lead medical and psychiatric practitioners to assume that White expressions of autism represent all expressions of autism, and in so doing they may fail to recognize minority expressions of autism for what they are. This effect is easily combatted with education; however, it is often paired with subconscious or conscious negative feelings towards minority individuals, which can further exacerbate issues with obtaining a diagnosis. A paper from 2021 outlines in detail how, specifically for Black individuals seeking an autism diagnosis, racism can influence every step of the process, turning what should be a journey of guided self-acceptance into a grueling battle for recognition.²⁸

This discussion illustrates just how pervasive racism can be, particularly in the United States. Medical and psychological practitioners, because of the nature of how autism support works in Western countries (see section I), have immense power over the lives and well-being of autistic individuals. If these practitioners harbor conscious, or even subconscious racist feelings, the results can be disastrous for minority autistic individuals. How autism expression and conception differs between racial groups is a fascinating topic, and requires much more in-depth, minority-inclusive research attention than is currently being provided to it. However, this research needs to be performed in concert with an active effort to achieve equitable treatment for those being studied; otherwise, there might as well be no point at all.

²⁷ Nathan V. Mallipeddi and Rachel A. VanDaalen, 2021, “Intersectionality within Critical Autism Studies: A Narrative Review,” *Autism in Adulthood* 00(00). 6.

²⁸ Diondra Straiton and Aksheya Sridhar, 2022, “Short Report: Call to Action for Autism Clinicians in Response to Anti-Black Racism,” *Autism* 26(4), 988–94. <https://doi.org/10.1177/13623613211043643>.

IV: Autism and Age

The identity intersection of age and autism is often overlooked in autism research, especially the study of those who are middle-aged or in their twilight years. However, this intersection is of great importance, as every autistic person, barring tragedy, will experience it at some point in their life. This section will focus, firstly, on the underrepresentation of older autistic individuals as subjects in autism research, and secondly, on how various factors influence the quality of life of the average autistic person as they age.

The study of autism has always been focused on childhood development. There are several reasons for this, which are discussed thoroughly in my already mentioned previous paper, but here it is more prudent to discuss the results of this focus.²⁹ One of these results is just that finding quality statistics and research on autistic adults is more difficult than doing so for children, and is especially difficult in the case of the elderly. A quick experiment I performed using Google Scholar revealed the following. Without using quotations, allowing for flexibility of word order, a search for ‘autistic child’ queued 1,420,000. ‘Autism young’ queued 1,410,000, ‘autism adult’ queued 1,180,000, ‘autism old’ queued 1,120,000, and ‘autism elderly’ queued a paltry 93,400. Due to this, accurately measuring data regarding older autistic people is difficult and, in some cases, impossible without more field research than is currently available. Another result is that many older individuals today who may be autistic are not diagnosed as such, as diagnoses for adults did not become normalized until relatively recently, and proper diagnostic tools were limited when they were children. This group is widely referred to as a “lost generation,” lost in that most of these people are scattered throughout nursing homes, mental institutions, and individual living situations, or are even long dead, such that there is currently no feasible way to reach all of them and glean valuable general information about their experiences

²⁹ Will Bortin. 7-9.

beyond a small group here or there.³⁰ One more result, which leads into discussions of adult autistic individuals' quality of life, is that support systems for autistic people, in the places that have such support systems, drop off dramatically once adulthood is reached, partially as the result of most disability services for children being bureaucratically tied to the school system. As a 2012 paper states, "Specialist support services for adults with ASD are generally inadequate despite their being, as a group, at an increased risk of social deprivation and isolation and of physical and mental health problems."³¹

A lack of support systems obviously has negative consequences for autistic adults; however, there are many other notable factors which also play a role, only some of which can be covered here. One of these manifests in a given society's conceptions of what it means to be successful. In the United States, this is often defined by getting a high-paying job, starting a nuclear family, and having a large friend group, all things which the autistic population achieves at lower rates than the general populace. This is not to say that autistic individuals who desire these things are wrong to do so; rather, it is to say that these are not true measures of how comfortably someone is living, only of how well they conform to societal definitions of prosperity.³² Autistic adults, just like anyone, may feel shame or hopelessness if they internalize these measures of success and then fail to achieve them, even if the failure is not their fault and they would be living a perfectly comfortable and fulfilling life regardless. Another factor that may affect older autistic individuals' quality of life, especially as they become elderly, is the general shortage of caregivers outside of one's family available in countries around the world.

