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# Neurodiversity and Online Communities: Why They Matter

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# Neurodiversity and Online Communities: Why They Matter

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# Abstract

Neurodiversity is an approach that accepts and embraces neurological differences as a natural variation, and neurodivergent people are those whose brains work differently from what is considered the norm by society. This thesis examines the impact of online neurodivergent communities on the neurodivergent people that participate in them through the use of a qualitative online survey distributed via Twitter and Mastodon, a decentralized Twitter alternative. It is informed by the researcher's experience as a neurodivergent person in these online communities and analyzes the functions that these online communities serve for the neurodivergent people who participate in them and how this participation affects them, by centering the voices of those participants and allowing us to speak for ourselves about our experiences. Based on this analysis, I argue that online communities provide neurodivergent people with a place to find friends, access vital support, and meet needs that are not being met or cannot be met offline. Participation in these supportive environments can also result in a changing self-conception, allowing neurodivergent participants to better understand themselves and accept themselves for who they are, and leading to a decrease in negative thoughts and self-hate.

# Acknowledgements and Dedication

This research is dedicated to the online neurodivergent communities that have proved to be invaluable sources of support and friendship for me, both before and during the course of this research, and to everyone who has helped to create these spaces and make them better through their participation. This research could not have happened without you, and I hope that it will aid us in creating even more accepting and accessible communities where we can be ourselves. I am thankful to everyone who has encouraged me, helped me to find vital resources, and to articulate my thoughts during the course of this research, and I am especially thankful to everyone who contributed their voice to this project by responding to my survey. Your words inspire and motivate me, and I am glad to be your co-writer.

I would also like to extend my thanks to the members of my honors thesis committee for their helpful feedback during the course of this project. I am especially thankful for my advisor Dr. Holli Seitz and her unwavering support and acceptance. Thank you for helping me structure this thesis and keeping me on track, and for allowing me to infodump excitedly to you about my findings during our weekly meetings. Thank you also to the Shackouls Honors College for the financial support that has aided me in producing and sharing this research.

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# Introduction

While much research about neurodiversity and neurodivergent people centers the voices of neurotypical people (that is, people who are not neurodivergent) and comes from an outside perspective that pathologizes and criticizes our movements and our rhetoric, this thesis presents an examination of the ways that online neurodivergent communities function and affect neurodivergent participants by centering the voices of those participants. It recognizes that neurodivergent people have much to contribute to the literature that often talks about us without us, and it celebrates those contributions. It is based on the personal experiences of the researcher as a neurodivergent participant in online neurodivergent community, and the responses of other neurodivergent community members to an online survey circulated in those communities. This thesis comes out of a celebration and acceptance of neurological differences as a natural part of life, neurodiversity, and examines what it means to be neurodivergent, or neurologically divergent from the societal norm. More research like this is needed which centers neurodivergent people and allows us to speak about our own communities and our own experiences.

In this thesis I present evidence that online communities serve an important function for neurodivergent people as sources of social support networks and social interaction, meeting needs that offline communities do not or cannot meet. Online communities are not simply an alternative to or complement of offline communities but provide opportunities for community building and unique types of interactions and relationships that are not possible offline. Online communities are also able to avoid access barriers that make participation in offline communities difficult or impossible for many neurodivergent and disabled people. In online communities, neurodivergent people can find friendship, support, and acceptance that helps us to understand ourselves and our needs, find ways of living that work for us, and enables us to embrace self-acceptance and stop pathologizing our natural ways of being.

# Literature Review

Though there are countless blogs, social media posts, YouTube videos, and anthologies published by neurodivergent self-advocates about neurodiversity and what it means to be neurodivergent, information on the subject from formal academic sources such as academic journals is severely lacking. What literature there is about neurodivergence and the neurodiversity movement in academia tends to be written by professionals in fields that are often hostile to neurodivergent people, such as psychiatry, and who are not themselves neurodivergent, but neurotypical. In contrast to works put out by neurodivergent self-advocates, this literature typically takes a biomedical, deficit approach to neurodevelopmental disabilities and neurodivergence which views these disabilities as a biological problem to be treated or cured. This approach focuses on neurotypical (NT) observation of neurodivergent (ND) behaviors and the ways that these behaviors inconvenience the families of neurodivergent people and prevent them from becoming ‘productive’ members of society following a very narrow normative model (Antze 2010, 314). This literature is also often based on models of diagnosis that require people to be impaired in certain ways to be diagnosed with these conditions, and which then deny the legitimacy of everyone who does not fit into these categories constructed entirely on observed behavior, pathologization, and social stigma (Runswick-Cole 2014, 4; Ortega 2009; Yergeau 2018, 165). As the focus of this paper is on community, where then can neurodivergent people find community in these narratives? How can anyone embrace self-acceptance and reject pathologization when this very pathologization is presented as the only path towards legitimacy?

The academic literature that does approach neurodiversity as a social movement typically focuses on the perceived problems with the rhetoric of the neurodiversity movement rather than examining the benefits of neurodivergent community for those that participate in it. Here I will examine three articles that illustrate this pattern: “The Cerebral Subject and The

Challenge of Neurodiversity” (2009) by Francisco Ortega, “'Us' and 'them': the limits and possibilities of a politics of neurodiversity in neoliberal times” (2014) by Katherine Runswick-Cole, and “On the Pragmatics of Empathy in the Neurodiversity Movement” (2010) by Paul Antze. These articles are written by people who present themselves in opposition to autistic or neurodivergent subjects as outsiders to the neurodiversity movement and focus on the ways that the rhetoric of neurodiversity is lacking, contradictory, or deficient in the view of the authors. Just as neurodivergent people are seen as inherently deficient by society, so too is our rhetoric. M. Remi Yergeau describes this state of affairs in detail in their book *Authoring Autism: on rhetoric and neurological queerness* where they explain that autism is medicalized as inherently lacking and defined by a profound involuntariness (2018, 7). In turn, this is used to deny the rhetorical capabilities of autistic people and to dismiss what rhetoric is produced by autistic people because, as Yergeau characterizes the refrain of neurotypical researchers, “Autistics don’t tell us what we want to hear, nor do they tell it to us in the manner in which we wish to hear it” (2018, 22). If the rhetoric of neurodivergent people challenges dominant societal models and social structures, often directly speaking about the ways that society is failing us, then that rhetoric must be characterized as lacking or deficient, or else we would be forced to reckon with the fact that the structures of our society are lacking or deficient.

In “‘Us’ and ‘them’: the limits and possibilities of a ‘politics of neurodiversity’ in neoliberal times”, Katherine Runswick-Cole identifies a conflict between the rhetoric of the neurodiversity movement that neurological differences in the human population are a natural variation and not inherently disordered, and neoliberalism, which relies on “identifying the responsible compliant citizens - ‘us’ - and those who fail to live up to the neoliberal ideal type - ‘them’” (2014, 3). In arguing that the rhetoric of neurodiversity is not effective in a neoliberal society, Runswick-Cole writes:

> “The neurodiversity movement has similarly claimed this corporeal difference; the cerebral subject with a differently wired brain is distinct from but no lesser than the ‘neurotypical’ body. Both the gay rights movement and the neurodiversity movement rely

> on an argument for equality based on ‘rights’ and ‘recognition’; in other words the rights of gay and autistic people should be recognized because, although they are different at the corporeal level, these bodies are no less valuable than straight or neurotypical bodies. The difficulty with this claim for equal rights is that it depends on simultaneously claiming that the neurodiverse/neurotypical body are both the same and different (Richardson, 2005). There seems to be an inherent contradiction here” (Runswick-Cole 2014, 16).

But the fact that the neoliberal society that Runswick-Cole writes about will not easily accept that a group can be inherently different and still deserve to be treated well, that it can’t understand that people don’t need to be deficient or disordered to deserve support (Runswick-Cole 2014, 17), is not an indictment of neurodivergent rhetoric. It is an indictment of neoliberal society.

But even more than problems with the content of the rhetoric of the neurodiversity movement, authors take issue with the position of neurodivergent people as the ones presenting this rhetoric. Though anthropologist Paul Antze recognizes the importance of the internet for autistic self-advocacy he argues that by the very fact of autistic self-advocates speaking about themselves, they have called into question whether they are qualified to speak on behalf of autistic people. Particularly online, Antze believes that because advocates are not being visibly autistic in the way that neurotypicals expect, there is “a tension between what they say about themselves and what they ‘perform’ in the saying of it” and “the end result is that while autism advocates have been very successful in presenting themselves on-line as persons or moral subjects…their very success in doing so has called their credibility into question.” (Antze 2010, 313). Mel Baggs, one of the autistic self-advocates whose credibility Antze questions, explains in hir video “About Being Considered ‘Retarded’”, “The biggest problem I have is people either refusing our personhood or refusing our cognitive disability, because they cannot handle both at once” (silentmiaow 2006, 9:40).

Antze argues that for our rhetoric to be taken seriously, autistic people must prove our autisticness visibly through video. Autistic activist Jim Sinclair described this expectation in 1994 in one of the earliest online autistic communities as being forced to become “self-narrating zoo exhibits" (Zifendorf 2002). This is what we as autistic people are told we must become if our rhetoric is to be taken seriously. Yet when activists like Mel Baggs do just what Antze is asking for, communicating their experiences visibly and without spoken words, being consumed as self-narrating zoo exhibits for the neurotypical gaze regardless of their intentions, their rhetoric is still dismissed. For example, Ortega in "The Cerebral Subject and the Challenge of Neurodiversity" (2009) also brings up autistic self-advocate Mel Baggs in these conversations about who should be allowed to speak for autistic people. Ortega and Antze have separately dismissed other activists for being "high-functioning" and not representative of autistic people, usually implying low-functioning to mean non-speaking. But when presented with the non-verbal rhetoric of non-speaking activist Mel Baggs in the video "In My Language" (silentmiaow 2007) they still find ways to dismiss hir. After asserting that most neurodiversity advocates are "high-functioning" and "low-functioning" autistic people are largely either silent or anti-neurodiversity, Ortega writes that Baggs "claims to be low-functioning" but then speculates about Baggs' actual cognitive ability, and casts doubt on hir self-identification (Ortega 2009, 431). In their book *Authoring Autism: on rhetoric and neurological queerness*, M. Remi Yergeau describes these constantly shifting goalposts on who is allowed to produce autistic rhetoric as demi-rhetoricity. Yergeau writes that demi-rhetoricity is:

> a historically useful strategy for denying the agency, rhetorical being, and personhood of autistic people. As a construct, demi-rhetoricity enables clinicians to claim the best of both worlds when they respond to autistic disclosures: (1) they can argue that autistic people are not autistic enough to make claims about autism; and (2) they can likewise argue that autistic people are too autistic to make claims about autism. Often, clinicians will make these arguments simultaneously and of the same autistic person (Yergeau 2018, 50).

Authors like Ortega, when they dismiss the claims of activists like Mel Baggs are employing demi-rhetoricity, only accepting the rhetorical arguments that reinforce their preconceived notions about autistic identity and finding ways to dismiss the rhetoric and rhetoricians that challenge it.

Many of these articles that present ‘critiques’ of and ‘problems’ with the neurodiversity movement claim to take a both sides approach, considering the perspective of parent-run autism organizations that see autism as a terrible disease which must be cured along with the neurodiversity approach which views autism as a natural part of human diversity that should be embraced and accepted. These authors seek to find a common ground between dehumanizing, eugenicist rhetoric and autistic self-advocates arguing against this rhetoric for their right to exist. Ortega writes:

> While it is understandable that some self-advocates feel offended by the pro-cure rhetoric of some parent and professional organizations, the latter are also justified in criticizing the aggressive identity politics advanced by the radical activists of the autistic movement, who appropriate the right to speak in the name of every person diagnosed with autism" (Ortega 2009, 427)

This last line is deeply ironic, given that the predominant pro-cure organization is literally named “Autism Speaks” and is run by non-autistic people who are constantly appropriating the right to speak in the name of autistic people. So, autistic people are “appropriating” the right to speak in the name of a group they are a part of, but non-autistic people who dismiss their voices and claim to speak for them are not? We should also note that it is autistic self-advocates who are described as “radical” and “aggressive” here and not the pro-cure organizations like Autism Speaks which regularly compare autism to kidnapping, cancer, and death.

