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Autism on the Net: An Autoethnographic Appraisal of Literature on Online Socialization, Empowerment, and Kinship of Autistic People in Digital Spaces

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Departmental Honors Thesis

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Abstract

In a world that is increasingly becoming more and more active online, social groups formed on the basis of interests and passions have the propensity to intersect with communities of those who experience marginalization, in this case, autistic people. As such, this work seeks to examine what the basis of an autistic cultural identity is, and how the social factors that it is built on, those being belongingness, social connectedness, and political connectedness, and how they manifest among various online communities, whether it be cosplay fandom, fanfiction communities, or virtual worlds within *Minecraft* and *Second Life*. These online communities illustrate these tenets of the autistic cultural identity, as well as how these communities, by the basis of being online, enable autistic social connectedness to occur more readily and smoothly then within everyday life in the "real" world, and the implications of online communities having their own culture groups have on both disability studies and anthropology.

This work is dedicated to the UTC Mosaic Program, who have helped me better understand my own autism as something that is inexorably part of me for the better, rather than something that drags me down. It is also dedicated to my family, friends, and professors that have helped me on this journey with no hesitation, and I am forever grateful.

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Introduction

Culture, Autism, and the Internet: an Introduction

Everyone is part of some culture, no matter how different they may be compared to another, and culture has generally been defined via much more concrete measures, often as simple as being born into a culture. The advent of the internet and the digital era has enabled a deviation from this, with people being able to essentially form cultural identities and groups beyond the scope of what was possible prior to online socialization. LGBT+ culture and fandom culture have been able to flourish with the coming of the digital age; people of similar interests and identities are able to congregate without the barriers of distance. However, while these cultures existed long before the internet, one emerging cultural identity has been able to emerge entirely due to the internet, that being the Autistic cultural identity. When the term 'Autistic' (notated with a capital A) is used within this work, it will be under a more explicitly cultural definition that will be outlined further in the methods and glossary section rather than just referring to all autistic people as a catch-all, as not all people on the autism spectrum are part of this cultural identity. This autoethnographic literature review is drawn upon my own experiences of being Autistic. As such, it aims to examine how autism, while not a culture within itself, has aspects that can be defined similarly to a culture, and these aspects of the way Autistic people observe and interact with their surroundings and interests can be used to analyze Autistic communities, especially online ones, in unique and novel ways. Notably, the internet has enabled community groups to form based on shared interests, hobbies, and identities, and the intersectionality between the Autistic identity and these groups. By defining the qualities outlined in the literature, I aim to identify the ethnographic methods for a future study to operate on. Specifically, I aim to examine

the three underlying themes of belongingness, social connectedness, and political connectedness.[1] These aforementioned tenets manifest in various Autistic social groups consisting of a large variety of varying interests and subject matters in spaces and fandoms. Apropos of this work as a literature review, how have other scholars noted how culture is formed online by those who are considered disabled?

Despite this, a disclaimer should be made clear: I am not a professional on the ins and outs of Autism Spectrum Disorder, I am just Autistic myself. However, combined with my own research on the formation, variation, and modes of empowerment within online social groups, and my own lived experience as an Autistic person within online spaces, I have since garnered considerable insight and gleaned some intriguing similarities among the communities examined within the literature. It is important to disclose that autism is not a monolith, and there is considerable variation between any two given Autistic people in terms of behaviors, interests, sociality, communication, and impact on one's life. To disregard that would be unprofessional at best and outright harmful at worst, as it ignores the reality that comes with simplifying and idealizing autism; and comes at the risk of ignoring autistic people who need extensive assistance in day-to-day life that are unable to independently participate within a culture, and applying a cultural definition to the entire autistic population ignores the material reality faced by many autistic people.[2] Making any sweeping and potentially harmful statement about autism would be entirely detrimental, my aims are to provide a literature review and it is not a definitive statement for all of the Autistic population, just an analysis of behaviors, trends, language used, shared

[1] Monique Botha, Bridget Dibb, and David M Frost. 2022. "'It's Being a Part of a Grand Tradition, a Grand Counter-Culture Which Involves Communities': A Qualitative Investigation of Autistic Community Connectedness." *Autism*, March, 136236132210802. https://doi.org/10.1177/13623613221080248.

[2] Roy Richard Grinker, "Autism, 'Stigma,' Disability: A Shifting Historical Terrain," *Current Anthropology* 61, no. S21 (2020): 348.

ideas, and communities that have been able to proliferate due to the onset and accessibility of the internet.

Methods and Glossary

As this is a literature review, my main method was a thorough and vigorous search for literature on the subject. I mainly used Google Scholar as a gateway to find sources, using search terms such as "autism as culture." "Autism online," "Autistic identity," and other relevant combinations. I mainly sought out academic journals that cover disability studies, anthropology, sociology, and/or journals that operate on an intersection of these fields. Examples of journals consulted include several from the journal *Autism* in particular, as well as *Digital Geography and Society, Information in Contemporary Society, Current Anthropology, Disability and Rehabilitation, Medical Anthropology,* and *The Senses and Society*, all of which feature publications that have delved into the cultural aspects of Autistic communities, especially in regards to online groups. I also utilized auxiliary sources for information that needed to be cited but it would be too awkward and long-winded to use literary journals for, such as consulting the World Health Organization for autism statistics and the BBC for video game sales data. However, the most interesting aspect of data collection I embarked on was my own efforts of making connections. For example, all the articles on *Second Life* and other virtual worlds got me thinking about the overlap between furries and Autistic people I have experienced in my own social circles, which led in turn to gathering information on autism in the furry fandom from journal articles and video essays. Notably I utilized an aspect of TEACCH's own cultural definition of autism, being making connections.[3] The motif of making connections is something

[3] Gary B. Mesibov et al, *TEACCH approach to Autism Spectrum Disorders.* Springer, 2014, 20-24

that will be expanded upon within the discussion section. As an Autistic person, it is one of the most profound ways in which I operate, and I used it to great effect within this literature review.