³⁰ T.A.M. McDonald, 2020, "Autism Identity and the 'Lost Generation': Structural Validation of the Autism Spectrum Identity Scale and Comparison of Diagnosed and Self-Diagnosed Adults on the Autism Spectrum," *Autism in Adulthood* 2(1), 13-23.

³¹ Patricia Howlin and Philippa Moss, 2012, "Adults with Autism Spectrum Disorders," *The Canadian Journal of Psychiatry* 57(5) 275-83. 276.

³² Natalie A. Henninger and Julie Lounds Taylor, 2013, "Outcomes in Adults with Autism Spectrum Disorders: A Historical Perspective," *Autism* 17(1), 103-16.

Autistic people, at much higher rates than the general populace, need a primary caregiver throughout their entire lives, a duty which often falls to a family member. As these people age, and parents begin to pass away, autistic individuals can often be left with no one to take care of them, and with no way to earn the money to pay for a professional caregiver, assuming they can even find one. These are just two of the many realities which cause autistic people to generally have a lower quality of life than their ‘neurotypical’ counterparts throughout adulthood, a statistic that has been proven through copious research. Interestingly enough, one of the papers studying this phenomenon also found that quality of life for elderly autistic people, when compared with ‘neurotypicals,’ was not reduced as extremely as it was in middle-age.³³ This could be for several reasons. The elderly are often ignored by the general population, possibly leading elderly ‘neurotypicals’ to have a worse quality of life more in line with elderly autistic people. Alternatively, people are generally more accepting of, or rather disinterested in, abnormal behavior in the elderly, meaning some autistic individuals’ more disruptive behaviors may be overlooked more easily, leading to a greater sense of acceptance and less stigma. It is certainly disconcerting that some of the ways in which society mistreats its elderly are the same factors which bring the quality of life measures of autistic people and ‘neurotypicals’ closer together.

Much like with the other sections already discussed in this paper, this section is a call to action. It is time to stop pretending that autistic adults do not exist. People do not stop being autistic when they turn 16, nor when they turn 30. Autism is an inherent part of these people’s entire lives, and research and support systems need to treat it as such. Until this is achieved, older autistic individuals will continue to be left twisting in the wind by support networks, by the medical system, and by society at large. It is time for us, as a people, to do better.

³³ Barbara F.C. van Heijst and Hilde M. Geurts, 2015, “Quality of Life in Autism across the Lifespan: A Meta-Analysis,” *Autism* 19(2), 158–67.

Conclusion

What is the purpose of studying the philosophy and psychiatry of autism? This question of course has several answers, but there is one that should always and forever stand above the rest: to help autistic people live fruitful and comfortable lives. Everything else is subordinate to this. However, in order to achieve this goal, it is not good enough to simply intuit what must be researched, and how support systems must be structured. To help autistic people, one must know autistic people, and that means *all* autistic people, especially those who are so often underrepresented and undervalued. With this paper, I hope that I have helped provide you with a small piece of that knowledge; but, know that the rest of it is out there, with living, breathing autistic individuals existing in all manner of places, forms, and situations. Even if you yourself are autistic, this sentiment still applies. Just because you understand your own autistic experience, as immensely important as that is, does not mean you understand all autistic experience. We are here because we must learn, and we must learn because we must help. If every one of us keeps that in mind, then the world will be a better place. I guarantee it.

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Appendix — Interview with Anonymous

The below interview is meant to serve as supplement to the essay *Autism and Intersectionality: Four Identity Intersections and Autism's Face* authored by Will Bortin. This transcript was hand-typed by Will Bortin using a recording taken of the conducted interview.

Q1: How do you self-identify? What labels, if any, would you use to describe yourself?