Ortega’s dismissal of autistic self-advocacy as “aggressive identity politics” is also telling and it is echoed by Runswick-Cole in her discussion of the limitations of the neurodiversity movement and other social movements (2014). Much of the literature that discusses identity politics in this way presumes it to be a negative, not stopping to define what exactly they are criticizing when they are dismissive of “identity politics”. Identity politics are characterized as reductive and essentialist, but Ortega and Runswick-Cole seem to use this term to refer to a wide variety of phenomena that are not necessarily related. After referencing Jane Meyerding’s discussion of her thoughts on how to categorize herself, eventually deciding to identify herself as “autistic, period”, Ortega writes, “Identity politics here implies essentializing neurological uniqueness and typologizing brain difference" (2009, 440). How Ortega came to this conclusion is perplexing, particularly as Meyerding does not appear to make any reference to identity politics and Ortega has not previously been discussing identity politics. Are we to take it that for Ortega considerations of how to identify are identity politics? For her part Runswick-Cole does not define what she means by identity politics, instead asserting it as a limiting approach that should be replaced with "a politics of identity that steps away from essentialist claims" (2014, 22).

So, what are identity politics exactly? To begin I think it's important to go back to where the term was first used, and which introduced it into the popular consciousness: The Combahee River Collective Statement of 1977. The Combahee River Collective was a radical Black feminist group formed by and for Black lesbian women. The reason for its formation and its political approach were rooted in what they came to call identity politics, as they explain:

> We realize that the only people who care enough about us to work consistently for our liberation are us. Our politics evolve from a healthy love for ourselves, our sisters and our community which allow us to continue our struggle and work. This focusing upon our own oppression is embodied in the concept of identity politics. We believe that the most profound and potentially most radical politics come directly out of our own identity, as opposed to working to end somebody else's oppression (Combahee River Collective 2017, 19)

The statement is clear that these identity politics are not meant to be essentialist or reductive, but instead enable their political work to fight oppression on multiple fronts, recognizing that "the major systems of oppression are interlocking" (2017, 15), an ideological predecessor to the concept of intersectionality which is so popular today. Many of the same people who praise intersectionality and intersectional politics though decry and dismiss identity politics, despite the fact that these approaches were meant to work hand in hand. For the Black women who wrote the Combahee River Collective Statement, it is starting from their own identities and their own experiences that allows them to see just how interlocking systems of oppression are and work together to fight them.

In *How We Get Free: Black Feminism and the Combahee River Collective,* Keeanga-Yamahtta Taylor revisits the Combahee River Collective Statement for its 40th anniversary, reprinting the statement along with interviews from its three authors: Barbara Smith, Beverly Smith, and Demita Frazier (2017). In the introduction Taylor explains that identity politics as it was formulated in by the Combahee River Collective was not reductive or exclusionary, but rather "a way that those suffering…oppression could become politically active to confront it. This meant taking up political campaigns not just to ensure the liberation of other people but also to guarantee your freedom" (2017, 9). This approach was rooted in coalition building among groups, while also understanding that the oppression of Black people and the oppression of women could not and should not be neatly separated because these oppressions were deeply intertwined in the lived experiences of Black women. As Barbara Smith explains in *How We Get Free*, coalition building is so important because "that's the only way we can win. The only way that we can win---and before winning, the only way we can survive is by working with each other, and not seeing each other as enemies" (2017, 64).

While I understand and appreciate that the creators of a term don't have a monopoly on how it is used, and that the meanings of terms change over time as our contexts changed, I think it is important to note that in popular critiques of identity politics today, identity politics is often used as no more than a strawman that is vaguely defined and constantly attacked. Identity politics was never meant to be reductionist or exclusionary, and I argue that the neurodiversity movement as it exists today mirrors the original intentions of identity politics much more closely than it does this strawman. In fact, I think Ortega and Runswick-Cole are correct that the neurodiversity movement does exemplify radical identity politics (even if they mean the term in a different sense than I do) but I argue that this is one of its strengths rather than a weakness. The neurodiversity movement encompasses many things but perhaps the most visible are a focus on community acceptance of neurological diversity and self-advocacy that emerges from this view, based on the assertion that neurodivergent people are uniquely capable of understanding and expressing their own experiences and needs. This radical politics that comes from one's own identity and involves fighting as a community to end one's own oppression can feel exclusionary to some, particularly those neurotypical people who have built an identity around speaking for neurodivergent people. When the Autistic Self-Advocacy Network (ASAN) and other groups run by and for autistic people proclaim the disability rights slogan of "Nothing About Us Without Us" it can feel like a threat to parent-run groups like Autism Speaks that profit off of speaking for (or rather over) autistic people. Yes, the radical identity politics of the neurodiversity movement and neurodivergent self-advocates is a threat to these groups—that's the point. In large part these movements have been articulated as a response to the dehumanizing propaganda of parent-run groups like Autism Speaks.

I would also like to return to the idea that the neurodiversity movement is reductive. Ortega writes that, "neurodiversity advocates tend to homogenize neurodiverse brains and minimize their differences so as to support their claims for the existence of a brain-based autistic identity" (2009, 441). This argument stands out to me because it has been the exact opposite of my experience in neurodivergent communities. In fact, these communities tend to be far more aware of our vast differences and more understanding of our differing access needs than most other communities I have experienced. I am constantly having or witnessing conversations about the ways that our diversity of neurological experiences can create barriers and conflicts within our communities. Though most autistic self-advocates reject functioning labels as they are used to silence and dismiss us, no matter where on this spectrum of functioning we are placed, there is still a deep understanding that autistic people experience the world differently from each other, and that the accommodations that we need vary greatly. In "Being Autistic Together", Jim Sinclair, co-founder of Autism Network International (ANI), which created one of the first online communities by and for autistic people, and Autreat, a retreat-style conference by and for autistic people, points out these differences between and among autistics and how they can come into conflict with each other. Sinclair explains, "In just about any area one can think of where humans vary, the range of variability among autistic people seems to be even *greater* than the range among NT people" (2010). In particular, Sinclair notes sensory sensitivity and social interaction as two of the best examples of this; where some autistic people are easily overwhelmed by sensory stimuli, others are sensory seeking, and these orientations can even conflict within the same person and differ across different senses. Similarly, autistic people have different preferences and needs for social interaction and these can conflict as well. But rather than erasing differences like these and homogenizing neurodiverse brains as Ortega claims, neurodivergent activists are constantly in conversation about them and working to find ways to meet all of our needs, while celebrating the beauty of neurological diversity.

## Participant Observation in Online Communities:

One of the core tenets of anthropological research and ethnographic fieldwork is a focus on participant observation. This approach has traditionally placed a great emphasis on face-to-face interaction with the community being studied by an anthropologist. Rather than simply observing a community, the anthropologist involved in participant observation becomes part of the community, participating with them in their daily life and interacting with others in the community, trying to understand them from an insider's perspective. For many anthropologists, participant observation implies physical presence, being in the same geographic place as the community which is being studied. But not all communities are based in physical locations, and increasingly even physically placed communities involve connection through a variety of means that are not based in physical space, such as the internet. While some researchers may see the internet primarily as a secondary site of connection between members of "real" communities and cultures (that is, physically placed ones), the internet is also a place itself and home to many other places and the communities and cultures based in them.

In describing his fieldwork in Second Life, a virtual community which allows users to create an online persona and a virtual life and is focused heavily on interactions between community members within Second Life, Tom Boellstorff explains that online communities must be treated as places and cultures in their own right, which can be studied using participant observation. He argues that when people enact virtual lives and identities, they are made real, and “to demand that ethnographic research always incorporate meeting residents in the actual world for ‘context’ presumes that virtual worlds are not themselves contexts” (Boellstorff 2008, 61). Boellstorff argues that digital anthropology should be built on participant observation, “for investigating the virtual and its relationship to the actual” (2012, 40). He asserts that the core method of any ethnographic research project should be participant observation and interviews and surveys should be enmeshed within this framework (54). Like any anthropological work, digital anthropology should be based in an understanding of and familiarity with the context in which the interactions it analyzes are occurring.

Virtual worlds have their own cultures that are constantly being created, negotiated, and reshaped by the people within them, and their connections to other communities, especially other online communities, exerts a large influence on this change. They do not just borrow from existing cultures in the physical world, but they are created by their community members as needed to address the particular context of a certain group of people interacting in a certain way in virtual community with each other. They can be used to explore and experiment with ideas of gender and sexuality, as in Second Life (Boellstorff 2008, 61), as a place of business in order to earn money and meet needs in the physical world, and as a way for marginalized groups like disabled activists to organize and find community (Miller and Horst 2012, 11).

Digital anthropology built on a foundation of participant observation is an approach which allows us to research the virtual while looking at the virtual on its own terms (Boellstorff 2012, 40). Rather than trying to fit outdated modes of research that aren’t appropriate for the context onto the anthropology of virtual communities, we can choose to use only those which work and modify them to meet our needs, just as virtual communities are modified to meet the needs of their users. In these new digital settings, concepts such as cultural relativism, obtaining consent, and participant observation are still widely applicable, but notions of travelling to a distant land in order to be in close physical proximity to the communities you are studying have become outdated. It does not make sense as anthropologists to attempt to engage in a community in a way that people within that community do not typically engage. Instead, the anthropologist should strive to understand and take part in the social norms of the communities they are studying in order to better understand them and be able to conduct research from within these communities. For online communities, this means that participant observation is interacting with others online in virtual communities, on their own terms.

Just as we must adapt our methods to keep up with shifting ideas of community and methods of communication, there is increasing pressure to adapt our anthropological frames themselves, which traditionally focus on analyzing the “other” from a Euro-American point of view. Despite an awareness of the harms of ethnocentrism and a call for cultural relativism, there are many things that an outsider’s perspective might miss or misinterpret. Lila Abu-Lughod explains that though anthropology as a field questions the idea of objectivity and has begun to question the anthropologist’s position as a “self” in contrast to the “other”, there is a fear that the anthropologist studying their own society will become too subjective. This shows that anthropology has still not moved past the idea that the anthropologist must stand apart from the “other” (Abu-Lughod 2008, 53). Despite this fear of subjectivity, I believe that in many cases the person most suited to study a culture is someone who is a part of that culture and community themselves, and I would question the assumption that an outside observer could somehow be more “objective” rather than just bringing their own biases with them. I think that there is great potential in the field of anthropology for an increase in this type of autoethnography of oneself and one’s community, and that conviction is in part the basis for this project.

The online communities that I examine in this paper are largely not ones that I come to as an outsider to research. Though I don’t have intimate personal experience in all of the particular communities I will discuss here, I come to this research as a member of online neurodivergent communities, having found community and support, and in many ways myself, in these places. My research grows out of my own personal experiences and from the connections and conversations I have had with the people I have been in community with. This work is not the result of isolated observations or new ideas which spring fully formed from my mind alone but is a continuation on what I have learned about myself and about others through these communities which have meant so much to me. Though I did not originally frame it as participant observation, I have been observing and then participating in online neurodivergent community, particularly on Twitter and the Fediverse, for the past 4-5 years. It was initiated by myself individually, but I see this project primarily as a creation by, for, and with the community at every step of the process.

