@utism: (Re)negotiating Collective Identity in the Blogosphere

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THESIS

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ZAR
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SUMMARY

Autism has been referenced in a variety of analyses from philosophical to medical to sociological. The study of Autistic culture has been rarely undertaken. In an effort to bring previously ignored voices into a conversation where they have been routinely ignored, this study locates Autistic culture as it exists persistently on networked online mediums. While studies of community have typically gone on through ethnographic adventures to foreign locales, many sites of community exist in networked locations, such as blogs. This study follows the work of Christine Hine’s landmark book Virtual Ethnography and comes to view Autistic blogs not as finite or completed texts but as settings or sites for conversation and communal meanings. Methodologically, the study identified two major blog websites, Radical Neurodivergence Speaking as well as Ballastexistenz and then used a filtering technique to identify four blogs from each website to analyze. Once located, the commentaries of bloggers were analyzed through a Foucauldian discourse analysis methodology that was able to read how bloggers positioned themselves and there community in terms of dominant nonprofits, medical discourses, the claims of parent groups and the thoughts of disability rights organizations claiming to represent them. Apprehending the series of critical discourses present in such Autistic blogs has been so engrossing of a task that the secondary aspect of this study remains largely unfinished. It is clear that future virtual ethnographies focusing on blogging communities in the future must focus their analysis on the comment sections where the real conversations happen.
I. Introduction

As a consequence of the move in disability studies toward a minority model of disability, it is no longer possible to understand disabled people through medical knowledge alone. An investigation of specific disability cultures, such as Autistic culture, is a requirement for effective engagement with the complexities of specific disability experiences.

Among other disability cultures, Autistic culture is peculiar and worth investigating for its communicative inventiveness and hybrid institutional location (Eyal, 2013; Grinker, 2010). While clinically aligned hypotheses about Autism have long trumpeted the isolation and aloofness of Autistic patients, one of the first battles waged by Autistic people and their allies has been to prove that socializing and communities can be maintained through alternative technologies. Further explorations of Autistic culture are urgently needed, in part because vast amounts of public knowledge and research have sought to understand aspects of Autism, but few have tried to learn from the innovations of Autistic people and Autistic organizations.

Autistic culture then is impactful as a field in which Autistic people have defined themselves as a unit among themselves. Within areas designated as part of Autistic culture, Autistics populate a shared experience and common ground with those elements that would speak to them and their comfort instead of an outside sources. In an effort to introduce an Autistic cultural viewpoint into a literature base already top-heavy with medical and clinical descriptions of Autism, this proposal aims to set the foundations for an ethnographic investigation into Autistic cultural spaces and into the self-meanings created by participants within such spaces.
A. Literature Review

Three trends in culture, social movements, and the medical complex motivate this research on internet-based Autistic communities: the rise in autism diagnoses, the explosion of internet-based Autistic communities, and the appearance of a wave of hidden Autistic adults (King & Bearman, 2009; Grinker, 2010; Grace, 2012).

1. Autism epidemic: Disentangling a myth

Gil Eyal (2013), Bearman and King (2009) and Eric Fombonne (2001) all offer different arguments demystifying the idea that there might be an autism epidemic constituted through an increase in the number of people with Autistic symptoms.

King and Bearman (2009) conducted a study illustrating that a number of patients in Developmental Services in the state of California received a change in diagnosis from Mental Retardation to Autism between 1993 and 2005. This explanation notes a change in diagnoses that can be located in the actions and practices of clinicians. There is no specific reason that has been identified for such practices of re-diagnosis, but some reasons present in the literature reviewed here include the more positive view of Autistic intelligence, the lack of inevitability in assigning permanent deficit to Autistic people and the claim made by clinicians to be able to ameliorate Autism symptoms.

Alternatively, Gil Eyal, a sociologist, finds the social causes of the so-called Autism epidemic to be attributable to a decentering in expertise from institutions and the psychiatrists to parent-psychology professional hybrids. Eyal’s argument essentially stated is that “Deinstitutionalization erased the old categories that reflected the needs of custodial institutions… while creating instead a new institutional matrix—community treatment, special education, and early intervention programs” (2013, p. 3). In this point, that the change in
diagnosis has more to do with the state-private apparatus tasked with taking care of the person, Eyal helps to prove how cultural and systemic changes, not scientific or biological ones, motivate the diagnosis of more new causes of Autism.