The term “Autism”, with a capital A, is what I will be referring to these social groups from here on. Derived from the lexicon of Deaf with a capital D, which specifically means those who are deaf that are part of the greater deaf cultural identity.[4] Just saying “autistic” with a lowercase a implies that the entire autistic population is being discussed when that is not the case. The subset of Autistic people being examined consists solely of those who have the means and intentions to both participate in online communities, and to imply otherwise would operate entirely in bad faith and would be misleading.

Background

Early Emergences and Dismissals of the Idea of Autism as Culture

One of the earliest discussions around autism as a culture comes from the TEACCH program, a program founded in the 1970s to help children and parents overcome the societal challenges of autism spectrum disorder. The TEACCH program’s manual provided this definition of autism: “A developmental disability caused by neurological dysfunction. Autism too, however, affects the ways that individuals think, eat, dress, work, spend leisure time, understand their world, communicate, etc., and people with autism tend to be devalued because of their differences.”[5] However, according to TEACCH, these differences aren’t better or worse from what is considered “normal”, they are just that — different. The manual further suggests that autism could be considered a culture because of how autism can often produce similar characteristics

[4] Tracey Skelton and Gill Valentine. 2003. “‘It Feels like Being Deaf Is Normal’: An Exploration into the Complexities of Defining D/Deafness and Young D/Deaf People’s Identities.” *The Canadian Geographer* 47 (4): 454

[5] Mesibov et al, *TEACCH*, 19

and thought patterns of those with autism.[6] This evaluation is provided by the TEACCH program's manual, although TEACCH's further deliberation unfortunately shows the age and problematic elements of this definition. The TEACCH manual goes into further detail on how they define autism through a cultural lens through the following characteristics: focus on details, ability to prioritize the relevance of details, distractibility, concrete vs abstract thinking, combining or integrating ideas, organization and sequences, generalization, and time.[7] Gary Mesibov, director of the TEACCH program, also outlined what he deemed as culturally impactful, such as strong impulses, excessive anxiety, and sensory and perceptual differences. [8] These were synthesized together in how they manifest in the form of culture including attachments to routines, tantrums and aggression, limited social skills and empathy, limited play skills, difficulty with initiation, and noncompliant behavior.[9] It is difficult to justify these as aspects of culture in a real sense, however, as this is a list of pathologized behaviors, rather than a culture. However, not all Autistic people display these traits and many of the behaviors outlined have been framed as pathological by physicians and psychologists. In short, Mesibov's description of Autistic culture is not an accurate descriptor of autism in a cultural sense. It is more useful to observe modern, internet-based groups where Autistic people themselves define their shared culture as they build community and connections with others with autism.

Autism as a Cultural Identity

For the purposes of a modern examination of the cultural identity of Autism, a holistic approach, defined by individual Autistic people within various differing social groups is more useful than the problematic and reductive definition provided by the TEACCH. The most integral part of

[6] Mesibov et al *TEACCH,* 19.
[7] Mesibov et al, *TEACCH,* 20-24
[8] Mesibov et al, *TEACCH,* 25-26
[9] Mesibov et al, *TEACCH,* 26-29

establishing a cultural definition is the establishment of community discourse that defines the very basis of a cultural identity. The established community discourse, in this case, is the duality between neurotypical and neurodivergent identities. There has been a shift from an understanding of autism as a pathology--something that needed to be cured or treated—to emphasizing Autistic people's self-empowerment, advocacy and community. Most interpretations of autism follow the model of a biomedical deficit, but those with the condition are spearheading an alternative paradigm via the means of narrative self-representation.[10]Without the understanding that autism is more than a collection of pathological conditions, any community built on the basis of shared Autistic identity would crumble. With this in mind, it is vital to any and all discussion of the cultural identity of autism; said discourse being the idea that autism is an identity within itself, not something to be cured or treated. In other words, autism is an inexorable part of their very being. The biomedical model, which sees it as a disease to be treated rather than a natural variation, would eliminate a fundamental and key part of themselves.[11] For many Autistic people, their autism is as much a part of their identity and thus the culture they share with other members of the group in the same vein as other cultural signifiers. If one's autism were eliminated, they would not be the same individual, and would that not be the same if another form of cultural identity was removed? If one's own ethnicity, race, sexuality, gender identity, interests or other intangible part of one that is the basis of a cultural identity, would they not change in a similar way? The cultural identity surrounding autism is not a list of pathological behaviors associated with it, but the very state of being within itself, its cure or removal would completely alter a person's very being and ego.

Basal Characteristics of Autism's Cultural Identity in Face-to-Face Socialization

[10] Nancy Bagatell "From Cure to Community: Transforming Notions of Autism". *Ethos* 38, no. 1 (2010): 33–55., 33
[11] Bagatell, "From Cure to Community",38

Before considering the literature on Autistic social groups online, it is important to note the specifics of socialization within Autistic social groups within a face-to-face context. While the internet enables a greater ease of social interaction for Autistic people, face-to-face socialization and community building is both integral and shares many of the characteristics of Autistic communities online. One of these characteristics, of course, is the shared discourse of the Autistic cultural identity. This shared discourse is exemplified in Idriss's ethnography of ACOMM, a community run by and run for Autistic adults. Within this community, Idriss observed behaviors identifiable with autism as a cultural identity, including distinctive forms of communication. In an interaction between two members at an outing to a local botanical garden, Idriss observed that discourse set a distinct social boundary between Autistic people and non-Autistic people, or neurotypicals. Neurotypicals were perceived by Autistic people in the study to operate on insincerity, with platitudes such as "let me know when you're ready" being understood as "hurry up".[12] This dynamic, which openly goes against the grain of neurotypical social conventions that Autistic people often perceived as insincere by many who are Autistic is why direct communication operating under the Autistic shared discourse is unfettered by the neurotypical restrictions of social norms, enabling communication instead more reliant on one's authentic and unfiltered emotions and opinions. However, is that even an argument to establish a cultural infrastructure for an Autistic cultural identity, let alone for the identity within itself? The idea of autism being even eligible to be a basis for a cultural identity is somewhat tenuous and has some considerable pushback. This is a relatively novel and not clearly defined cultural identity, especially compared to other cultural identities based on nationality, ethnicity, faith, and

[12] Cara Ryan Idriss, Infrastructure: Ethnographic Reflections on an Autistic Community." Medical Anthropology 40, no. 2 (2020): 129–40. https://doi.org/10.1080/01459740.2020.1849185. 138

sexual orientation, to name a few, and has considerably less material available, let alone if it can even be qualified as a culture to begin with.