These personal experiences as a member of online neurodivergent communities led me to this research project. Along with my peers, I am frustrated by the lack of academic research on experiences in neurodivergent communities conducted by members of those communities, and I hope to begin to remedy this situation. Because I have not been able to identify previous research on this topic, this project takes a broad approach, attempting to establish a foundation for future research. To this end, I investigate the research questions of “What function do online communities serve for neurodivergent people?” and “How does participation in online communities affect neurodivergent people?” through the use of an online survey of neurodivergent people.

## Methods

The arguments I present in this thesis are the result of this participant observation and data collected through the distribution of an online survey on Twitter and the Fediverse. This survey, hosted on Qualtrics, solicited responses from people with neurodevelopmental disabilities or mental health conditions or who otherwise consider themselves neurodivergent who participate in or have participated in online communities of neurodivergent and disabled people about their experiences in these online communities. The full survey instrument will be provided in the appendix of this thesis, but it consisted primarily of open-ended questions about neurodivergent identity, experiences in online and offline neurodivergent and disability-centered communities, and how these experiences affected respondents. There were also two questions which asked about importance of these online communities and satisfaction with them which utilized a multiple-choice format; however, due to the use of two different scales for these questions, it is hard to adequately compare the responses. Because of this, the responses to those questions will not be analyzed in this thesis, but using a more consistent scale, they may provide useful data in future projects. Questions were based on my past experiences in online neurodivergent communities and adjusted and arranged with feedback from committee members. Open-ended questions to elicit qualitative responses were chosen because I wanted to give respondents the ability to express themselves however they wish, with as few limitations imposed by me as the researcher as possible. I was also aware as a neurodivergent person who has taken online surveys before of the frustration that can come from a survey which won’t allow for the input of accurate and precise answers, so I wanted to avoid creating that experience for respondents.

After the creation of the survey instrument and recruitment materials, research approval was sought from the IRB at Mississippi State University. Here the project met with its first challenges as the IRB questioned whether the participants sought by this study, for example people with intellectual and developmental disabilities, could consent to their own participation. In spite of the fact that the survey would only be directed at people over the age of 18, the IRB suggested that we may need to seek consent from parents or legally authorized guardians of respondents, a proposition which I was unwilling to accept as it denies neurodivergent and intellectually and developmentally disabled people the right to speak for ourselves and could potentially put respondents at risk of a loss of privacy or worse. I know of many neurodivergent people who are stuck living with abusive families for whom online neurodivergent community is one of their only sources of community support and socialization with people who accept them for who they are. Requiring us to get consent from their parents or guardians prior to participation in this study would either exclude those participants or put them at risk of being completely cut off from access to supportive community, making them even more vulnerable.

In response I cited the Academic Autism Spectrum Partnership in Research and Education (AASPIRE)'s inclusion guidelines, arguing that researchers should not assume that neurodivergent people have impaired decisional capacity when it comes to their ability to consent to participate in research, and in fact that it is highly offensive and discriminatory to do so. The report explains:

> our ethics committees have allowed us to forego assessment of decisional capacity in low-risk, online studies. Justification for this approach lies in the assumption that if an individual can access the internet independently, they are regularly making decisions that carry a level of risk at least as high as that of taking part in our survey (Nicolaidis et al. 2019, 11).

Though the project was initially conceptualized as occurring in two phases, one of which would include a survey and one which would consist of more in-depth interviews to explore the data received from survey responses, this second phase was dropped in order to reduce the risks associated with participation in this project and in recognition of time limitations. No direct identifiers were collected from participants such as names or IP addresses, and participants were unable to continue with the survey until they indicated that they had read an informed consent form and consented to participate in the survey. The informed consent form, recruitment materials, and survey questions were approved by the IRB through an expedited review, and we received approval to move forward with the survey.

The survey was open, and responses recorded between December 7, 2020, and February 6, 2021, with most responses collected in December. There were 121 responses received, with 3 respondents who were not permitted to continue because they indicated that they were under 18 and 2 respondents who indicated that they did not consent to participate. Additionally, I discarded and did not analyze responses which failed to get past the demographics section of the survey, leaving me with 78 responses to analyze, 62 of which were more or less complete. Though the survey was distributed on both Twitter and the Fediverse, the majority of respondents appear to have found it on the Fediverse, as the Twitter posts about the survey did not receive much interaction. This is likely due to the way that the algorithm and structure of Twitter make it hard for posts by newer or smaller accounts to be seen and gain traction, as well as my greater experience posting on the Fediverse and my already having some connections to the neurodivergent community on the platform.

The Fediverse is a decentralized network made up of individual servers that federate with each other and it hosts alternatives to many corporate social networks. One of the most popular is Mastodon, a microblogging software which is similar to Twitter and which allows users to create instances with their own moderation policies and privacy options or to join one of these instances and communicate with people on other Mastodon instances. My survey was shared via the Mastodon instance scholar.social and most of those who shared it and responded to it were likely using Mastodon as well, though it could also be shared with the wider Fediverse. The microblogging part of the Fediverse is also often just called Mastodon by users, even if all of the people they are referring to may not technically be using the Mastodon software. The Fediverse tends to attract people with an interest in tech and privacy, or who have been harassed or had other negative experiences on other social networks. As a result, there is a large population of neurodivergent people, but the Fediverse is hardly representative of all other online communities. However, many participants on the Fediverse do have experience in other communities, and there are regular mass migrations from places like Twitter, Tumblr, or

Instagram, so experiences on those platforms are represented in this data to some extent. In fact, shortly after the survey was made live, there was a mass migration from Instagram to the Fediverse and the survey circulated among some of these new arrivals, so there are quite a few people with various experiences in Instagram communities represented in this data. While I don’t claim that this data is representative of all online neurodivergent communities, it can provide some insight into experiences on many different platforms.

I chose to focus this research specifically on Twitter and Mastodon because those are the online neurodivergent communities I have the most experience with and that I understand the best. Different spaces have different norms and understandings of the appropriate ways to interact with people and share information, so I wanted to stick with spaces that I have some background knowledge in. As I was working on this project, I also relied on the support of my community of neurodivergent people on Mastodon who encouraged me in my research, shared helpful insight, helped me locate important sources, and aided me in articulating my findings and my thoughts in conversation throughout the research process. My research is informed by my position as a participant within the online neurodivergent communities which I am discussing, and I believe that this has helped me to provide more depth to the data I have collected and analyzed, as well as enabling me to collect the data in the way I have in the first place.

Responses to the survey provided a wealth of data that addresses the research questions for this project: “What function do online communities serve for neurodivergent people?” and “How does participation in online communities affect neurodivergent people?” In fact, so much useful and interesting data was collected that I was not able to address all of it in this thesis, and there remains much that can be analyzed in future publications. I conducted a qualitative analysis of responses using NVivo through a grounded theory approach, engaging in literature review after developing an independent analysis based on coding the themes that emerged from the data. As with Kathy Charmaz’s approach to grounded theory, “I assume that neither data nor theories are discovered. Rather, we are part of the world we study and the data we collect. We construct our grounded theories through our past and present involvements and interactions with people, perspectives, and research practices" (2006, 10). I approached this research viewing respondents as "active agents in their lives and in their worlds" and assuming that "people can and do think about their actions" meaning that respondents can provide insightful accounts and interpretations of their own experiences in online neurodivergent communities (Charmaz 2006, 7). I construct my theories along with respondents and other members of my communities. My observations and theories do not originate with me alone, nor do they simply exist out in the world waiting to be discovered, but they are constructed through conversations, interactions, and relationships with other community members.

In recognition of the work of interpretation done by respondents through the discussion of their experiences, this paper is filled with many direct quotes from survey respondents with as much of the original context preserved as is practical. Many of these respondents have already begun the work of interpretation themselves and offer invaluable insights into their own motivations, experiences, and feelings as well as those of other community members. In some cases, I felt that the quotes could speak for themselves and give greater context to each other, so I have not provided much further explanation or interpretation, while in others I attempt to give more context or draw the reader's attention to particular points or wordings. I have not edited these direct quotes aside from a few small spelling adjustments where spelling differences do not appear to affect the meaning expressed and may distract from the point being made. Survey respondents are in many ways my cowriters on this project, and I am immensely thankful to them for their contributions and inspired and motivated by their words.

## Demographics:

I collected demographic data from respondents regarding age, gender, race, and place of residence in order to understand what groups are being represented in this sample and who it may exclude. The following demographic analysis is based only on those 78 responses which answered more than just the demographic questions, and which were the subject of further analysis. The majority of respondents were between the ages of 18 and 44, with the most respondents falling in the 25-34 age range. Respondents were given a range of options and asked to select all of the boxes for words that describe their gender, as well as the ability to provide other labels or descriptions in a textbox. A large majority of respondents indicated that they were transgender or nonbinary, with 37 respondents selecting the box for nonbinary, and 32 selecting the box for transgender. Some of the other most common identifiers were woman with 20 respondents, genderqueer with 19, gender non-conforming with 16, man with 13, genderfluid with 10, and agender with 9 respondents. There is overlap between these categories as many respondents selected multiple boxes.

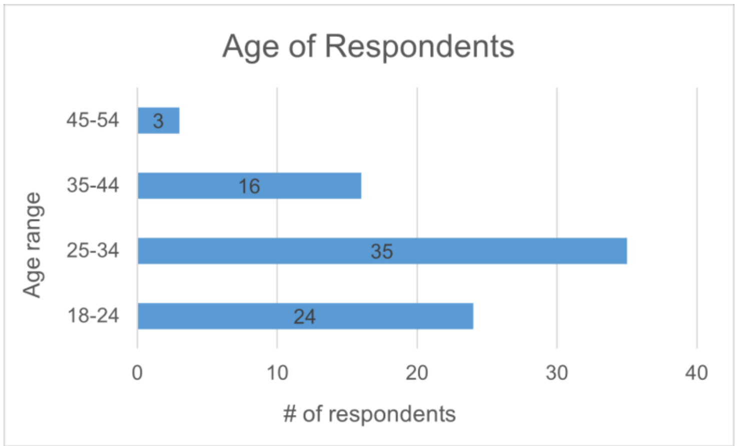
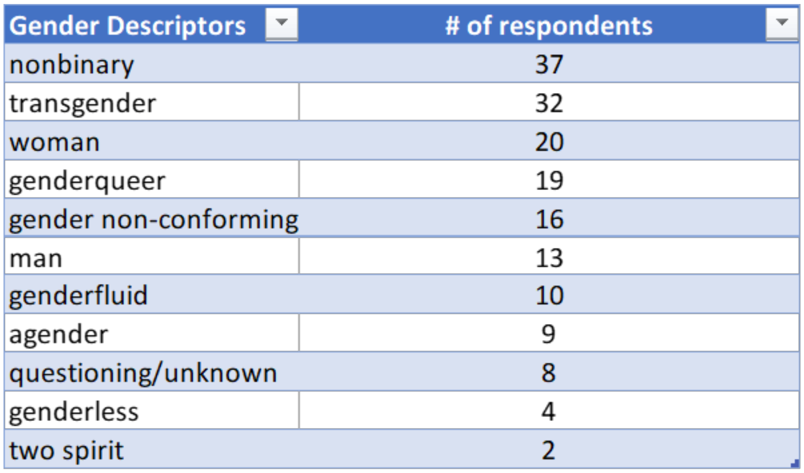


*Figure 1: bar graph of respondents' ages*



| Gender Descriptors | # of respondents |
|---|---|
| nonbinary | 37 |
| transgender | 32 |
| woman | 20 |
| genderqueer | 19 |
| gender non-conforming | 16 |
| man | 13 |
| genderfluid | 10 |
| agender | 9 |
| questioning/unknown | 8 |
| genderless | 4 |
| two spirit | 2 |

*Figure 2: table of respondents' gender descriptors*

The questions for race and country of residence were open-ended, allowing respondents to write in whatever answer worked best for them. I chose to format these demographic questions in this way to avoid forcing respondents to place themselves into racial categories that may not reflect their own understanding of their race, while also recognizing that respondents may come from many different parts of the world that have their own identifiers and categories. The vast majority (87.2%) of respondents described themselves as white or some specific European ethnicity. Additionally, most respondents lived in the United States (64%), with a few respondents in the UK (8%), Canada (4%), Germany (4%), France (4%), and the Netherlands (4%). As a result, this data is not very diverse when it comes to race and country of residence, though it may tell us something about who is present in these particular online communities on the Fediverse and Twitter.