Finally, Fombonne’s commentary, “Is There An Autism Epidemic?”, in the 2001 issue of *Pediatrics*, is telling in that it supports the Bearman and King thesis. However, he also explains that all psychological diagnosis rates have jumped. He continues to suggest that the standards for Autism and the multiplicity of categories within it have not been controlled culturally, leading to a series of sub-notations and diagnoses to be grouped within the Autism label. These include Asperger’s syndrome, Rett syndrome, and several others. Supporting the previous assertion that Autism is the product of institutional, not biological changes, these myriad sub-diagnoses are more sub-classifications that make the person connected to them eligible for different routines within special education, community care, and mental hospitals than they are distinct biological states of being.

The arguments of all three sets of authors demonstrate that changes in institutional and clinical behavior are the primary explanation for the increasing numbers of people clinically diagnosed or labeled Autistic after the 1980s and into the mid 2000s. In other words, there are more Autistics in the population because the identification and consequently, treatment, of Autistic people became more widespread in this time period. The increasingly overt use of diagnoses codified with professional medical expertise for largely service consumption oriented purposes foreshadows the ownership of these terms and proliferation of them outside of the ranks of strictly professional jurisdiction. The seeming arbitrariness of one diagnosis over another makes the use of psychological concepts as identity in online communities much less surprising---that Autism became widespread because of dual-role parent-professionals makes its
mobilization for identity politics by patient-activists and patient-bloggers as well as patient-professors seem entirely reasonable.

2. **Autistic people and the Internet**

   Elizabeth Grace, Judy Singer, and Nancy Bagatell each offer different versions of a popular argument that Autistic culture and the internet were “made for each other” and that such structures were mutually beneficially. Grace (2012) argues that Autistic culture being located on the internet is natural because many Autistics are more comfortable typing to communicate than speaking anyway. Meanwhile, Singer (1998) argues that Autistics simultaneously invented the internet and use it to create self-empowering narratives, but provides a disclaimer that the Autistics she mentions are “high functioning” only. Bagatell (2007) also confines her analysis to people with “high functioning” autism but focuses on the co-production of narratives and voices in Autistic spaces. She sees the value of such spaces as being in their possibility to lead their members from, and to, in-person meetings with other Autistics.

   Bagatell, Grace, and Singer offer opposing views of how online cultures function vis a vis in-person Autistic spaces. Grace (2012) approaches a possible history of Autistic culture as having had telephone-based, in-person and internet stages from the 1980s forward. Within this framework, increased access to and acceptance of the internet by US society beginning in the 2000s is reflected in the significance of the internet in mediating Autistic culture.

   Singer (1998) views internet use not as a stage in Autistic organizing, but rather as one of the *defining characteristics* of the Autistic community that locate its members under the stereotypes of “nerd” and “geek”. Finally, Bagatell (2007) thinks of the internet as serving a *bridging function*, a method of connecting Autistic people in the times and spaces between in-
person Autistic conferences, which she identifies as the primary sites of Autistic community. Thus, the internet provided a mechanism through which to continue community conversations.

Collectively, the authors identify the internet as a medium that offers Autistics greater opportunity to communicate than ever before. Specifically, the intent provides a virtual opportunity to generate messages indicative of their unique perspective and to form ties with other oppressed groups. It is precisely the possibilities provided via the internet and the ways in which these opportunities have been accessed that compel the study of Autistic culture in the networked context.

3. **Autistic adults: Forgotten**

The academic literature on the quality or content of Autistic adulthood is scant; indeed, the in-depth study of the experience Autistic adulthood has not proceeded very far. Their invisibility in the current situation makes any discussion of Autistic adults necessarily focused on their general absence. A parallel in the invisibility of Autistic adults (to Autistics transitioning to adulthood or young adults imagining themselves as adults) can be drawn to the experience of bisexuals in the 1970s, as documented by Weinberg, Williams, and Pryor (2009). As with these bisexuals, who must refuse not one but two identities inadvertently mapped upon their social bodies (both gay and straight), Autistic people in the 1990s had to refuse up to three possible disparate classes of misidentification: 1) quirky/eccentric, 2) mentally retarded, and 3) mentally ill.