Anonymous: *Let's see, there is "woman," um, "Indian-American," "bi-romantic," "demisexual," probably some others that aren't coming to mind right now, obviously autistic. Um, yeah, there's that.*

Will: *Yeah, um, so, I guess for this interview I would like to, if you're comfortable with it of course, we could talk a little bit about sexuality and autism kind of towards the end of the interview, but for the bulk of the interview I want to focus on the autism and Indian-American part. That's, kind of, the part I want to focus on. So, I guess I have another, just, clarifying question — and you don't have to give me an exact answer — but were you born in America and raised in America and everything, or did you, were you born in India and then moved to America?*

Anonymous: *Yeah, I was born here. My parents moved here soon after they got married, and then they had me some years later.*

Will: *Okay, so how was it, in general — so your parents are first-generation immigrants then?*

Anonymous: *Yep.*

Will: *Yeah, okay, so in that sense how was it growing up, just in terms of general feelings, how was it growing up with first-generation immigrant parents, but also being in, very much growing up in America with being surrounded by American culture. Like, how was that kind of experience, just generally?*

Anonymous: *Honestly, it was really rough because I had trouble finding a place of belonging. Like, I was too Indian for here, I was too American for there. As I got older I was able to, kind of, find my place more, and I feel like I associate myself more with America, but, like, India's always going to be a part of me. And it's hard because it's like, because of cultural differences, like, I learned some things through, like, Indian culture that don't happen in American culture. And some of them are pretty, how do I put it, some of them are relatively normal. There's stuff like, "don't gift someone a bag without putting any money in it," like, that's, kind of, fine. But then there was stuff like, my parents couldn't always help me with social skills in terms of American settings and such. Or, sometimes, people would misunderstand intentions.*

Will: *Mhm, yeah, and so that sounds to me like it plays a lot into, like, it intersects very heavily, that specific part intersects very heavily with being autistic. Just, like, the idea that, whereas a person whose parents are from a culture, when that person is born with autism and they have, obviously, just some trouble with social interactions, their parents are, kind of, there to, and they're already super familiar and embedded in the culture and can, kind of, be that lodestone, I guess, for, "okay, what's the proper way to act in this situation?" But it sounds maybe like, to a certain extent, that was not as available for you growing up?*

Anonymous: *Yeah that's definitely right. Or there are just some things that they, some things are just generational differences to an extent. Like, my parents got an arranged marriage, whereas, you know, I've been dating and, like, when I started, like, expressing interest in dating,*

specifically in college, I remember my dad said, like, “I support you, but I don’t know how to help.” I did, I think I mentioned earlier, like, I’m bi-romantic. I did try to come out to them when I was younger, and they just straight-up said, like, “we don’t believe you.” It’s like, they shoved me back in the closet. I was like, I wasn’t expecting that kind of answer. So, like, I did have a girlfriend in high school, but it was really easy to hide because they didn’t, like, even think that was possible.

Will: *Yeah, I think that is very valuable, so thank you for describing that. I think that the idea, you’re coming from a very specific perspective —*

Anonymous: *— Yeah.*

Will: *— But one that I think, in America, is generally very common of the idea of the person who is born and raised in America, but whose parents are first-generation immigrants. And that experience, I think, you’re saying a lot that is generally, kind of, stuff that people in your situation have to deal with, but stuff, like, with the social interactions specifically, stuff that, maybe, the social issues that can arise from being autistic in a non-autistic world, those can be exacerbated by certain aspects of this experience.*

Anonymous: *Yeah, definitely.*

Q2: When did you first experience “culture shock” at any level, be it something mundane or something really intense? How did that experience make you feel?

Anonymous: *Okay, you say “first experience,” I’m not sure exactly the first experience, but I do know, like, I don’t know if I remember this happening, but, like, over there you can throw stuff on the street. I don’t know if it’s that common anymore, but, like, where my grandparents live, like, if they want to throw something out and, like, we were on the road, they could just*

throw it out onto the street. And, like, when I was six, I, like, threw something on the floor in America, and I guess some, like, faculty members or whatever, you know, they basically said, like, “you can’t do that,” and I was like, “my grandpa said I can.” So that’s, like, one example. I’m not sure if this exactly counts. I’m not sure if this is an Indian thing, but my mom, she used to write “P.T.O.” on, like, the bottom-right corner of a paper; meaning, “please turn over.” So, I started adopting that, and a lot of people were confused. They’d be like, “you didn’t do your homework,” and I was like, “I wrote P.T.O.” And then one teacher suggested that I draw an arrow instead, or say, like, “turn over,” like, write it out. So I started doing that, and it, like, cleared up a lot of confusion.