Criticisms of the Autistic Cultural Identity's Legitimacy

It is still debated nonetheless if Autism itself is a cultural identity in the first place, and unlike other culture groups, it is very nebulous in its nature, as well as its tangibility within a physical space. Autistic people aren't generally born into a family of other Autistic people, in the way ethnicity is enculturated, nor has there been a long-standing institution of dogma like religious identities, or a well-ingrained counter culture such as LGBT+ culture; its nature as a cultural identity in the first place is scaffolded by its intangibility, in the sense it is considered an "invisible" disorder and on its reliance on the internet for social function, the veracity of the Autistic cultural identity is still a burgeoning one. The sentiment of autism lacking a cultural identity, the sentiment that TEACCH has that it is a neurological disorder with pathologized behaviors and nothing more, and even some Autistic people who advocate for Autistic rights state that Autistic people lack a distinct identity. Even scholars such as Judy Endow, who are Autistic themselves, reject the notion of an Autistic cultural identity, with Endow stating in a 2009 presentation:

> I hate to say that I conclude that autism is not a culture. I really do not like that at all, I do not want that to be even close to the truth yet autism does not meet the-the [sic] current definition and standards we use. Nobody is happily proud to welcome their child into the world of autism. Autistic adults have not invented a new pattern of behavior and nor do we transmit this pattern to others who acquire it from us. Autism is not culturally transmitted.[13]

[13] "Judy Endow's Culture of Autism Presentation," The Autism Society, August 27, 2009, YouTube video, 8:32, https://www.youtube.com/watch?v=hlO9j8UuC-w.

However, the online landscape and neurodivergent discourse have changed drastically since 2009. Autism itself may not be culturally transmitted, but the community discourse around it certainly does, and it is reflected in both the online spaces and cultural artifacts produced by people who identify with the Autistic cultural identity.

Results

The Three Tenets

In terms of how the Autistic cultural identity is defined by Autistic people themselves, three tenets are the bulwark of the identity: belongingness, social connectedness, and political connectedness. In an interview conducted in the journal *Autism* where 20 Autistic subjects were asked for their thoughts on the matter, these three stood out as forming a cultural base for the Autistic identity. Firstly, the matter of belongingness, "participants described feeling connected to and accepted by other people who are Autistic or neurodivergent. The similarity was expressed in terms of being on the same wavelength and instant connection, one where they are accepted for their differences rather than disparaged for them."[14] Belongingness is integral for any cultural group, it is a foundation that all else is built on, and the inherent belongingness that is felt due to the shared discourse of neurodiversity and shared experiences of being "othered." A community that is not built on belongingness is sure to not last, and this theme of belongingness is present within every Autistic community that is mentioned within this paper from here on. The next tenet, social connectedness, refers to the social connections formed with other people on the spectrum, the establishment of a space that feels like "home" and the necessity for spaces like this for others to join and meet others in. [15] Social connectedness is indicative of the unique qualities endemic to friendships between those under the shared discourse of neurodiversity,

[14]Botha et al, "Grand Cultural Tradition", 2155

[15] Botha et al "Grand Cultural Tradition", 2155-2156

because people under the shared discourse of neurotypicality are just unable to understand the neurodivergent experience to the same extent, just as if someone from an ingroup were to study a culture of an outgroup they were not a part of. Despite how much they study or interview, they will inherently not know what it is truly like to be the other that they are studying. This shared experience of being Autistic enables social bonding and connectedness in a vein similar to the mutual experiences felt by those who are part of culture groups, even if they are not exactly the same, the baseline shared experience combined with the shared discourse enables strong cultural grounds of healing, understanding, and a mutual state of being, all of which are integral to the formation of a cultural group.

Finally, the third category is the utilization of the shared discourse as a form of praxis, or political connectedness. While more nebulous and differential than the other tenants, Political connectedness is a subdomain focused on the goal of neurodivergent equality, rights acquisition and elimination of mistreatment, and has a wide variation of political connectedness, with some being very active socially and not very politically active, and vice-versa.[16] As stated, the shared discourse of neurodiversity and Autistic identity permeates throughout the neurodiversity movement despite the considerable variance of political involvement. That discourse is one that is anti-cure, pro-Autistic rights, and global access to diagnosis and support. This discourse also refers to how the three tenants are more subdomains of a larger social construct rather than individual ones. I posit that the social construct in question is the Autistic cultural identity, with these three subdomains being present in varying extents in each of the Autistic communities examined. These three subdomains, along with the utilization of the internet as a space of

[16] Botha et al "Grand Cultural Tradition", 2157

socialization, are the criteria that support the concept of an Autistic cultural identity above all else.