Anthropologist Roy Grinker (2010), experimental psychologists Bishop et al. (2008) and British psychiatrists Brugha et al. (2012) all present differing explanations for Autistic adult misidentification.
Grinker (2010) argues that the truths of Autism are fragmented across unofficial stakeholder knowledge and the positivist scientific claims and that both offer incomplete explanations. This massive dissemination of many different kinds of Autism has opened the way for Autistic self-definition and self-identification in ways that don’t always oppose official Autism science. The twin disjunctures identified by Grinker (2010) between official science and what might be called quack science as well as between broader scientific discourse and stakeholder communities such as parents and Autistics themselves. Grinker’s (2010) explanation then views Autism as having too many voices that crowd out the essential ones; conspiracy theorist voices are heard louder than scientific ones and Autistic community voices are barely heard at all.

Bishop et al. (2008) has distinct hypothesis, allowing for the possibility that there is a subset of Autistic adults who developed Autistic symptoms with age. That is, they were not Autistic children who were undiscovered until adulthood, but rather that they transitioned into Autism alongside the maturation into adulthood. The implication is that Autism is not as permanent or indomitable a diagnosis as previously thought, but more that symptoms can be periodic or worsened by life-circumstances.

Finally, Brugha et al. (2011) discuss how misidentification might have occurred, extending both the arguments provided by Bishop et al. (2008) and Grinker (2010) by suggesting that factors such as gender, income, and social status might inflect the breadth of the diagnostic substitution suggested by others. The concept of “diagnostic substitution” (Bishop et al., 2008) locates the relabeling of misidentified Autistic people on the shoulders of medical professionals. According to them, professionals, nursing homes, and medical institutions heavily monitor their charges and thus have plenty of time to continuously consider the validity of their diagnosis.
With the evidence offered by Bishop et al. (2008), Grinker (2010), and Brugha et al. (2011), it may be easy to argue that most diagnostic substitution has occurred in patients identified as being mentally retarded, developmentally disabled, or intellectually disabled, because such patients already face more observation and receive more care than others.

B. **Autistic Internet Culture: Answering the Call**

Previous research has documented the significance of the internet as a space in which Autistic culture has developed in the absence of a singular location from which to operate. An important contribution made in this paper is the argument that Autistic and likely other disability cultures can be located on the information or communication networks instead of in physical places. In putting forth this point, it is important to emphasize the ways in which information technologies that have seemingly developed parallel with the science and politics of Autism are used to extend Autistic abilities to communicate and make up for signals that are perhaps not received in in-person events taken part in by Autistic people. While Autistic in-person meetings do occur, internet and other types of communication networks provide a way to establish a place for such individuals to interact without worrying as much about violating subtle interpersonal rules and structures underlying communication. The blog form is uniquely suited to the Autistic cultural form known as the “info-dump” or the rant. It can be thus argued that the digital Autistic community supplements a real omnipresent lack of in-person community in Autistic lives, not only because of impairment, but because of the illegibility of Autistic lives within Neuro-normate social spaces.
II. BACKGROUND SECTION

In order to better understand contemporary forms of resistance and new cultural formations engaged by Autistics, it is necessary to explore the pathways through which institutional concepts of autism developed, traveled, proliferated, and crystallized. In this section, I will address two of these pathways: 1) by charting the roots and tangles of the psycho-socio-medical category of Autism - one that has its historical origins as a justification for institutionalization and resultant dehumanization within the field of psychology -- specifically, psychoanalysis; and 2) by providing an abbreviated history of two of the most clearly identifiable (and vocal) autism social movement organizations operating in the U.S. Taken together, these two pieces of context will allow for an entrée into the social processes through which Autistic bloggers respond to and contest hegemonic definitions of autism and those who hold the microphone claiming to speak for Autistics.

A. **Autism as Isolation**

Foucault’s strategy for engagement with histories of ideas is to seek out regularity and even when regularity is hard to find, to plumb deeper in order to find a lost coherence. In bringing Foucault’s discourse strategy to the discourse of Autism, this essay locates Bruno Bettelheim classic “Refrigerator Mother” theory of autism as an emergence point for the notion, that isolation and social detachment are the key characteristics by which autism can be “discovered” and “diagnosed” (1967). While the neurodevelopmental turn (Eyal, 2013) in Autism science challenged Bettelheim’s theory, that challenge primarily rejected the psychoanalytic implication that Autism is conditioned by parenting behaviors. However, this development in the ideas about autism kept coherence with Bettelheim’s claims about the isolatedness of the Autistic.
To appropriately illustrate the discourse of Autism as isolation, it will be necessary to start with Bettelheim’s original formulation. Bettelheim describes the Autistic when he says “their vague, empty gaze at the far distance, nonfocussed and directed at nothing in particular…the height of such deterioration of the self the extreme forms of nonaction and of interest withdrawn from the world, these are reached when all communication is given up” (1967, p. 8).