Respondents were asked what words they use to describe themselves, particularly in reference to their neurological differences or disabilities. About three quarters of respondents (75.6%) self-identified as either autistic or on the autism spectrum. The most common terminology used by these respondents was to identify simply as autistic. Nearly half of respondents (48.7%) self-identified as ADHD or having ADHD. Depression and Anxiety each apply to 20.5% percent of respondents. Those who described themselves as plural or part of a plural system[1] made up 16.7% of responses. Other common labels and descriptors include (c)PTSD or traumatized (10.3%), mentally ill (6.4%), Bipolar (6.4%), neuroqueer (5.1%) and dyslexic (5.1%). Most respondents used multiple labels to describe themselves and fall into more than one of these categories, along with other descriptors not listed here.

| Identifier | # of respondents |
|---|---|
| Autistic (or on the Autism spectrum) | 59 |
| ADHD | 38 |
| Depression | 16 |
| Anxiety | 16 |
| Plural | 13 |
| PTSD/traumatized | 8 |
| Mentally ill | 5 |
| Bipolar | 5 |
| Neuroqueer | 4 |
| Dyslexic | 4 |

*Figure 3: table of respondents' identifier labels*

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[1] Plural is an umbrella term generally used to describe "the existence of multiple self-aware entities inside one physical brain" according to https://morethanone.info/. Conditions such as DID and OSDD are generally considered plural, but they do not encompass all incidences or experiences of plurality.

As mentioned previously, most respondents found the survey on Mastodon/the Fediverse, so it makes sense that the most respondents would have experience there. Of the 78 respondents, 43 (55.1%) specifically mentioned participation in online neurodivergent community on the Fediverse/Mastodon (a variety of terminology was used). Respondents also mentioned experiences on Twitter (14.1%), Discord (14.1%), Instagram (11.5%), Tumblr (9%), Facebook (6.4%), and Reddit (3.8%) among others. Many respondents mentioned participation in multiple online communities, both in the past and in the present. Some respondents spoke more generally about their experiences in online communities and did not specify what specific platforms they used to connect with their communities. As others pointed out, these communities are much more centralized on large social media sites than they were in the past, when much online neurodivergent community was centered around individual blogs and forums.

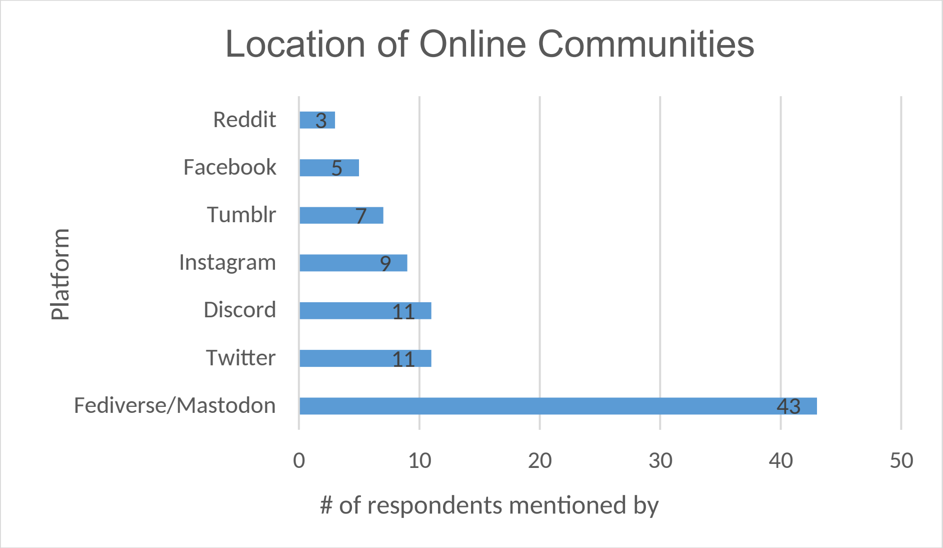

*Figure 4: bar graph of respondents' reported participation on specific online platforms*

# Data Presentation, Analysis and Discussion

## Terminology:

When asked about the term neurodivergent and what it means to them, the majority of respondents responded with something along the lines of "someone whose brain differs from what is considered the norm by society". This sentiment was expressed in many different ways and using a variety of wordings, but it is essentially at the heart of what it means to be neurodivergent for the majority of respondents. Because the specific wording used is particularly illuminating, I will share some direct quotes from these responses here. Here are just a few of the ways that respondents described what it means to be neurodivergent:

> "Being 'Neurodivergent' means that something about how your brain works is different from what is considered standard by modern society"
>
> "People who don't fit societal constraints of how their brain works."
>
> "It's nice (for me at least) to have one word that covers 'people whose brains work un-normally'"
>
> "people whose brains function differently from what is accepted as the neurologically normative status quo"

As you can see, though they use different wording, many respondents think of being neurodivergent as having a brain that works differently from the norm, or as one respondent expressively put it: "neurodivergent feels specifically about us brainfucky weirdos who are outside the abled norm". Several others also mentioned a relationship between neurodivergence and weirdness or taking pride in not being normal:

> "It's clear that most people's minds, and the minds they make textbooks and general behavioural strategies about, work differently to the way mine does, and [neurodivergent] is more specific than 'weird'."
>
> "I consider myself neurodivergent. I am different from what people consider normal, and I'm proud of it."

One respondent wrote "Before I considered myself autistic I used to describe me as 'weird'" which is a very familiar experience to me as someone who did the same thing. For many neurodivergent people, weird and other similar words were the first identifiers we found, only later coming to understand ourselves as neurodivergent or autistic or something else. In fact, some respondents identified themselves as "brainweird" either in conjunction with labels like neurodivergent, or to the exclusion of other labels.

For others, neurodivergence is defined not only by differences of brain function but also by differences of experience, processing, and expression:

"I feel very neurodivergent because I have always felt different up in the brain. Different

> viewpoint in life, different methods of processing information, and different ways of expressing emotion."

> "I think of myself as neurodivergent. I recognize that I don't behave and process things like the majority of people."

> "the way I experience life is notably different from the majority of people around me"

Being neurodivergent is an experience and a recognition that that experience differs from the norm. One respondent specifically defined neurodivergent as having to do with an awareness of this difference: "Neurodivergent: not having a neurotypical brain & suspecting or knowing you do not and might have a specific condition." Before one can come to identify as neurodivergent, they must first recognize that their experiences do diverge from something. For many of us this begins with self-description as weird or abnormal; for others it can begin with a specific diagnosis for a condition that they come to view as being neurodivergent. But of course, these are not mutually exclusive experiences and there are many paths to recognizing oneself as neurodivergent.

Several respondents described the articulation of oneself and others as neurodivergent or embracing neurodiversity as a liberatory experience of fighting back against the boxes we are forced into by society. When asked what words like neurodiversity and neurodivergent bring to mind, one wrote:

> "What comes to mind is the strict confines a person has to fit into to be considered a regular person, or even be granted basic humanity, and how one of the many ways somebody can fall out of that box is with how one processes thoughts and sensory input and the mannerisms, behaviors, and capabilities affected by that difference. Diverging on an axis of neurology, neurodivergent."

Another similarly finds comfort in these words for the freedom they give compared to the traditional diagnostic models,

> "recognising that individuals will often have a better and clearer picture of the functionings of their mind and body than many so-called professionals. It provides room for those disenfranchised from traditional models but who have a sense of their deviation from expected ways of working with and interpreting the world."

For many, claiming a neurodivergent identity is a radical act of claiming space, of claiming expertise on their own experiences, and rejecting the rigid boxes that are prescribed to us by society. Recognizing oneself as neurodivergent creates new possibilities, giving hope for a life that mainstream society may see as atypical or inappropriate but in which we can find freedom and happiness regardless.

There is of course some debate about just how expansive and inclusive our ideas of neurodiversity should be. In fact, as one respondent pointed out to me, before neurodivergent there was neurodiverse as an identifier, which some autistic people believed should be restricted from use by non-autistic people. Others disagreed, arguing that neurodiversity and neurodiverse identity could be an inclusive tool for connection, rather than used to divide people by specific diagnoses. It was for this reason that Neurodivergent K of Radical Neurodivergence Speaking coined neurodivergent as an explicitly inclusive term. However, despite the coiner's clear intentions that "Neurodivergent refers to neurologically divergent from typical. That's ALL… It is not another damn tool of exclusion. It is specifically a tool of inclusion. If you don't want to be associated with Those People, then YOU are the one who needs another word. Neurodivergent is for all of us." (sherlocksflataffect, 2015), there are still people who argue that neurodivergent as a term should be restricted to those with certain conditions. While a few respondents expressed a dislike for the inclusiveness of this label: "given that [neurodivergent] has expanded to become extremely inclusive (i do like inclusion!), it's gotten to the point that i find it is becoming so broad as to be impractical for communication", others wished for less gatekeeping on the use of terms like these and expressed their appreciation for neurodivergent as a broad umbrella term. Some even saw neurodivergent as too narrowing of a term, as "It implies there is a "standard" brain wiring when in fact there are multiple configurations, all valid".

In spite of many peoples' intentions to use neurodivergent as an umbrella term to encompass everyone with any sort of brain that diverges from the typical, the word is specifically associated with only a few conditions in many peoples' minds. As I've mentioned previously, the majority of respondents to this survey self-identified as having ADHD or being autistic, and these are the two conditions that seem to be most commonly associated with the term neurodivergent. That this is reflected in my demographic data is undoubtedly not a coincidence as one respondent noted, “It seems like the term neurodivergent traditionally only applies to people with something like autism. I feel like a bit of an imposter taking this survey.” Indeed, though I made the recruitment materials for the survey as broad as possible, indicating that it was open to anyone who is neurologically divergent from the typical, including those with neurodevelopmental disabilities, mental illnesses, and anyone who considers themselves neurodivergent, some people still expressed confusion over whether they were allowed to participate. For example, I received a message expressing concern that I may want to change the broad wording in my recruitment materials because it appeared to be open to non-autistic people and they were under the impression that I was only interested in responses from autistic people. While this confusion may have been a result of unclear communication on my part, I think it is also representative of the confusion that is present around who exactly is included in this terminology within the community.

Part of this problem may be because of autistic communities using neurodivergent interchangeably with autistic and neurotypical interchangeably with non-autistic. Autistic and ADHD communities may imply that people who are neurodivergent broadly fall in these spheres, erasing others. This reinforces perceptions that neurodivergence is just about autistic and ADHD folks and may stop others from identifying with these terms. As one respondent pointed out, “neurotypical in autistic communities is often used interchangeably with allistic (meaning non-autistic) so in the autistic community we often forget that autism isn't the only neurodivergence.” As they explain, there are autistic specific terms that can be used instead of neurodivergent and neurotypical when the conversation is specifically about autistic experiences, but for example neurotypical is often used simply to describe someone who is not autistic, leading to confusion and erasure of other neurodivergent people. While as an autistic person I do recognize the importance of autistic community, it is also true that the autistic

> community already has much more visibility and presence than many other neurodivergences, and I think we should be careful not to talk over and erase other groups when we could be building coalitions together.