Fandom as a Form of Autistic Sociality

One of the main environments Autistic cultural identity has been able to flourish is within fandoms, notably those that fall under the "geek" subculture. In particular, the internet, which eliminates certain social stressors, enables Autistic people to thrive in fandoms. In essence, communication via the internet enabled those in the "geek" subculture with communicative impairments to "connect to others more easily. Awkward individuals have the opportunity to review and edit their responses as many times as needed for comfort before sharing them. Significant communication issues (such as autism or social anxiety) can be hidden more effectively. A ready-made commonality with other geeks diminishes fear of being judged for their love of their subculture."[17] In the social sphere of day-to-day life, a commonality based on shared special interest or hyper fixation, is a boon especially when socialization in general is an inherent difficulty for Autistic people. Having a shared interest or commonality within an online community is integral for the utilization of the internet as an Autistic node of socialization as well as the establishment of an Autistic cultural identity, and harkens back to the first subdomain of Autistic cultural identity, belonging, proposed by Botha and examined earlier within this work. Essentially, a space changing from the confines of the physical world to the internet enables fandom to be part of daily life. This shift enables people with social difficulties to immerse themselves in communities in the digital world, with an example of one with these

[17] Dale Peeples, Jennifer Yen, and Paul Weigle. "Geeks, Fandoms, and Social Engagement". *Child and Adolescent Psychiatric Clinics of North America* 27, no. 2 (2018): 247–67. https://doi.org/10.1016/j.chc.2017.11.008. 252

communities being the cosplay community.[18] This integration is achieved by making fandom spaces operate as a space of empowerment, both by making spaces that welcome and embrace Autistic people not in spite of their autism, but because of it, as well as fan-created fanfiction to normalize and de-stigmatize the Autistic identity.

An example of a community that wears neurodiversity on its sleeve is a collection of cosplay[19], and related posts, blogs, and forums of the Autistic cosplayer experience that were ethnographically analyzed by Alice Leyman as a form of utilizing the internet for Autistic self-expression and community. Through analyses of these Autistic voices, Leyman detailed how these members of the cosplay community felt generally isolated in day-to-day life from their peers. These records detail the extent of social adversity that many Autistic people go through in their day to day life, how the macro forces of social pressures often feel insurmountable and overwhelming to youth on the spectrum, as well as establishing the importance of online spaces that fall under the three tenants of online Autistic socialization (belongingness, social connectedness, and political connectedness), all of which are present in the cosplay communities that the interviewees mention being a part of, which is a wonderful and fantastic thing that shows the importance of online communities in the formation of an Autistic cultural identity.[20] It is apparent that through the acceptance of others within these communities, connectedness with others on the basis of a shared Autistic identity, and a shared political connectedness under the neurodiversity model, the notion that autism is just another way of existing and not inherently flawed or wrong. Leyman notes how joining cosplay communities enabled Autistic people to

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[18] Alice Leyman, "Use of Digital Platforms by Autistic Children and Young People for Creative Dress-up Play (Cosplay) to Facilitate and Support Social Interaction." *Digital Geography and Society* 3 (2022): 100039. https://doi.org/10.1016/j.diggeo.2022.100039. 3

[19] Dressing up as fictional characters, typically at conventions

[20] Leyman, "Use of Digital Platforms", 4

build social skills and be around people with similar interests,[21] discovering commonalities with other people on the spectrum,[22]handling overstimulation from large social gatherings,[23] expanding their horizons in trying new things,[24] using cosplay as a form of self-acceptance and embracing one's self,[25]and as a way to destress from the chaos and bustle of daily life.[26]

These factors, when taken in consideration with the three subdomains of Botha's premise of Autistic sociality all help in providing credence in the internet's unique traits that enables the formation of the Autistic cultural identity within online spaces. As the internet was an integral infrastructure for such communication and community building to happen in the first place, it is apparent that the internet was beneficial in the conception of the Autistic cultural identity. However, culture inherently implies the production of unique cultural artifacts, such as writing and art. It is important to examine under a critical lens the materials that are produced with the intent to be shared with others, and examine why online fandom is so important in facilitating the construction of cultural artifacts in the form of fanfiction and shared community discourse around said artifacts.

The Repercussions of Non-Autistic People Constructing Autistic Narratives

Narratives about Autistic people are unfortunately not reflective of the realities of being Autistic, and the ones proliferated within mass media and the collective consciousness are distorted by the biases and stereotypes that neurotypical authors utilize in their works. This is sadly a theme that is not uncommon in regard to narratives about marginalized people, and it is often up to marginalized people themselves to rectify that by constructing their own narratives. There are

[21] Leyman, "Use of Digital Platforms", 4
[22] Leyman "Use of Digital Platforms", 4
[23] Leyman "Use of Digital Platforms", 4
[24] Leyman "Use of Digital Platforms", 5
[25] Leyman "Use of Digital Platforms", 5
[26] Leyman "Use of Digital Platforms", 5

tropes that are generally utilized to profile and assign narratives to Autistic characters in media. The first is the inclusion of an Autistic character just to show impact and develop another character rather than a character with depth by Autistic characters being included in a narrative for limited purposes. Purposes such as being used as a tool to impact other characters (such as generating sympathy for another character) rather than being complex characters a reader could identify with; or as just as a vehicle for comedy or entertainment through awkward interactions, and as sympathy bait for another character to be nice to; as well as minimizing Autistic characters' own experiences, such as focusing on an Autistic character's actions instead of their internal struggles of being neurodivergent in a neurotypical world.[27]

The second trope found in children's and young adult literature is autism being a debt that needs to be repaid to others. This trope is apparent in forms such as moving towards neurotypicality as positive or and end goal, or through Autistic characters that are savants, or exceptionally skilled at a useful task to compensate for the "burden" of being Autistic[28]. In the third trope, Autistic characters are generally portrayed in a typical way, usually as socially isolated, white, middle-class men, which obfuscates the reality of autism and perpetuate autism only manifesting in a certain stereotypical way.[29]

Fanfiction: Shared Art as Community Discourse and as a way of Sharing Experiences

These tropes have unfortunately proliferated throughout the media, resulting in many of the stories that are constructed and told to an audience of mass consumers to misconstrue the realities, struggles, joys, and triumphs of being an Autistic person, and this disparity has tangible negative effects that needs to be addressed. From the assumption that autism is only a condition

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[27] Rebecca Black, Jonathan Alexander, Vicky Chen, and Jonathan Duarte "Representations of Autism in Online *Harry Potter* Fanfiction", Journal of Literacy Research 2019 51:1, 30-51 31-32
[28] Black et al, "Representations of Autism",32
[29] Black et al "Representations of Autism", 32

affecting white, cisgendered, straight men (due to their disproportionate presence in media about autism) to the myth of savant syndrome, it is apparent things need to be changed in regard to the portrayal of autism in the media. In essence, "if the representation in the media perpetuates stigma and negativity, they[30] may be discouraged from seeking help and even begin to view their own characteristics in a negative light. As a consequence, media representation of Autistic people should include the voices of Autistic people themselves, as there is often very little self-representation, except on social media."[31] This limitation of being confined to social media, however, is what has enabled Autistic cultural artifacts to flourish. When the narratives and stories of those who are marginalized and generally disbarred from the higher echelons of media production, then making stories in the form of writing and other media in a way separate from the modality of mass production is crucial, and this is where fanfiction comes into play.