Bettelheim’s account of Autistic communicative isolation does not differ in so many ways from later theories of Autism, such as that of Bernard Rimland (1964), Ole Ivar Lovaas (1974) and Simon Baron Cohen (1985). In fact, the most pronounced difference in these clinical thinkers’ conceptualizations of Autistic communication is in their arguments about the causes and scope of Autistic communicative isolation.

Few, if any, contemporary psychologists and psychiatrists question the description of the Autistic as withdrawn. The discursive formation of Autism is then one that totalizes the communicative possibilities of an Autistic person based on their ability to fit into cultural normative communication styles. Much of the clinical discourse of Autism does not ask whether alternative forms or styles of communication can be used by an Autistic person, instead formulating the nonverbal communicative expectations of an able-bodied and normative social conduct as the baseline for any kind of communication. The American Psychiatric Association says that Autistic people have “Difficulty relating to people, things and events – trouble making friends and interacting with people, difficulty reading facial expressions, may not make eye contact” (2015; p.1).

This enclosure of the communicative possibilities of Autistic people originates in Bettelheim’s psychoanalytic conclusion but becomes materialized through claims about
developmental disability and behavior, in the performances or presence of the body. While the isolation thesis, in both its original form and its in more material expression is hardly ideal, the reaction to it may be just as bad in that it locates communicative problems in the body and in discipline systems. Bernard Rimland and Leo Kanner’s argument that Autism is neurodevelopmental had the effect of grouping Autistics within the psychological theory of the idiot savant. The discourse of idiot savantism constructs Autistic people as sometimes heroically useful but most often as uselessly idiotic and only valuable for parlor tricks.

B. Autistic as Idiot-Savant

In Rimland’s foundational *Infantile Autism* (1964), it is notable that he links Autism to a pre-existing description present in the psychological discipline of the idiot-savant. In connecting Autism strongly to this concept of the “idiot-savant”, Rimland’s work plays a strong role in terms of formulating a discourse of autism based in inherent neurodevelopmental and bodily deficit. Treffert (2014) has already considered the myths and fallacies associated with the idiot-savant phenotype in the psychological and clinical disciplines. He notes that while Down (1866) coined the term, it did not reach popularity of use until its feature in the popular 1989 film, *Rain Main*. It can be seen then that based on the trajectory of “idiot-savant” as a category reliant on popular media for its dissemination, the definitions and limits placed upon the term have faded and the uses of the term have fallen our of synch with the scientific arguments, experiments and discoveries associated with it.

Treffert’s most important success in re-examining “autistic-savant” is to decouple it from the assumptions of low IQ and specific forms of savant skills or islands of genius. While this effort may in its implications be counterproductive to a disability politics more interested in accepting vulnerabilities in the body and calling upon institutions to make up the difference, it
offers an in-road to understanding how the proliferation of the “idiot savant” category from
formal psychology into a popular discourse that imagines a useless “idiot” occasionally capable
of parlor tricks. We can see how the term “idiot savant” supports an atomization of Autistic
people, into two separate functions may prefigure the devaluation of the Autistic person by
parental and medical discussions. The presence of idiocy offers a moral-positivist justification
for degradation, while the notion of savantism invokes an image of Dustin Hoffman memorizing
numbers.

The idea of the “idiot” has still yet to be jettisoned from the idiot-savant category by the
time of Treffert’s 2014 article proving that the discourse of developmental disability and the
reductionism of many types and forms of immeasurable intelligence and intellectual possibility is
too much of a simplification. This paper then identifies the trope of the idiot-savant and further,
the continuity of the trope of idiocy and its essentialization of Autistic possibility to be a
continuing basis across the history of the idea of autism. Toward the end of his study Treffert
cautions against early identification and broad presumptions about autism and idiot-savantism,
noting that without such caution, parents may be unnecessarily frightened and overwhelmed. The
making of Autism as a concept occurred largely without debate between its constituents or
presence in politics, to explore the depth of the concept it will be necessary to engage with these
elements of the complexity that is Autism.

C. **Autism Speaks and Autistic Self Advocacy Network**

There are multiple stakeholders in the debate over what autism is and what it means to be
(in the sense of embodied existence) an Autistic. Two of the most prominent and prolific
stakeholder organizations in the United States are Autism Speaks and ASAN. Focusing on these
two social movement organizations allows for an understanding of the politics that center on a
conflict between the state and corporate sponsored organization Autism Speaks and the rights and minority model centered Autistic Self Advocacy Network. While representing very different perspectives, both are organizations that have been accused of misrepresenting the broader complexity of Autistic interest.