Many respondents expressed their dissatisfaction with this state of affairs, where being neurodivergent is often equated with being autistic or ADHD, erasing other types of neurodivergent people. And even those multiply neurodivergent people who are autistic or ADHD expressed frustration that their other neurodivergences are often overlooked or not talked about, as with Neurodivergent K's epilepsy. One respondent wrote of this erasure, “It's easy to think of it as just signifying the more high-profile and internet-palatable adhd and autism traits, though, and not as representing a huge set of minds that sometimes have access conflicts.” Many respondents explained that though in their mind neurodivergence is most immediately connected to things like autism and ADHD, they understand that this is not the full extent of neurodivergence, with one writing: “I think of autism spectrum disorder, ADHD, and most recently a post about how neurodiversity encompasses everything from cerebral palsy to epilepsy to depression. I feel I have more to learn.” Another respondent expressed appreciation for neurodivergent as a label and the concept of neurodiversity because they offer an opportunity for people with less socially acceptable and more stigmatized conditions to “get an even footing” and “participate in conversations about all the bizarre ways brains work”.

Though unfortunately this is often not a reality, it is clear that many people who use the neurodivergent label want it to be, as well as many others who may not currently use it for themselves because they feel that it is not for them but would if given the change. When asked what they wish was different in online neurodivergent communities, some respondents mentioned specific conditions and experiences as needing more recognition and support:

> “I wish that there was more support and visibility for people who have Cluster B personality disorders.”
>
> “More people with differing experiences of reality and psychosis spectrum people.”

Other conditions mentioned by respondents as falling under the neurodivergent umbrella include depression, schizophrenia, bipolar, personality disorders (such as borderline or schizoid), OCD, anxiety, dyspraxia, dyslexia, cerebral palsy, plurality, epilepsy, Tourette's, and trauma disorders like PTSD. Even this is not an all-inclusive list, and indeed attempting to compile an all-inclusive list may be self-defeating for the aim of utilizing neurodivergent as an umbrella label. Not everyone who falls into one of these categories will consider themselves neurodivergent, and people may understand themselves as neurodivergent in a multitude of ways. For some, being neurodivergent isn't related to any condition in particular but is simply a recognition that something about the way they experience and process the world diverges from a neurotypical norm.

For my part, I argue that there is a massive amount of potential in using neurodivergent as a broad umbrella label for coalition building between groups that are neurologically divergent. As Barbara Smith said, building coalitions, working together, that's the only way we can win, and before winning, that's the only way we can survive (Taylor 2017, 64). Where "diagnostic categories are imprecise and vary as a function of social, cultural, and historical contexts", terminology like neurodivergent provides a unifying language for coalition building that does not rely on diagnostic criteria or validation by outside 'professionals' who wield institutional power over us (Gillespie-Lynch et al. 2020, 15-16). As Gillespie-Lynch et al. argue in "Can We Broaden the Neurodiversity Movement Without Weakening It?: Participatory Approaches as a Framework for Cross-Disability Alliance Building", "Neurodiversity provides a conceptual framework that people with diverse conditions can use to identify shared forms of oppression and work together to change them" (2020, 40). There is a radical potential in neurodivergent community for us to work together on the issues that affect us while also recognizing and even embracing our differences as the beauty of neurological diversity. Yes, there are differences among and between us, but as we are all working together for liberation those differences can even give us strength. There is no contradiction in embracing diversity while fighting for equality and liberation, but there is power in supporting each other and working together for our survival.

## Loneliness:

Many respondents wrote that loneliness or a sense of alienation is what brought them to online communities. I remember feeling deeply alone as a kid. Even when I was surrounded by people, even when I had friends in name, I often felt deeply isolated. There was this aloneness that I could not shake and that cast a dark shadow over my life. Like these respondents, participation in online neurodivergent communities has helped me to feel less alone in a way that I've barely felt before. In the past I have started to finally feel a sense of connection in other communities, only to have it yanked away from me when I realized that these communities would never accept me for who I am. But in online neurodivergent spaces I can be myself and be accepted and be not alone. I don't have to hide parts of myself. I can find other people like me and be seen and understood. I can make meaningful connections with others without feeling like I am somehow still always an outsider looking in. It seems that a common neurodivergent experience is to feel utterly alone and isolated in a crowd of people. We must often walk a fine line of having enough time to ourselves to not be overwhelmed, while also still having some social contact so as not to be lonely.

Online communities full of other neurodivergent people are one way to meet this need. For many neurodivergent people realizing that there are others like us, with similar experiences, helps us to feel less alone. Though the world at large may be no less hostile, we no longer have to face it on our own. Many respondents explained that engaging with these communities helps them to feel less isolated and more confident, and others indicated that they intentionally provide emotional support to other people in these communities to let them know that they are not alone. This is a powerful experience as one respondent explained: "Seeing other neurodivergent and disabled people speak about their experiences and organization efforts reminds me that I am not alone and that advocacy is an option."

Still, online neurodivergent communities are not a cure-all for loneliness. Though they may offer community and support, some neurodivergent people still find themselves unable to fully access this. Whether it’s a lack of energy or a lack of words to express themselves or difficulties initiating contact with others, there are still barriers that block some people from community and connection with other neurodivergent people, so loneliness persists. Many respondents mentioned a predilection towards lurking or observing rather than direct participation, primarily engaging with these communities by reading the posts of others and perhaps favoriting a post on Mastodon or upvoting a thread on Reddit. These lurkers may occasionally provide support or answer a question in the form of a comment, but don’t engage directly very much because they do not wish to draw attention to themselves or because they lack the energy or words or confidence to reach out. They may still gain second-hand validation however, by seeing someone else talk about their experiences and relating it to their own. And on occasion these lurkers may engage more directly as “lurking sometimes leads to commenting sometimes leads to posting”.

## Accessibility in Offline vs. Online Spaces:

Some lurkers suggested ways that online communities could be more accessible to them and to others, allowing them to engage in ways that work for them, such as having more options for participation that don’t necessitate direct communication. Many feel alienated by the requirement to form and present a particular online identity in order to participate, as this seems to require a stable sense of self that many neurodivergent people do not have or find difficult or draining to maintain. One respondent explained, “I wish I could participate without "speaking" or drawing attention to myself. I wish I could curate, filter, tag, transcribe and otherwise help make the overall experience without making it about me. (Wikipedia is a good example of this.)”. Another wishes that there was more outreach to make sure that everyone is included and actively invited to participate in the community, expressing a desire for:

> more specific encouragement and perhaps groups that sought out others and specifically talked to them, introduced them to others etc, sometimes it can feel like a clique and having such a group rather than having to put yourself out there without knowing it would be safe in terms of either being seen or being safe in being yourself can feel daunting.

Of course, in light of the previous comment it is clear that this approach would not work for everyone, which illustrates the point that a multitude of approaches are necessary, and that one approach will not work for everyone, especially when it comes to neurodivergent community.

This is why it is so important to provide multiple ways to interact and participate so that we can make our communities more accessible to more people. Rather than privileging certain types of interaction there needs to be space for people to interact in the ways that work for them. Providing space for nonverbal and indirect communication is especially important as this is something that is very limited on most social media. For example, one respondent explained that, “Being physically present in the same room but without actually doing anything in particular or talking is important to me, but that's not possible to replicate online, because online you have to *do* something to keep the contact, instead of just idling.”

As I’ve explained, many neurodivergent people feel deeply lonely, and there is a certain sense of isolation that can arise from primarily being around people who don’t understand you, who seem to approach the world in a completely different way from you. It can be exhausting to live in a world that is not built for us and that does not take our needs into account, to be constantly told that there is something wrong with us and that we are deficient or lacking. For many there is a two-fold isolation: physical isolation and spiritual/psychological isolation. Many people are physically isolated because of access barriers to their participation in offline communities as I will discuss later. But even when neurodivergent people are able to participate in offline communities there can still be a psychological isolation of feeling like you are always looking in from the outside, of sensing that there is some deeper connection you are missing out on or knowing that no one truly accepts and embraces you as you are. But finding likeminded (pun intended) people offline can be difficult. Neurodivergent people are spread out all around the world and are often forcibly separated from others like us by a society which tells us that we must try to fit in and hide our true selves, putting on a mask to please neurotypicals. Even when we find each other it is often in neurotypical spaces with neurotypical expectations. We are told to quiet down, to dampen our joy, to stop moving like that. I've had conversations with my likeminded peers interrupted by neurotypical parents who feel the need to apologize and constrain their children from communicating and interacting in the way that comes naturally to them, and I've been taught by my own parents that the way that I communicate is wrong and deficient, that I must bend myself up into the little box society has assigned to me.

Our community spaces that do exist in physical space often take the form of support groups or institutions run by neurotypicals, parents and so-called professionals, such as the book club described by Remi Yergeau in *Authoring Autism: On Rhetoric and Neurological Queerness.* Yergeau writes of this book club consisting of eleven autistic adults and run by four allistic (non-autistic) moderators:

> the purpose of this book club was therapeutic: we were not there to meet and discuss a book; we were there to practice the art of socializing, of mimicking allistic customs and behaviors such as voting, turn taking, small talking, eye gazing, and voice modulating (2017: 116).

They are spaces where we are perpetually children who need to be fixed and talked down to, not spaces where we can celebrate ourselves for who we are and take pride in our communities and cultures. One survey respondent described a similarly traumatizing experience with a so-called support group:

> When I first got diagnosed (in DSM-IV times) with Aspergers' I joined what I was told was a support group… I found out later it was a research group that did little to support us, just more traumatize us. Like showing us Autism Speaks videos comparing us to cancer, and then asking how it made us feel, as if it wouldn't make us feel like shit???

It seems that to much of society neurodivergent people are test subjects and objects of inquiry. If we are gathered together in a group, it must be to study us or fix us. And of course, it is largely neurotypicals who run these spaces, who decide how we are allowed to interact and when, who tell us what we need from community. Most respondents who have participated in offline neurodivergent or disability communities speak of rampant ableism that discouraged them from future participation:

> “Offline neurodivergent/disability [communities] aren't exactly available to me, and those that are; they are run by neurotypicals/abled people that infantilize people like me.”
>
> “A lot of ableism. Went to an autism therapy group when I was 15, and they didn't care for my issues and told me I was "overreacting". So, I tend to remember that horrible experience everytime I hear about an "Autism therapy group" or any disability group.”
>
> “very ableist language often used and very few if any options to communicate in a way that actually works for me.”

Bad experiences such as these at neurotypical-led mainstream conferences led Jim Sinclair and other members of Autism Network International (ANI) to establish Autreat in 1996, a conference by and for autistic people. Sinclair explains that “environments created and run by NT (neurotypical) people are not autistic spaces, even if the majority of people within them are autistic” because neurotypical people are still the ones in charge and making the rules (Sinclair 2010).

Many respondents explained that though they have searched for offline neurodivergent communities, they have largely avoided them because of an anticipation of similar issues to those described above:

> “I'm afraid I've always avoided offline ND communities as those I've ever come across have been autism moms with no personal experience themselves and usually a rather ableist take that views us all as children or minors and incapable of speaking for ourselves.”
>
> “In my searching for groups, services, and supports I have been unable to find any that aren’t based in misinformation, ableism, eugenics, infantilizing, autism speaks connections, ABA, etc.”
>
> “[An] upside to the online communities I've joined is that they were usually created by ND people, for ND people. In offline environments, I feel like there's still a lot of pressure to meet neurotypical expectations, and that's not as present online.”