Fanfiction is a genre of derivative literature about an existing piece of media, such as a tv show, film, video game, novel, comic, and various other forms of media, that is written by fans of said media, for the purpose of providing auxiliary content taking place in that world. Originating in the late 1960s during the Star Trek fanzine boom,[32] fanfiction is now a certified fixture of the internet, with several websites dedicated to the publication and proliferation of fanfiction of all kinds. Because of the non-centralized nature of fanfiction as a form of media production, it enables certain things that are not possible within the realm of standard media production. Essentially, fanfiction is utilized as self-produced narratives written by Autistic people about their own marginalized perspectives, in this case, the experience of being

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[30] (Autistic adults)
[31] G. Mittman, B. Schrank & V Steiner-Hofbauer. "Portrayal of autism in mainstream media – a scoping review about representation, stigmatisation and effects on consumers in non-fiction and fiction media." *Curr Psychol* (2023). https://doi.org/10.1007/s12144-023-04959-6 9
[32] Joan Marie Verba and Janet D'Airo. *Boldly Writing: A Trekker Fan and Zine history 1967-1987*. Minnetonka, MN: FTL Publications, 2003. 1

disabled[33]. This process, called "refocalization,"[34] changes the focus of a work away from portrayals of characters that reinforce the mainstream to those who are downtrodden and ignored by the narrative. This extends to a variety of marginalized character types, from women, people of color, LGBT+ people, and especially in this case, disabled people.

In Black et al's study of the representation of autism in *Harry Potter* fanfiction, they generally found that it manifests in three distinct ways: the power to speak,[35] points of intersection,[36] and promoting empowerment, understanding, and agency.[37] These traits echo the framework of Botha's 3 subdomains of belongingness, social connectedness, and political connectedness, and how they manifest as digital cultural artifacts on the Autistic experience. When shared through online communities, they serve a dual purpose of communicating their lived experiences among those who have experienced similar treatment and informing non-Autistic individuals on the intricacies, nuances, triumphs, joys, and sorrows of being Autistic. Rather than letting the 3 harmful tropes of representation within a limited capacity, autism being a burden, and autism having a monolithic appearance and identity, as defined by Leyman earlier within this work, fanfiction writers employ a different approach. Autistic authors of fanfiction write about autism as "an opportunity to present ideas and affects about ASD that are missing in most popular media, except in unflattering and stereotypical ways."[38] The construction of this counter narrative to the ableism, unintentional or not, pushed by large media producers done by Autistic writers in their communities is a valuable and commendable way to further representation in both the real and fictional narrative space. As such, fanfiction is an important

[33] Black et al "Representations of Autism" 32-33
[34] Black et al, "Representations of Autism", 33
[35] Black et al, "Representations of Autism", 40
[36] Black et al,"Representations of Autism", 43
[37] Black et al, "Representations of Autism", 38
[38] Black et al, "Representations of Autism", 46

cultural artifact utilized in changing both the perception and visibility of Autism and its cultural aspects.

Virtual Worlds, Gaming, and Non-human Avatars as a Mode of Expression

One of the most intriguing online spaces that have emerged as a mode of sociality are video games, specifically ones centered around online simultaneous multiplayer, as that enables robust community building and communication among people of all ages, creeds, neurotypes and required infrastructure notwithstanding. One of the first freeform massively multiplayer online platforms is the game *Second Life,* which has been online and active since 2003.The freely-available game enables a wide and varied player base to form over the years, with niche communities. What makes game spaces such as *Second Life* different from other forms of online communication is the "space" aspect of it all, which is exemplified by two factors. The first factor is how virtual spaces, unlike social media platforms or forums, is the actual immersion of being in a virtual world, which gives people a sense of presence within these communities.[39] The immersion of a virtual world enables a presence and tangibility to social interaction that is not reflected in other forms of online interaction, which enables greater social cohesion and belonging for the formation of communities. The second primary aspect is how avatar communication in a virtual world enables social presence. Social presence, in the context of virtual worlds, refers to:

> The degree of awareness of other individuals in an interaction, and also the appreciation of an interpersonal relationship through such interaction…Embodied social presence is used to discuss social presence in virtual environments…The sense of social presence with others is important, as is the relationship and sense of social presence between the human and the avatar.[40]

[39] Karen Stendal & Susan Balandin (2015) Virtual worlds for people with autism spectrum disorder: a case study in Second Life, Disability and Rehabilitation, 37:17, 1591-1598, DOI: 10.3109/09638288.2015.1052577 1592
[40] Stendal & Balandin "Virtual Worlds", 1592

With social media and online gaming both becoming increasingly prominent, the combined synthesis of the two, the virtual world, is incredibly impactful in regards to community building and socialization. This propensity to be used as a tool for socialization and community building is best examined via an ethnographic examination of the users of *Second Life*. Researchers Stendal and Balandin chronicled the experiences of an Autistic man that goes by "Wolf", as his avatar is an anthropomorphic wolf, and his experiences and thoughts on the platform, *Second Life.* Wolf joined the platform as part of a program, one that seeked to " as one of a group of seven people with a range of disabilities who were recruited with the help of Virtual Ability Inc. (Aurora, CO) (virtualability.org), which operates an island in Second Life to support people with disabilities entering into the virtual world."[41]Wolf was an early adopter of *Second Life*, playing since launch, albeit sporadically.[42] Despite that, he remained a frequent netizen of the social worlds of *Second Life.* His main reason for playing was to escape from the stressors of day-to-day life as well as to facilitate his own social needs. As he put it, "I was always such an outcast in my peer group that finding company and companionship was nearly impossible in real life. I never really had a need for a great many friends but finding even a few was challenge enough that I looked elsewhere." [43]

The combined forces of social fatigue and isolation Wolf faced, which is a commonly shared experience among Autistic people within primarily neurotypical spaces,[44] and is a notable social stressor that makes socialization difficult, which is why it is so important that virtual worlds exist as a space for Autistic people to express themselves and make social connectedness.