Will: *Mhm, but you had to, kind of, alter the way you were brought up doing it in order to, kind of, assimilate. And that also sounds like something that ties in with being autistic: the, kind of, need to abandon certain ways of doing things that seem natural in order to assimilate to the, kind of, dominant culture of the area you’re in. Like, that sounds like, if that is indeed an experience of being multicultural, then it sounds like a place where there would also be a lot of overlap.*

Anonymous: *Mhm.*

Q3: Would you like to speak on the notion that it is sometimes hard to determine if a miscommunication is due to you being autistic, or instead due to cultural barriers?

Anonymous: *Sure, I guess I’ll think about...*

Will: *... And take your time, of course.*

Anonymous: *I guess with a lot of things it's hard to tell, is it because of the culture or is it because of the neurodivergence. And, like, I may not ever get, like, a concrete answer to anything. I'm sure there have been... I'm pretty experienced with miscommunications, I don't know why I'm drawing a blank.*

Will: *Nah, it's totally fine. It's classic "things that happen during interviews." But yeah, just in general — if you think of, like, a specific experience, like, feel free to talk about it and interrupt to talk about it — but, just in general, it sounds like and interesting, kind of, intersection, and it sounds like sometimes it can be a mixture of both.*

Anonymous: *Yeah, definitely.*

Will: *Like, it can be that, like, a picture that I'm getting in my head, and you can tell me whether or not this is accurate, from what we've been talking about, a picture I'm imagining is, something happens like, for example you throwing trash on the floor —*

Anonymous: *[chuckles]*

Will: *— and a staff member coming up and telling you not to do that. The picture I'm imagining is something like that happening, and the person coming up and telling you not to do that, and it taking, kind of, I guess not longer, but you being very, like, disoriented in this social interaction, and maybe the fact that, and maybe the being neurodivergent maybe can make that interaction more difficult to wrap up than maybe if it was just two 'neurotypical' people as it were. I don't know if that's accurate, but yeah.*

Anonymous: *Yeah, I think that makes sense. I also don't know how much of it had to do with me having been a child at the time [both chuckle].*

Will: *That's true, yeah.*

Q4: Do you find yourself picking and choosing aspects of one culture or the other — let's say Indian culture v.s. American culture — where it's like, "This aspect of this culture makes it really hard to exist as an autistic person, but this aspect makes it easier," and how does that juggling of cultures, and what makes it more comfortable for you to live, make you feel if it is indeed a process you go through?

Anonymous: *Yeah, that makes a lot of sense. I would say yeah, I do pick and choose. I do like some aspects of Indian culture, like Bollywood — there are a lot of issues with Bollywood that I'm aware of, but I love Bollywood — the clothing is absolutely beautiful. I like to have elements of Indian culture where I can. Like, I have some Indian tote bags, but I don't have, like, my rooms plastered with, like, Bollywood posters or anything like that. But I do often listen to Indian music when I'm, like, when I'm walking and I want to listen to music. I usually listen to Indian music. And I don't actually, like, I listen in multiple languages, and I don't speak all of those languages. I don't know what it is, but it's fun to, like, listen to a song and know what it's about, but not know exactly what they're saying. Or you understand, like, some words here and there.*

Will: *Yeah, yeah I get that. I definitely get that, and I wonder if, like, and this is a little off-topic, but do you ever get the feeling where, like, if you know all of the words to a song and*

you listen to the song, you almost find yourself, like, focusing on, like, “Oh, this is what the next lyric is going to be,” and, like, thinking about the lyrics so much that it kind of takes you out of the song a little bit? Is that something that has ever occurred to you?