These unfortunately are reflective of my own experiences. When I reached out to on-campus services simply because I wanted to be able to talk about my experiences as an autistic person, I was met with people who were dismissive of what I had to say, while clearly knowing much less about autism than I did, and worst of all I was directed to a clinic at the university whose main focus appears to be performing ABA on children. Here was my autistic community: neurotypical students torturing children like me in an attempt to make them indistinguishable from their peers (Because many, many autistic writers and activists have already explained in detail the harms of applied behavioral analysis, I will not be rehashing those arguments here as that is not the focus of this thesis[2]). Though the response I received offline was far from helpful, I had thankfully already begun to find online autistic community at this point, so I knew that I was not completely alone and had access to resources made by and for autistic people.

In fact, the majority of respondents indicated that they have not participated in offline neurodivergent communities because of issues like these, barriers to accessibility, or simply a lack of such communities in their area. A few mentioned the Covid-19 pandemic specifically as a reason for not engaging in offline communities, but many explained that they don't participate in offline communities regardless and did not participate in offline communities before the pandemic. For many respondents, online communities are simply more accessible in general for a variety of reasons. Anxiety in various forms was one of the most commonly mentioned reasons among respondents:

> "Social Anxiety makes me too terrified to participate in anything."
>
> "I haven't participated in any offline communities. Seeing people in person makes me too nervous."
>
> "These places are inaccessible to me because I would have so much anxiety in attempting to attend or participate that I do not do so."

In many cases this anxiety is directly related to negative and traumatic experiences around

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[2] M. Remi Yergeau gives a good overview of the history, use, and rhetoric of applied behavioral analysis in *Authoring Autism: on rhetoric and neurological queerness* (2018), especially in chapter 2: Intervention. For additional analyses on the harms of ABA, see Carol Millman's "Is ABA Really 'Dog Training for Children'? A Professional Dog Trainer Weighs In" (2019), https://neuroclastic.com/2019/03/27/is-aba-really-dog-training-for-children-a-professional-dog-trainer-weighs-in/; Amy Sequenzia's article "My Thoughts on ABA" (2015), https://awnnetwork.org/my-thoughts-on-aba/; and Finn Gardiner's report for the Autistic Self-Advocacy Network: "First-Hand Perspectives on Behavioral Interventions for Autistic People and People with other Developmental Disabilities" (2017), https://autisticadvocacy.org/policy/briefs/interventions/.

socializing due to neurodivergence, as well as fears that their needs will not be taken seriously:

> “I have agoraphobia that links to my neurodivergency through /terrible/ experiences socialising with others.”
>
> “Having a difficult time speaking up or knowing what to say in the moment sometimes and thinking due to trauma that all my ideas are silly and I will be ignored.”
>
> “I am very anxious and afraid of meeting new people and explaining the difficulties I face in verbal conversation, it's much easier to read and write online.”

Several respondents mentioned anxiety in combination with other access barriers such as physical exhaustion or sensory processing issues, for example:

> “Anxiety and exhaustion keep me at home almost all the time”
>
> “I have severe social anxiety and sensory processing issues. Bright or flashing lights, overly hot or cold environments, loud noises (overlapping conversations, clinking silverware/plates), and strong smells all cause me to have an anxiety response. If enough of these are present I typically refuse to participate or retreat from participation. After enough or bad enough negative experiences, I give up entirely on such activities.”

For some people, physical access barriers make participation in offline communities impossible or so exhausting and difficult that the tradeoff is not worth it. As one respondent explained, “I usually can’t even get from my car to the front door, let alone inside. Most spaces are not wheelchair accessible, and groups seem to love to use those for some reason.” For others, geographic and travel limitations make it hard to find any offline communities near enough to them or that they are able to get to.

> “I live in a rural place and we don't really have a lot of these kinds of spaces and communities around”
>
> “it's quite difficult to find others geographically close to me”
>
> “I rarely participate in offline disability- or neurodivergence-centered communities. Travel times make them high cost for me and also mean that others rarely make it to them, which significantly reduces the value for me.”

Indeed, not everyone has access to safe or effective transportation that works for them, and this can lead many neurodivergent and disabled people to feel trapped and isolated; issues which can be compounded by living in a remote or inaccessible place such as rural areas or suburbs, as one respondent lamented, “I WISH I had access to offline communities. It’s not safe for a narcoleptic to drive and I'm fucking stuck in suburban hell."

In addition to access barriers like these, some respondents explained that the type of communication that tends to happen in offline spaces is inaccessible to them, especially in comparison to the myriad types of engagement available online. Where offline communities tend to privilege the ability to speak verbally and respond rapidly, online communities allow participants to communicate over text and take a longer time to read and respond to messages, as survey respondents explained:

> "Being online, I can take the time I need to formulate sentences, find the words I mean, delete things I decide aren't good to say or rephrase them before I hit send, and overall articulate far better than I ever have vocally. Being able to say what I mean without the rush of conversation pacing is freeing. I feel comfortable when I can write what I want to say, and have the time to organize my thoughts into a coherent order and trim off the rambling tangents I can get lost in. Vocally, I am quiet, I am slow, I am clumsy and when I have to speak fast enough to keep up with a conversation, my thoughts tumble out haphazardly or else true thoughts stay locked away and I mask behind scripts that only hold up for a few minutes."
>
> "I am much better at written communication. I experience selective mutism. Groups of people often freak me out. I like to hang out with people in a way that gives me more space to self regulate. I can't do that as well in offline group settings"
>
> "i find that online community suits me best, dealing with people (even other autistics or other ND folks) offline is hard, takes a lot of energy so i dont feel as comfortable particularly about the things i say, i rather have the time to write them out and delete them if i get stuck or feel on second thought, i better not say this right now."

Because of barriers such as these and indeed many others, some respondents indicated that they do not participate in any offline communities, of any nature:

> "I do not participate in offline communities of any kind currently, and I have not done so for many years"
>
> "I don't often participate in offline communities in general."
>
> "I have been a social recluse for years so offline communities isn't really a thing for me."

For these respondents, online communities are often their only source for socialization and community of any kind. And though many of these people explain that they wish there were less access barriers so that they could participate in offline communities, others seem content with this arrangement. Not everyone wants to participate in offline communities when online communities meet their needs far better and enable them to live a life that works for them.

Even among those who do wish to participate in offline neurodivergent or disability-centered communities, these communities seem to be few and far between. It appears that in many places they simply do not exist or at least are not easily discovered. Despite their searching, respondents reported:

> “I have not found any neurodivergent or disability-centred communities near me, and struggle with social anxiety and sensory processing issues to a great extent, making it difficult to continue seeking them out.”
>
> “I haven't found offline neurodivergent and disability-centered communities, and I did look.”

So where are neurodivergent people to find community with others who understand them and who they can relate to in light of all of these barriers to offline communities and the apparent lack of accepting offline spaces? Many neurodivergent people turn to online communities which, though they have unique access barriers of their own, tend to be much more accessible and welcoming to neurodivergent people.

While offline the company of other neurodivergent people may be hard to find or to access, in contrast, as one respondent noted, “it is easy to find people like myself online”. Though maybe not entirely easy for everyone, in most cases it certainly seems easier than finding offline neurodivergent communities that meet one’s needs. Neurodivergent people can search for others who are like them and even learn new words and terminology to describe their experiences, enabling them to discover communities that they never knew existed. With these search terms and hashtags and online groups and forums, suddenly a whole new world of possibilities for connection are opened up. Throughout the responses are sprinkled phrases and sentiments like these: “it's hard to find people like me offline” and “I think online communities are great for people who feel they don't belong because online there's always someone who feels the same way.” One respondent explained that they participate in online communities like the Fediverse “Because I see myself represented in them far more resoundingly than I do in any real life or other online platforms”.

No longer are geographical barriers an issue, though language barriers might be. Online we are not restricted to so-called support groups run by neurotypical parents and ‘professionals’, but we can make our own communities. Even if the platforms we use may not have been made with us in mind we can make our own spaces within them, such as the #actuallyautistic hashtag and others on Twitter and Tumblr, subreddits focused on various neurodivergences, Facebook groups for autistic people, and Fediverse instances centered on neurodivergence whether implicitly or explicitly. Here we can find communities by and for neurodivergent people. Though, notably, it can still be a struggle to maintain spaces like this as seen from the example of the #actuallyautistic hashtag which was created specifically for autistic people to talk about their experiences because other hashtags related to autism were constantly overrun by “autism parents”, that is allistic parents of autistic children who constantly speak over autistic people with “you’re not like my child” and ardent support of ABA and other harmful “therapies”. A few respondents mourned the loss of communities gathered around blogs and forums that seem to have been much more common in the past when the internet was more open and not dominated by large social media sites, lamenting, “I wish that so many bloggers had not moved to twitter, and that more people offered a private decentralized way to contact them rather than a public comment field, twitter handle, or Facebook profile”.

## Friendship and Socialization:

For neurodivergent people who find offline friendships and socialization hard or undesirable, online relationships and interactions can fill a need for social contact.

One respondent described online communities as “my primary places for social contact with other people”, explaining, “If I didn't participate in them, I'd be quite lonely.” Another described their participation in online communities as a form of positive withdrawal, writing “I think because of asociality I feel uncomfortable with close friendships in real life”. In spite of this asociality however, they explained “I still need to be around people, just in a different way”. Online communities can fill this need, allowing neurodivergent people who feel uncomfortable with traditional conceptions of friendship or social relationships to still experience some form of social interaction and be around other people in a way that works for them.

Personally, direct social interaction whether in person or even through video calls or direct textual communication can be very draining for me, but I still enjoy being around other people to some extent, especially people who care about the same kinds of things that I do and who want to engage in similar types of communication. Online neurodivergent communities allow me to be around other people in a variety of ways that are not as exhausting, whether that is reading what other people have written, sharing information, observing other people’s interactions, or posting about the things that interest me with no expectation of any particular response. This then allows me to engage in directed communication more naturally when I feel up to it, by responding to a post about a topic I am interested in or carrying on a conversation with someone who replies to me. Rather than wading through the trouble of small talk and initiating a conversation I can skip right to conversations about things I want to talk about with people who want to discuss them with me and avoid those that don’t interest me or are draining to me. Eventually, through the course of several conversations and interactions or simply from reading each other’s posts, I can begin to form friendships with people who have similar interests or who I feel safe around and get along well with.

Many respondents mentioned friendship as a reason for participating in online communities, describing them as spaces for meeting and maintaining contact with friends. They spoke in affectionate terms of the friendships they have formed, describing the positive impacts of these friendships on their lives and the deep care they have for their friends, for example:

“when i hear neurodiversity it reminds me of community & friends”

“I have formed genuine and powerful friendships from my involvement”

“being around neurodivergent people and disabled people has made our politics more

> informed, our self-conception more real, and our friendships deeper.”

Online friendships are a key part of the support systems of many neurodivergent people, who both receive and provide support in various forms online:

> “I would consider the friends ive made online, especially on mastodon, to be key members of my support system.”
>
> “We partake in these communities because it is important to us to have queer neurodivergent and plural friends and communities that can support us when we have a hard time coping with our disabilities.”
>
> “i want to see my online friends thrive, i love them deeply”

While for some these friendships are a joyful reality that form a vital part of their support systems, for others the idea of friendship takes on a more longing, hopeful tone. These are spaces full of the possibility of friendship if only one can grasp it:

> “hang around long enough and you might make friends”
>
> “I can relate to others neurodivergents, and sometimes be able to make a friend (if I have the energy to allocate to a new one)”
>
> “its a wonderful place to find friends if u dont have any !”.