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[41] Stendal & Balandin, "Virtual Worlds", 1593

[42] Stendal & Balandin, "Virtual Worlds", 1594
[43] Stendal & Balandin, "Virtual Worlds", 1594
[44] "Autistic Fatigue - a Guide for Autistic Adults." n.d. Www.autism.org.uk. https://www.autism.org.uk/advice-and-guidance/topics/mental-health/Autistic-fatigue/Autistic-adults.

Wolf reiterates this by explaining that the nature of virtual world socialization innately lacks the nonverbal social cues that give him and many other Autistic individuals trouble,[45] but the nature of having non-human avatars also enables the implementation of non-verbal social cues that are much easier for other Autistic people to pick up on, specifically making the tail of his wolf avatar wag to show that he is happy.[46] This idea of specifically using a non-human anthropomorphic avatar, or a "furry" character, to display actions or feelings, is a mode of expression that is not entirely uncommon in online spaces, with a notable increase in frequency among Autistic people. The estimated percentage of the furry population that is Autistic is believed to range anywhere between 4 and 15%,[47] which is substantially higher than the estimated frequency of just 1%, as reported by the World Health Organization.[48] The exact cause for this notable increase in self-identity is not concretely known, but the input provided by those who fall under both the furry and Autistic provides some insight on this notable increase.

Patricia Taxxon, a video essayist and musician with approximately 105k subscribers on YouTube at the time of writing, uses her own personal experiences as an Autistic person to explain why she identifies with the furry label. In her 2023 video essay *On the Ethics of Boinking Animal People*, Taxxon posits that there is a distinctive Autistic quality to furry art, including the quality of "being simultaneously human and nonhuman."[49] Taxxon said she had experienced that duality throughout her life, stating that the only reason she is able to talk directly in the way that

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[45] Stendal & Balandin 1594

[46] Stendal & Balandin, "Virtual Worlds", 1596

[47] Sharon E. Roberts, Chelsea Davies-Kneis, Kathleen Gerbasi, Elizabeth Fein, Courtney Plante, Stephen Reysen & James Côté (2024) Seeding the Grassroots of Research on Furries: Lessons Learned from 15 Years of Creative Knowledge Mobilization, Valuing Community Partnerships, and Correcting the Record on Stigmatized Communities with Evidence-Based Scholarship, Deviant Behavior, 45:1, 50-79, DOI: 10.1080/01639625.2023.2237634 53

[48] World Health Organization. 2023. "Autism Spectrum Disorders." Who.int. World Health Organization: WHO. November 15, 2023. https://www.who.int/news-room/fact-sheets/detail/autism-spectrum-disorders.

[49] Patricia Taxxon, "On the Ethics of Boinking Animal People", YouTube, September 4, 2023, video essay, https://www.youtube.com/watch?v=ws9g3igw51s&list=PLMNu19HiwYYEkBkJr9pxVS0oSpymIadR-&index=1, 28:32

she does is due to the fact that she was subjected to literal dog-training techniques in the form of Applied Behavioral Analysis therapy,[50] to which she posits that it is no wonder that she sees herself in that manner, as her whole life was her being at the boundary of being viewed as something that is both human and nonhuman. The relation between the human and inhuman as a form of identity empowerment is also present in Wolf's rationale for depicting himself as a wolf and utilizing the symbolic and sensory aspects of the wolf persona as a form of empowerment within a virtual world. Wolf chose "to be represented by a wolf, and described feeling connected to the wolf and its characteristics. "[51]This connection between human and nonhuman self expression is made possible through virtual spaces enabling the usage of avatars, which is just another facet of Autistic cultural expression within online communities. However, identification and empowerment is just one facet of virtual worlds, one that directly facilitates the creation of community groups.

Virtual Worlds as a Form of Community and Healing

While virtual worlds enable Autistic people to explore their identity beyond the scope of what is possible in the real world, they also enable a greater ease of community-building and social interaction. Aside from the greater ease of social interaction and motility Wolf experienced that was mentioned prior, the virtual landscape of *Second Life*, the ability for him to be himself lead directly to stronger social bonds and interactions. Wolf recalls that despite attending the same place of worship for 5 years, he was unable to form any deep social connections with his congregation, and generally felt unincluded.[52] In an interview, he elaborates on how he perceives his own neurology being the primary reason for his social difficulties outside of *Second Life,* as

[50] Taxxon, "On the Ethics of Boinking", 24:19
[51] Stendal & Balandin, "Virtual Worlds", 1596
[52] Stendal & Balandin, "Virtual Worlds", 1595

the immersion, self-empowerment, and ease of communication has led him to make a long-lasting group of friends, and even a partner he plans to move in with, who also identifies as a furry.[53] Virtual worlds such as *Second Life*, however, are notably niche, which makes the process of building a large and active community based on a shared neurological identity more difficult. However, since the advent of online gaming, larger virtual worlds have arisen and offer both the digital and cultural infrastructure required to make a virtual world that stands the test of time.