1. **Autism Speaks**

On their own website, Autism Speaks states that it is “the world's leading autism science and advocacy organization, dedicated to funding research into the causes, prevention, treatments and a cure for autism.” While this set of goals may seem innocent to non-Autistics, for people who view their creativity and excitements as coming from the same place as their difficulties with focus and emotions, it is nothing short of a eugenic agenda, seeking the removal of an entire sub-group of people from the genome. Autistics, championing an anti-cure politic as well as opposing certain types of ineffective treatments that are as much torture as they are a normalizing agenda that shames Autistic people for their born proclivities. The criticisms of Autism Speaks, however, have gone further, criticizing their affiliation with institutions, their lack of Autistic representation among their leadership as well as their ill treatment of Autistic family members within the organization and finally the mass media portrayals of Autistics as diseased and inhuman as part of their fundraising. Defenders of Autism Speaks would and have told Autistics criticizing them that the only one’s speaking are those that don’t need a cure and that the organization is doing important work toward treatment, but it the Autistics criticizing them use the unwillingness of the organization to listen as proof of its problems. However, Autistic Self Advocacy Network, the organization opposite this one, may be an example of too much pragmatism.
2. **Autistic Self Advocacy Network**

In opposition to Autism Speaks, Autistic Self Advocacy Network states that it “seeks to advance the principles of the disability rights movement with regard to autism” as well as believes that “the goal of autism advocacy should be a world in which Autistic people enjoy the same access, rights, and opportunities as all other citizens (2015:p.1).” Autistic Self-Advocacy Network, on its website, uses language and ideas borrowed from some of the brilliant bloggers that this study cites. While the group is organized entirely by Autistic people, many of those Autistic people are the elite of the Autistic population. Furthermore, while they do commit to doing cross disability work that includes developmentally disabled and intellectually disabled people, the group eschews identification with the mad or psychiatrically disabled community. While it cannot be doubted that Autistic Self Advocacy Network, as legislative advocates do important work for Autistic people and that compared with many other organizations that bare no connection to Autistic people the group is head and shoulders ahead, but as will be represented by some of the bloggers analyzed in this study, Autistic Self Advocacy Network has attempted to integrate a broad and complex Autistic community within an over-simplified political rights framework.
III. METHODS SECTION

This study seeks to use the collective meeting point of the internet as a basis from which to describe and analyze the variation in perspectives and self-descriptions of Autistic people and an Autistic community. The analysis begins with an exploration of collective Autistic life-meanings attached to the space of the internet itself and then traces how conflicts over proposed collective meanings demonstrate and produce new more localized and individualized meanings in conversation with those offered by the bloggers. The questions to be addressed are: how do collective Autistic life-meanings manifest on the internet? How do more local meanings come into existence? Finally, how are such meanings relate to the institutions which embedded all discourses of identity?

Unlike many other ethnographic projects, Autistic cultures are not physically located in a single geographic area, but instead exist virtually on forums, websites, and groups on the world-wide-web. Consequently, Hine (2000) will be employed to investigate Autistic culture. From this perspective, internet media is a background or setting for interactions. For this study, the very “material” of Autistic culture will be located in the blog posts (produced by bloggers who self-identify as Autistic) and responses to/contestations of the discourses invoked, practiced, and resisted in these posts. However, discourses do not exist within the bubble of a single community but are refracted through institutions, histories and global trends that impact how these discourses operate to reformulate and/or transform economic, social, sexual, and political dynamics. Once identified and outlined by Autistics, the discourses about autism, Autistic people, and Autistic culture will then need be placed in conversation with and in the context of larger discourses about personhood, community, group identity, and impairment.
A. **Methodological positions and tools**

This essay uses ethnography, virtual ethnography and institutional ethnography to engage with Autistic blogs critically as a community and kinship group, instead of the typical representation of patient groups as having a purely medical or rehabilitative purpose. Ethnography is used to offer the Autistic community the respect given to an ethnic group that is rarely given to disabled people because their similarities and unity in thinking are often denied by an ableist society. Virtual Ethnography is levied to approach the Autistic community’s presence consistently on the internet and to engage with the arrival of many marks of the culture in networked spaces. Institutional ethnography is utilized to place the commentary of Autistic culture in the context of dominant social institutions such as nonprofits, the state and capitalism. These ethnographic tools are utilized to understand developments in Autistic culture in terms of its existence as a community instead of making the move present in other critical disability theories of reducing to representations.