Some mentioned that they joined Mastodon in particular in the hope of making friends, because they viewed Mastodon as a more promising site for forming friendships with people like themselves:

> “I joined mastodon to try to make friends because my discomfort being in public makes that difficult. I felt that the people there were more likely to be accepting of me.”
>
> “Mastodon: out of hope that I will eventually make friends with people I can relate to.”

One respondent explained, “I feel more comfortable talking to people on mastodon because so many people take pride in being ‘weird’, but I do not really feel like I am part of a community in the sense of having made friends or developed a support network.”

So though online communities such as Mastodon hold out a hope of friendship to neurodivergent people, this is not always accessible to everyone. As I mentioned previously, some people are still lonely; some still lurk on the peripheries of community unable, unwilling, or unsure how to join in and make friends. Even aside from friendships though, there are still many ways that these online communities can provide support to neurodivergent people, and even some of those who mentioned a lack of friendships or self-identified as lurkers tended to report receiving informational support and even some emotional support from these communities.

## Social Support:

Nearly everyone who responded to my survey indicated that they give or receive some form of support in online neurodivergent and disabled communities. This support was primarily emotional, financial, and informational in nature along with the somewhat passive support of just being in a community of likeminded people, though all of these forms are very interconnected, and most respondents participate in more than one. This support is also largely mutual and goes in many directions, rather than some people taking on the role of supporter and others the role of supported. And with the exception of financial support, which is often unidirectional because of differences in financial need and financial security, most respondents receive the same types of support they give and vice-versa. As one respondent noted, “we all have problems and we can all be there for each other”. Another described the powerful impact that community support has had on their life and then went on to discuss how they also provide support to their community, explaining “In the same ways my community supports me, I offer back support. I would not be helpful to anybody, merely a burden, without these communities.” Though support needs differ between community members and across time these “care webs” allow neurodivergent and disabled people to move from dependence to interdependence, both receiving and providing support, working “from a model of solidarity not charity—of showing up for each other in mutual aid and respect” as Leah Lakshmi Piepzna-Samarasinha describes in *Care Work: Dreaming Disability Justice* (2018, 20).

Among respondents to my survey, emotional support was the most commonly reported form of support both given and received. Of the 64 people who responded to the questions about support, 45 reported giving some type of emotional support and 51 reported receiving some type of emotional support. The emotional support that respondents provide takes many forms, and is often informed by the particular experiences of those providing the support:

> "I often find myself being the one to remind people their lives have value and meaning and have had more than a few cases of walking people through fits of despair or pulling them back from suicide."

> "I have been a help to a couple people from this website on complex trauma, since (I forgot to say I also have C-PTSD) I've dealt a lot with emotional dysregulation and I or the host (I'm not sure) tend to be very good at using skills and being a compassionate presence from years of therapy."

> "i send lots of <3 (heart emoticons) and try to come up with kind supportive replies"

In my experience, sending heart emojis or emoticons to people who are going through a hard time or feeling upset, sad, or alone is one of the most common ways that people provide support on the Fediverse. This allows those who may not have the spoons or words to type out a longer reply to show friends and community members that they care and that they are not alone. It can be an especially useful approach because words and advice are not always helpful when someone is feeling bad and it is easy to say the wrong thing, especially when you don't know what is helpful for that particular person to hear. Though not everyone appreciates these heart responses, they can be a good way to show support and solidarity even without words. Many respondents expressed that they try to provide emotional support but that it is difficult because for example, "I'm not good with interacting", however there are more indirect ways to provide emotional support even for those who have trouble communicating or interacting. One respondent explained that though they are usually unable to communicate, they are able to provide some emotional support on Reddit by upvoting posts and comments and on Mastodon by favoriting a post or thread.

Others indicated that though they try to provide emotional support they are unsure how successful they are. Still, most respondents reported receiving some form of emotional support, such as "helping me to feel less isolated, accepting me as i am, supporting me in figuring out who i am and how to work with and be okay with my traits” and “listening to my vent or offering advice”. Even those who self-identify as lurkers or who have a hard time engaging directly are able to access passive emotional support indirectly, through second-hand validation- “I see someone else talk about their struggle and I can relate it to my own”. Though not everyone is able to access this emotional support, these communities still hold out the hope of future emotional support: “If I ever have the courage to open up and it's seen I hope I can get emotional support”.

Many respondents reported giving and receiving emotional support along with informational support, in the form of advice for example. One respondent described a sort of intersection of these types of support, as “not just emotional support, more like analyzing our individual psyche and social contexts and how they function”. This is not simply a transference of information but rather a figuring out together, working to understand oneself, one’s community, and the world at large. It is meaning making and embarking on a journey of self-discovery and understanding together. In addition to this communal meaning-making and theorizing, many community members share and find resources online along with lessons learned from personal experience and observation. This type of support has been immensely helpful to me in creating this project as community members share their experiences, theorize with me, share important sources and community history, and as we discover and create new communal information through conversation.

This informational support also comes in the form of questions asked and answered, practical tips given, educational information and resources shared. Some of this support also involves helping people to navigate medical, governmental, or psychiatric systems to avoid harm and secure resources, for example “helping them determine what questions to ask their doctors to better figure out their issues”. Community members share information and resources based on their own personal experiences as well as passing on what has been shared with them to others or the results of their own research. A few respondents indicated that they are involved in research and knowledge-curating on the topics of disability and neurodivergence:

> “I've done a lot of research on the topic of neurodiversity and so when people ask questions, I often have scientifically backed answers. I share my own stories to normalize behaviors.”
>
> “I frequently discuss autism, disability and related topics for the furtherance of understanding.”
>
> “sharing things of interest to neurodivergent people, such as helpful links. Or I might share tips on things that has helped me.”

Indeed, I have benefited from this informational support and am deeply grateful for the community members on the Fediverse who helped me to find sources for claims and directed me towards information that has aided me in my research. A lot of the background knowledge that I bring to this project is also a result of years of conversations, observation, shared resources, and answered questions.

Another key form of support in online neurodivergent communities is financial and material. Several respondents indicated that they have received financial support, either occasionally, in the past, or more regularly, and one respondent expressed that these communities are a possible future source of financial support if needed. Some also provided and received material support such as housing, whether for someone just passing through town or longer term, or gifts of crafted items and artwork. Some artists and writers also sell their work in online neurodivergent communities and are supported financially in this way, while also providing joy and entertainment to their communities. Many respondents reported sending money when they have it to help others pay for rent, food, medical care, or escaping an abusive situation. One respondent explained “without online communities, I am isolated,” describing their experiences of homelessness and physical and sexual abuse that resulted from this isolation and lack of support. But online community provided a way out, and a path to safety:

> Through online communities, I found somebody I can trust to live with, I started a family, I found other lesbians to befriend and date. I found a therapist, got medications and a means to work through trauma. I have a home and people who respect my needs as an autistic person, and love me, with a household I can contribute to according to my abilities. I have safety…Without online communities, I am not safe, I do not have what I

> need to survive, I can't help other people as aptly, I would not have family and friends and shelter.

For some neurodivergent people, online communities are literally lifesaving because of the financial, material, emotional and informational support they provide. They can provide social interaction and friendship with people who finally understand and accept us for who we are. Many of us create found families from these relationships. Though we may be rejected and abused by our birth families, past partners and relationships, and society as a whole, here we can find invaluable social support that in many cases enables us to continue fighting to survive in a world that is hostile to our very existence. As Piepzna-Samarasinha writes, “In the face of systems that want us dead, sick and disabled people have been finding ways to care for ourselves and each other for a long time” (2018, 19).

## Changing Self-Conception:

Having access to this kind of support and to communities that accept you as you are and celebrate neurodiversity can have an invaluable impact on participants’ mental and emotional wellbeing as well, leading to increased self-acceptance and confidence and decreased negativity and self-hate. When asked if participation in online neurodivergent and disability communities has affected how they think about themselves, the vast majority of respondents answered yes and spoke enthusiastically about how much of a positive impact these communities have had on their self-concept and sense of self. These communities have helped respondents to learn more about themselves and understand themselves better, finding practical coping mechanisms for dealing with their specific conditions and enabling them to celebrate themselves for who they are, rather than despairing at their inability to meet neurotypical norms and standards.

Many respondents spoke about how being in these communities has helped them to understand themselves and others, introducing them to terms and concepts they may not have known of before and helping them to find a community who understands what they are experiencing:

> “I feel more confident knowing that I'm not alone in a different experience of the world. And I'm much better now that I understand better why I am this way. I love that there is people that I can just tell what I experience and they believe me and know what I mean.”
>
> “They give me a sense of belonging! They make me feel less alone in the "weird" things I do, and they give me explanations for things that have previously frustrated or isolated me. I like feeling like there are other people who experience things like me, and that there are reasons I experience these things.”
>
> “Seeing other people talk about their lives and experiences helps me frame my own. I now have labels to use for behaviours and situations. I am able to apply some labels to myself, and recognise what people might mean when they apply certain labels to themselves.”
>
> “I’ve learned so much about autistic meltdown and burnout! Neurotypicals don’t tell you this shit!”

Respondents were enthusiastic about this increased understanding which helps them feel better about themselves and develop and learn about important coping mechanisms that make it easier for them to accept themselves as they are and interact with the world in a way that works for them. As one respondent explained, “It's helped me to feel more comfortable using different strategies for making my life work *with* my brain, and has generally made me happier.” Another wrote, “It's made me consider behaviors in a new light that help me find ways to help myself”. Being around other neurodivergent people like themselves has exposed respondents to new ways of approaching their conditions, allowing them to learn tools for dealing with ADHD, gain greater understanding of their own autism, and even discover for the first time that there are words to describe their experiences, such as plurality.

These new tools, understandings, and support networks can lead to greater self-acceptance for participants in online neurodivergent communities. They allow neurodivergent people to understand their difficulties not as deficiencies within themselves, but as the result of living in a society that is not made with their needs in mind: “It's helped us learn and realize that we aren't "broken" and that it is the world around us that is unforgiving to neurodiverse folk. It's also helped us not feel like we are a lost cause, that we can still find ways to live a happy life". Many respondents explained that participation in these communities has given them hope for the future and enabled them to see themselves more positively, no longer thinking less of themselves for their neurodivergences, and recognizing that their needs are important and that they are deserving of support:

> "I feel less inclined to call myself names or be upset with myself for my mental differences. While they may be frustrating to me and cause me a lot of discomfort and pain, they do not make me less of a person, nor are my needs any less important than the needs of those around me."

> "i used to feel a lot of shame about how my brain works. participating in online community has helped me think about my neurodivergence as something interesting and potentially good."

> "It has definitely helped with self-esteem and self-acceptance. I don't think less of myself for having the brain issues I do."

In turn this self-acceptance is often accompanied by an increase in self-esteem and confidence, encouraging neurodivergent people to embrace themselves for who they are and assert that others should as well: "The online community has greatly fostered a positive self-outlook in me. I am more comfortable and confident in embracing my Autistic identity as a result."

In this way neurodivergent identities become a source of strength, confidence, and community rather than weakness, shame, and isolation. There is a transformative power to neurodivergent community.

## Negative Experiences:

While most respondents reported that participation in online neurodivergent and disability communities has changed their life for the better, levels of satisfaction vary. And unfortunately, some people reported much more negative experiences, that had a harmful rather than positive impact on their life. While these do represent the minority of respondents, it is important to account for the fact that those with the most negative experiences in these communities are unlikely to still be participating in them to see this survey and respond to it. In fact, I have unfortunately seen many people chased out of these online communities due to harassment, from both inside and outside of their communities. Many of the people heavily involved in the Fediverse, where most of my respondents were recruited from, are there because they have been kicked out of or gotten fed up with other online spaces. This can be because of over-policing on corporate social media that ends up targeting marginalized groups as well as under-moderation of the people that use social media to harass those groups. Others may feel that the platforms themselves are hostile or inaccessible to them or that it is hard to be heard in those places.