No game reflects the infrastructure previously described more than the game *Minecraft*, which has sold a total of an astonishing 300 million units across various console platforms, mobile devices, and personal computers.[54] With such a large and robust player base, it is no surprise that communities based on the Autistic cultural identity are prominent, with one example being the self-titled "Autcraft" server. As much as the internet has the potential to harbor safe spaces for Autistic socialization and community-building, it is also a very dangerous place. Autistic people are often the unfortunate victims of online trolling, i.e. mockery and deceit, especially Autistic children. Ringland observed that in online spaces, such as YouTube comment sections, 'autism' is used as a derogatory or insulting ways, and the concentration of marginalized people (in this case, Autistic people), all together in one place, attracts a direct and focused line of harassment and bullying, with one commenter referring to the Autcraft server as a "trolling paradise".[55]

It is very apparent from the bullying faced by Autistic people online, that despite the internet being such a useful tool for Autistic socialization, there needs to be curation to ensure

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[53] Stendal & Balandin ,"Virtual Worlds",1595

[54] Tom Gerken. 2023. "Minecraft Becomes First Video Game to Hit 300m Sales." BBC News, October 16, 2023, sec. Technology. https://www.bbc.com/news/technology-67105983.

[55] Kathryn E Ringland,"'Autsome': Fostering an Autistic Identity in an Online Minecraft Community for Youth with Autism." *Information in Contemporary Society*, 2019, 132–43. https://doi.org/10.1007/978-3-030-15742-5_12. 136

that bad actors and people looking to cause problems are not allowed entry into such spaces, and for general gaming spaces, as they are typically unmoderated in that regard. Therefore, establishing safe spaces through a process of vetting is wise. This is done by establishing a dedicated space, or “server”, where only people with permission can have access to joining the server. This is exactly what the aims of the “Autcraft” server are, the establishment of a safe space, said space operates under the ideals of belongingness, social connectedness, and political connectedness. While it may seem counterintuitive to claim a space with a policy of exclusion, it is necessary to do so to ensure the safety of the members of the server. This policy is best justified when viewed under the lens of how ‘autism’ is unfortunately used as a pejorative, where those who identify under the label are victimized by other people online, and are often targeted, which perpetuates and normalizes a culture of violence towards Autistic people, so the only recourse the Autcraft community could do was to simultaneously uplift an Autistic identity while also making a space that is no-tolerance for victimization.[56] The victimization Autistic people face, especially children, is why such exclusionary measures are taken, and it is necessary for the sake of Autistic belongingness. It is paramount to establish these boundaries in any space for those who are marginalized and mocked to form a space based on the shared belongingness of being part of a marginalized identity.

Regarding social connectedness, the social structure in the Autcraft server is self-defined as a sort of familial kinship, with “family” in this case being described as a system that “incorporates the idea of being accepted for who you are, including faults and quirks. Acceptance is a cornerstone to making being ‘different’ more tolerable and reducing the social isolation and loneliness that frequently surrounds difference. The Autcraft community displays

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[56] Ringland, “Autsome” 137-138

this acceptance through the creation of autism-centric words, such as 'autsome'.... These act as signals to community members they are accepted as Autistic."[57] By explicitly making autism as something to be accepted and embraced in this community, in spite of any social faux pas or difficulties, based on the shared experiences and understandings of the Autistic societal discourse, is an incredibly apt example of social connectedness within the Autcraft server.

Finally, insofar as political connectedness, the Autcraft server is essentially built on it, in a sense. As previously stated, the adoption of terms such as 'autsome' and other autism-derived terms utilized by users are done so in a way that reflects the idea of political connectedness. This reclamation of the term "lends to a sense of identity with others who have the same or similar medical diagnosis. Aside from using 'aut' or 'Autistic' in their usernames (i.e the names that are displayed with their avatars and forum posts, rather than a real-world name), the Autcraft community displays this acceptance through the creation of autism-centric words, such as 'autsome.' According to a community post, 'autsome' means:

> 'Having autism and being extremely impressive or daunting' and 'extremely good; excellent.' Disability Studies scholars have described how those with disability are often held to a higher standard and those who are 'extreme' tend to be held up as inspirational…. This type of 'inspiration' frames disability as something to be overcome, while achieving difficult objectives ... Language such as 'autsome' is meant to be inspirational not for others looking into the Autcraft community, but for the Autistic children who are otherwise dealing with a barrage of negative language about autism. This is a reframing of the autism label as an identity that is worth embracing, rather than overcoming.[58]

This recontextualization and reclamation of autism and disability as something to be embraced, something that has value, is indicative of the strong sense of political connectedness within the Autistic cultural identity, even among young people.

[57] Ringland, "Autsome", 94
[58] Ringland, "Autsome" 138

This inclination towards a political understanding of neurodivergence, as they are diligent in their efforts to "work to reshape the mainstream dialog about autism. Primarily, members try to lead by example, following a set of tenets set out by community founders that encourage and promote prosocial behavior. Community members also engage in outreach to both educate others and to make their own expressions of their Autistic identities more visible to others. Members of the Autcraft community engage in activities—much like creating memorials for victims of violence—that purposefully shed light on the hardships they have faced. These efforts are examples of how those with marginalized identities fight back against oppression".[59] Even in an online space dedicated for socialization under a common banner of a shared interest, the amount of political connectedness to increase the understanding of autism among both neurodivergent people and neurotypicals, such as the families and friends of the server members, is truly inspirational and commendable.