Anonymous: *I don’t think that’s the case with me. I do listen to, like, English and Spanish music, so, like, sometimes I do like to know what they’re saying.*

Will: *Gotcha, yeah. And would you say there are aspects — I mean obviously American culture is something that is kind of hard to pin down ‘cause it’s, I don’t know, American culture’s weird [both chuckle] — would you say that there’s anything about American culture that is especially like, “Oh, this is fantastic for me,” either as an autistic person or as in general, or aspects where it’s like, “Wow, this is terrible for me.” as well?*

Anonymous: *Okay, well, one thing I love about America is individuality. One thing I love about India is the community. Like, there’s such a community aspect, but I feel like it can be almost detrimental. Like if, I don’t know, let’s say in an extreme case, let’s say, someone raped their niece people will just be like, “Shh, don’t talk about it, he’s your uncle. Let’s just act like nothing happened,” you know. I haven’t dealt with that personally thank God, but I know it’s a thing. There’s also, like, over there, and also to an extent over here, there is that issue of conformity, and it’s, like, really hard to live up to certain expectations, especially when you don’t feel like it. You know what I mean? For example, I don’t plan to have kids, and I know that’s, like, I’m not trying to be like, “I’m so quirky, I’m not having kids.” It’s more just like, that’s not the life for me. And I think it’s a lot easier to be like that over here because over there, like — I don’t*

know how much you've heard about honor killings and such. It's not the majority, but, like, it's hard there, I'd say, to be individualistic. But I do love the community aspect over there.

Will: *Yeah, so that, that I think is very, that's very interesting to me because it's like, on the one hand the individualistic aspect of American culture can be very freeing, especially because, like, you're neurodivergent — not that you have trouble assimilating because it seems like you do a pretty good job of that in general — but obviously, like, there are going to be places or times when there's a thing happening and you're like, "I don't want to be part of that," but — and I guess that's just a general experience — but I imagine if you're neurodivergent then it might happen a little more often.*

Anonymous: *Yeah, it's not a little more. There may be situations where I'm like, "I want to do this thing," and people may not understand it. And I have dealt with the reverse, where someone else might say, "I want to do this thing or don't want to do this thing," and I think, "I don't want to do that, but good for them."*

Will: *Mhm, yeah. So that, you're more free to be able to, kind of, have that opinion and do that in America, but then, like, the community aspect of India, I imagine, on the flipside, maybe there's more support. Like, maybe there's more of a safety network for you. I don't know if that's true.*

Anonymous: *Yeah, that makes sense.*

Will: *Well, that's pretty much all the explicit interview questions I had. This was very enlightening —*

Anonymous: — Yay!

Will: — *which is what you want from an interview, so thank you. Is there any last thing that you'd like to say before we close out?*

Anonymous: *I guess I'd like to say that I'm proud of my different identities. Like, I am happy to be Indian-American, I'm happy to be autistic. But sometimes it can be rough, but that doesn't mean I don't want it. I just need to, I guess, accept myself more. But, like, I don't have any regrets. Like, if God were to be like, "You won't have these issues of biculturalism, you can just be monocultural," like, I wouldn't want it. Or if God was like, "You could be allistic," and I'd say, "No thanks."*

Will: *Yeah, and that makes perfect sense. I think most people on the spectrum, and I think most people in general would agree with you. Just because it's easier to be a certain way it's, like, is it really worth becoming a different person and losing the person that you are? And I think most people would say no.*

Anonymous: *Yeah, and speaking of God, I don't have that much to say, but I was raised Hindu, but I don't personally believe in Hinduism in general. But I do like some of the values, so I pick and choose those values, and I think the stories are fun. But I don't personally believe in Gods like Rama, Sita, like, I don't believe in those kinds of Gods, but I do believe there is higher power. But I don't exactly follow Hinduism. Does that make sense?*

Will: *Yeah, I mean, from my own perspective I'm agnostic leaning towards atheist, so I can, I can both relate and not relate [both chuckle]. But yeah, it makes sense for sure.*

Anonymous: *Cool. I think that's it.*

Will: *Yeah, alright. Well, thank you so much for joining me.*

Anonymous: *Thanks for having me!*