Indeed, one of the respondents who expressed the most negative feelings about online neurodivergent and disability communities appears to have moved to the Fediverse in a recent wave of migration from Instagram, spurred by frustration with the site's policies. They report being heavily involved with the chronic illness community on Instagram in the past, as well as neurodivergent/mental illness communities on Instagram and Tumblr and despite putting in lots of effort into those communities getting very little support in return, explaining, "Most of the people I interacted with were more focused on a hierarchy of who was hurting more & a model of upholding white supremacy and silencing multiply marginalized voices". They found that because of their multiple marginalized identities on multiple intersecting axes it can be better not to participate in the first place, and they have often been told that they are "too much" and "redirected to sub-communities that erase other aspects of who I am." In neurodivergent communities for example, "the overarching presence of white supremacy, sexism, and physical ableism…is overwhelming". This respondent explained that:

> "Toxic positivity, a hierarchy of who has it worse, and white disabled supremacy completely messed with my head. It tanked my self esteem and self image, it caused excessive levels of medical burnout, and it nearly sent me back to psychiatric inpatient. I've become a much stronger & more radicalised person because of the process of unlearning and correcting what it did to me. It has ultimately left me feeling like I don't have a community that wants me, but has also given me the desire to make one."

As this last comment shows, it is not online community as a concept that is inherently the problem here, but the fact that these communities still have a tendency to uphold systems of supremacy. Online neurodivergent and disability communities are still full of the racism, ableism, sexism, transphobia, and antisemitism (among other things) that is pervasive in society, and this is something we must be relentless in fighting if we ever want to have truly inclusive and welcoming communities. Though many people come to the Fediverse hoping to find a safe space away from the toxicity of mainstream social media, it has many of its own problems. While the Fediverse, or at least the circles I am in, has a reputation for being especially welcoming to queer and trans people, it has a well-known problem with racism, particularly with Black people being mistreated and harassed off of the site. Many respondents specifically mentioned that racism is a huge problem in these communities and that they are not safe for neurodivergent BIPOC. One respondent explained, “Too many people of color have been driven out of these communities by harassment, insufficient moderation and protection from harm from other online presences.” Another stressed the importance of anti-racism and solidarity in online neurodivergent communities: “Anti-racism has to be there as a key concept. Throwing BIPOC under the bus simply should not be an option. Without solidarity, we're just going to all get run over by neurotypicals because they will continue to divide-and-conquer us.” It is easy to just make a copy of mainstream society with all of its bigotries and discrimination, but neurodivergent or disabled this time; we must do better than that. It is clear that these online neurodivergent spaces are still overwhelmingly white, as evidenced by the fact that 87% of survey respondents self-described as white or of some specific European ethnicity. Without concerted anti-racist action that centers the neurodivergent people being harmed by racism, these community spaces will continue to center whiteness as the default and exclude neurodivergent BIPOC.

# Conclusion

This thesis addresses the research questions “what function do online communities serve for neurodivergent people?” and “how does participation in online communities affect neurodivergent people” by examining responses to an online survey of neurodivergent people. Based on these responses I argue that online communities are important sources of social support and social interaction for neurodivergent people and meet needs that are not met or cannot be met offline. I discuss the liberatory potential of neurodivergent terminology and the ways that online neurodivergent community present an opportunity for friendship and the creation of support networks to those who participate in them. I also provide evidence that these online communities meet accessibility needs that can not be met offline and provide methods of interaction that work better for many neurodivergent people. I argue that online communities are not simply mirrors of or companions to offline communities but places of community formation and socialization that should be examined as such, as I do in this paper.

While these online neurodivergent communities still have their own problems and limitations which must be addressed, such as a lack of diversity and centering whiteness as the default, they are full of potential for liberation and empowerment. As survey responses show, participation in online neurodivergent communities can provide participants with emotional, informational, and material and financial support, and encourage self-acceptance, leading to a decrease in negative thoughts about oneself. There is a need for more of these communities created by and for neurodivergent people, particularly multiply marginalized neurodivergent people, to meet a diverse set of needs and provide opportunities for many different types of interaction. Similarly, there is also a need for more research like this which allows neurodivergent people to talk about our own experiences and communities, rather than centering the voices of neurotypical people who continue to pathologize and dismiss us. This will require a change in perspective for many academics and psychiatric professionals, to view us as experts who are qualified to talk about our own conditions on the basis of our lived experiences. We must be recognized as people with autonomy who have insight into our own experiences and communities and who can speak for ourselves, in whatever forms our communication takes.

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# Appendix: Survey Instrument

Q1 Please read the following consent form:

Q2 **Mississippi State University Informed Consent Form for Participation in Research** **IRB Approval Number**: IRB-20-374
**Title of Research Study**: Language and Culture of Neurodiversity and Disabled Self-Advocacy in Online Communities
**Study Site**: Twitter and the Fediverse
**Researchers**: Dr. Holli Seitz, Mississippi State University

**Purpose**

The purpose of this research is to look at how online communities of neurodivergent people work and what they mean to the people in them. This research is based on letting neurodivergent people speak for themselves about their communities and what is important to them. The goal of this survey is to share what neurodivergent people have to say about their own lives and their experiences online.

**Procedures**

If you participate in this study, you will be asked to fill out an online survey about your experiences in online neurodivergent communities. This survey will consist of a few demographic questions and primarily open-ended questions about your experiences and how you identify yourself. On average this survey will take about 15 minutes to complete, but you may take as long as you need or want. You can stop taking the survey at any time and skip any questions that you do not want to answer.

**Risks or Discomforts**

Because no personally identifiable information will be collected, the only known risk to participating in this study is potential psychological discomfort when reflecting on possibly traumatic experiences. If at any time you feel uncomfortable, you are free to stop taking the survey or skip any question.

**Benefits**

Participants will be able to talk about issues that are important to them and their communities and an analysis of the data collected will be made freely available to participants and their communities after the completion of the study on the same social media accounts that participants were recruited from. This information will be useful in understanding their own communities, including differing opinions and experiences, and beneficial and harmful practices.

**Confidentiality**

Only indirect identifiers such as demographic information on age, gender, race/ethnicity, and nationality will be collected and there will be no way to directly link a participant to their responses. Your responses will not be shared with anyone but the research team and they will be stored in secure locations.

Please note that these records will be held by a state entity and therefore are subject to disclosure if required by law. Research information may be shared with the MSU Institutional Review Board (IRB) and the Office for Human Research Protections (OHRP) and others who are responsible for ensuring compliance with laws and regulations related to research. The information from the research may be published for scientific purposes; however, your identity will not be given out.

Thank you for considering participation in our research. This research is for people who are over the age of 18; if you are under the age of 18, please do not complete this survey.

Note that Qualtrics has a specific privacy policy of its own. Qualtrics has been instructed not to record any personal information, but you should be aware that these web services may be able to link your responses to your ID in ways that are not bounded by this consent form and the data confidentiality procedures used in this study. If you have any concerns, you should consult Qualtrics directly.

**Questions**

If you have any questions about this research project or want to provide input, please feel free to contact student researcher Laura Ingouf at lni19@msstate.edu or their faculty advisor Dr. Holli Seitz at hseitz@comm.msstate.edu.

For questions regarding your rights as a research participant or to request information, please feel free to contact the MSU Human Research Protection Program (HRPP) by email at irb@research.msstate.edu, or visit our participant page on the website at https://www.orc.msstate.edu/human-subjects/participant-information.

To report problems, concerns, or complaints pertaining to your involvement in this research study, you may do so anonymously by contacting the MSU Ethics Line at https://www.msstate.ethicspoint.com/.

**Voluntary Participation**

Please understand that your **participation is voluntary.** Your **refusal to participate will involve no penalty or loss** of benefits to which you are otherwise entitled. You **may discontinue your participation at any time** without penalty or loss of benefits.

**Please take all the time you need to read through this document and decide whether you would like to participate in this research study.**

If you decide that you want to participate, please click the option below that says, "I consent to participate in this research study". If you do not wish to participate, you may exit the survey now or click "I do not consent to participate". You may wish to print this consent page for your records.

○ I consent to participate in this research study

○ I do not consent to participate in this research study

Q3 **What is your age?**

- ○ Under 18
- ○ 18 - 24
- ○ 25 - 34
- ○ 35 - 44
- ○ 45 - 54
- ○ 55 - 64
- ○ 65 - 74
- ○ 75 - 84
- ○ 85 or older
- ○ over 18, but prefer not to share exact age

Q4 **Which of these describes your gender?** select all that apply

- ☐ man
- ☐ woman
- ☐ transgender
- ☐ nonbinary
- ☐ gender non-conforming
- ☐ genderqueer
- ☐ genderfluid
- ☐ agender
- ☐ boy
- ☐ girl

☐ genderless

☐ questioning or unknown

☐ Other (please specify) ________________________________________________

Q5 **What word or words describe your race and/or ethnicity?**

________________________________________________________________

Q6 **In what country do you currently live?**

________________________________________________________________

Q7 **What words do you use to describe yourself? Specifically, what words do you use to describe your neurological differences and/or disabilities?** But please feel free to list any labels or identifiers which are important to you even if they are not related to neurological differences.

Q8 **Do you think of yourself as disabled?** Feel free to explain why or why not.

Q9 **Do you think of yourself as neurodivergent, neuroatypical, both, neither, or something else?** Why or why not?

Q10 **What comes to mind when you read/hear the word neurodiversity? Neurodivergent? Are you familiar with these words?**

Q11 **Can you list or describe the online communities you are involved in? Do any focus on disability issues or neurodivergence? Do you use them to connect with other neurodivergent or disabled people?**

Q12 **Do you remember what brought you to these online communities?** If so, please explain.

Q13 *For the following questions please provide information about your experiences in any online communities of neurodivergent or disabled people that you indicated you participate in. These do not have to be formal communities, but should include at least some connections with other neurodivergent or neurologically disabled people.*

Q14 **Why do you participate in these online communities?**

Q15 **How important are these online communities to you?**

- ○ Extremely important
- ○ Very important
- ○ Moderately important
- ○ Slightly important
- ○ Not at all important

Q16 **Do you get support from these communities? How? In what form?** (e.g. financial, emotional)

Q17 **Do you provide support to others in these communities? How? In what form?**

Q18 **How do these online communities compare to offline neurodivergent and disability-centered communities? Do you usually participate in those?**

Q19 **Do you experience any accessibility issues that make it hard or impossible to participate in <u>ONLINE</u> neurodivergent or disability-centered communities?**

Q20 **Do you experience any accessibility issues that make it hard or impossible to participate in <u>OFFLINE</u> neurodivergent or disability-centered communities?**

Q21 **Has participation in online neurodivergent and disability communities affected how you think about yourself?**

Q22 **How do your intersecting identities** (e.g. race, gender, age, sexuality, other types of disabilities) **affect your experiences in online neurodivergent spaces?**

Q23 The **biomedical model of disability** usually says that **disabilities are biological problems to be treated or corrected**, and the **social model of disability** says that **many disabled people are disabled by a society that does not meet their needs and is not accessible**.
How do you feel about the biomedical and social models of disability? Do you prefer one over the other, some of both, or a different model?

Q24 **How satisfied are you with your experiences in online neurodivergent and disability communities?**

- ○ Extremely satisfied
- ○ Moderately satisfied
- ○ Slightly satisfied
- ○ Neither satisfied nor dissatisfied
- ○ Slightly dissatisfied
- ○ Moderately dissatisfied
- ○ Extremely dissatisfied

Q25 **Is there anything you wish was different in these communities?**