Overlap, Similarities, and Differences with D/deaf Culture

Concerning the cultural development of the Autistic cultural identity, it would be remiss to not analyze the similarities to D/deaf (with a capital "D") culture, and the parallels and differences that both possess. Similar to how Autistic culture rejects the idea of autism being a pathologized biomedical condition and is against the notion of a cure, "Deaf culture, in its strongest form, can reject people it sees as accepting the biomedical model definition of 'deafness', that is people who identify as hearing impaired. It is extremely critical of cochlea implants and campaigns for them not to be carried out on children."[60] However, unlike autism, there are real and tangible "cures" for hearing loss in the form of the aforementioned cochlear implants, which enables

[59] Ringland, "Autsome" 140
[60]Skelton & Valentine, "'It Feels Like Being Deaf Is Normal'",454

D/deaf culture to be more exclusionary in regards to the treatment aspect of the biomedical model, as no cure or treatment exists for autism. As such, divisions are more common, as well as feelings of conflicted belongingness. Some D/deaf people have described themselves as being in an 'in-between' position due to the divisions established by the cultural and political discourse of the D/deaf identity, notably the outright rejection of the notion that deafness even is a disability.[61] While this is not a problem faced within Autistic communities, due to autism not being "curable," if a "cure" ever is discovered and made available to the public, based on how political connectedness based on the idea of autism being a natural difference rather than a pathological condition, in all likeliness, schisms and changing discourse will follow. However, it is much more conducive to analyze the similarities these communities share, especially in regards to digital communication facilitating the formation of communities.

Due to deaf studies having an aforementioned schism with the label of 'disability', and D/deaf culture's belief that deafness is a distinct linguistic and cultural identity, the D/deaf community has resisted being associated with disability studies as a whole, but there have been an increasing amount of intersectionality with other forms of difference.[62] The form of difference, in this case, is autism, and the intersectionality between autism and deafness. As both deafness and autism have varying impacts on communication, depending on the individual, auxiliary modes of communication are often used both to communicate. From Deaf professors who conduct classes entirely through online text-based mediums to the use of texting among deaf people in India to Autistic communities congregating on *Second Life* as a means of social interaction with others, digital communication has had a profound impact on the lives of deaf

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[61] Skelton & Valentine, "'It Feels like Being Deaf is Normal"', 454-455
[62] Michele Friedner and Pamela Block. 2017. "Deaf Studies Meets Autistic Studies." *The Senses and Society* 12 (3): 282–300. https://doi.org/10.1080/17458927.2017.1369716. 285

people and Autistic people alike.[63] As such, the intersectionality of how communicative tools are used by both groups is conducive for establishing an Autistic cultural identity, as despite the innate differences, the parallels between the generally accepted and established D/eaf culture, especially in regards to anti-curative political discourse, and the usage of alternate forms of communication.

Discussion

An Autoethnographic Takeaway

From my own perspective as an Autistic person, what does this all mean? It would be worthwhile to start with some personal history. I was diagnosed with autism spectrum disorder at the age of 18, after a disastrous first term at college. During that time, I was depressed, barely attended classes, and very unsure of myself. My entire life, I always felt I was a bit “off”, and getting diagnosed was a huge weight off my shoulders. However, as soon as the metaphorical weight was lifted, another came crashing down. Understanding that I was Autistic was a bitter pill for me to swallow, years of harassment by my peers and my own social follies were finally put into context, and to say I was awash with anguish and self-loathing. Attempting to understand a life lived in a context that changed is a struggle, and I was resentful at first with my new identity. I grappled with internalized ableism and a seething desire to understand myself better. But as the years marched on, I began to better understand myself, and sought to use my interests to better understand myself as well as others. During the pandemic, I was online quite a bit, and was exposed to various online subcultures, mainly just out of curiosity. What struck me the most, was the seeming density of neurodiversity within specific communities. From people making videos using rudimentary animation programs to make various children’s television

[63] Friedner & Block “Deaf Studies Meets”, 291

show characters get grounded for the most mundane of actions to fan sites and wikis documenting the opening and closing logos of production companies, something just struck a chord with me. The fixation, community, and appreciation for the most seemingly mundane things is what drove me to study anthropology in the first place. Understanding others through their cultural practices, and hopefully in doing so, I am better to understand myself. Because I never really knew I was Autistic for such a long time, getting diagnosed with it all of a sudden during a transitional period in my life from child to adult, I felt like part of my own lived experience was lost. I was a chicken raised by hawks and friends with hawks, but deep down, I knew I wasn't really a hawk, and yearned to understand myself on a deeper level, to revel and be content with my true self. Understanding the Autistic cultural identity has been a key aspect of this, and throughout this project, from its conception to its conclusion, I have also been able to understand myself more, and my future research endeavors have a more developed and impassioned base of knowledge.

Conclusion and Lessons Learned

While the analysis of the intersection between disability studies and cyber-ethnography, both burgeoning fields in their own right, is still a very young field, there is definite potential for the further proliferation and analysis of this ethnographic synthesis. The present literature review should serve as a basis for further ethnographic research. It is also to be noted, that autism and those who identify as Autistic are not a monolith in any way, and this paper does not seek to insinuate in any form. Future research projects should investigate this diversity and the ways it can be found in online communities. I seek not to conclude with the notion that I am an authority, but a call to action for myself and others to do what we can to learn and make voices heard, from minds of all kinds. Anthropology has a troubled history of dehumanization,

scrutinization, and theft from those who are not considered "normal" from a societal standpoint, and as anthropologists, it is our duty to uplift and let the voices of those whom are silenced, and appreciate the natural variance of humans, which is the basis of the neurodiversity movement in the first place.

Regarding utilizing this literature review as a launching point for future research, learning about the manifestations of cultural tenants within Autistic groups online gives me a greater indication of what trends to look at and questions to ask in a proper ethnographical study. Considering the trends outlined earlier within the work, analyzing the Autistics within the Furry community as it intersects with disability and Autistic culture, and outlining how the three tenets of belonging, social connectedness and political connectedness apply within a different, yet similar, space. The sensory aspects of being Autistic and how it intersects with interests and community building is also another topic worth exploring, as it shines a light on an aspect of utilizing technology to fulfill sensory wants and needs. Aspects of using technology as a means of sensory fulfillment were outlined somewhat within this work, but as a research subject it is definitely one that is becoming more and more prominent with advancements in consumer technology, notably commercial virtual reality headsets. As new technologies allow for a greater form of immersion within virtual worlds, the growing consumer-base of those who use virtual reality as a form of socialization are a very promising future fieldwork endeavor, as it is essentially a logical progression from examining traditional virtual world communities.

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