B. **(Virtual) Ethnography as Setting and Action**

In Murchison’s guidebook on how to do ethnography, it is argued “from the standpoint of ethnography, the only plausible way to study cultural phenomena is to study them in action” (2010, p. 4). When the cultural phenomena are largely on the Internet, the focus must be diverted to the series of “uses and understandings of the technology” (Hine, 2000, p. 4). An ethnographic methodology that is centered on Autistic Culture as it exists on the Internet must commit itself both to text, in which how internet documents are collectively produced social artifacts, and to interaction, addressing the engagement of these artifacts by the community that produced them.

In writing about how Virtual Ethnography can retain a connection to past concepts and types of ethnographies concerning placements and areas of life, Hine (2000) chooses to think
about the Internet itself as a *place*. This idea does not so much contradict other conceptions of the Internet but adds something to them. As an interactive space, it is inappropriately limiting to think of the Internet merely as text or a document, because documents or texts are by their nature static. Instead, web pages go through a variety of changes caused by the overlay of social interactions occurring through them, around them and on them. A consideration of facebook groups, forums and other online architectures as places, clusters of locations that are organized by users as unique constellations honors the agentic role of the user as maneuvering and organizing the internet as a place. As these constellations form and are (re)arranged the ways in which knowledge is produced and contested can be charted.

Such a perspective would render document interpretation alone ill-equipped to properly consider technologies that do more than merely convey representations, but function as a backdrop for a wider set of interactions to occur. To get a sense of how conversation operates, however, we must return to Hine’s chapter on how the internet may function as an artifact with social meanings and uses.

While blogs alone may be very similar to texts in that one writer speaks to a reader, the difference is that blogs are almost immediately commented on and visibly interconnected to a variety of other voices. What is confined and scorned in the margins are an interior element of what makes a blog. Bloggers are in continuous dialogue in the space they share both with their comments and in links to other online minor publications. Comments on blogs sometimes speak back to the blogger, but at other times lead to sub-conversations between commenters. In this use, the blog becomes something other than a text but a basis for conversation, in many cases, independent of the blog itself. This is why this essay uses ethnography to place marriage as a setting and an artifact instead of as a comprising text that can be analyzed independently.
C. **Discourse Analysis In Dorothy Smith and Foucault**

Dorothy Smith’s *Institutional Ethnography* details a method of data analysis that is heavily influenced by Foucauldian discourse analysis as well as by poststructuralist thought. Crucial in Smith’s thinking is that individual experiences are “embedded” in a broader set of “social relations”. As a technique of qualitative data analysis, Institutional Ethnography would force social scientists to cope with “how the local is penetrated with the extra- or translocal relations” (2005, p. 70).

Smith’s thinking on how ethnographic data should be thought about is then more clear in her later statement that while entire institutions and discourses are not visible entirely in qualitative inquiry, “they come into view only partially as they are explored from the standpoint of people who in one way or another are involved in them” (2005, p. 68). A data analysis method is then gained from her work. Discourses and institutional complexes are looked at clumps in the researcher’s own remarks on a given idea and in the subject’s remarks and logics. One instance that Smith uses is “mothering discourse”, wherein in one of her own studies, a series of attachments and assumptions become stuck to the implication of mothering (Smith, 2005).

Approaching Autistic people as a culture is an important methodological and conceptual transformation to “studying autism”, distinguishing this study from being merely a medical sociology or medical anthropology one. For this study, institutional ethnography will be useful to illuminate some major discourses circulating around and through individual and collective Autistic experiences, including: “the normal”, “the competent”, “community”, and “sensitivity”.

In Michel Foucault’s seminal *Archaeology of Knowledge* (2012), the base unit of discourse is explained to be the statement, a proposition which is historically and culturally located and is based in the connection of a subject or speaking voice, to the objects between
which a relation is cemented. A Foucauldian engagement with discourse would mean tracing the epistemic roots of speaking subjects back to the institutionally located propositions that give rise to their evocation as definitive social meanings. For this study, this looks like analyzing the presences or traces of outside institutions in the speech of the blogging and comment community and in turn investigating how those communities resist such institutions.

Sampling techniques used in the study of blogging cultures vary widely, but some reliable ways already used by researchers involve narrowing down available data according to levels of popularity, relation to key words that are common within a communal lexicon and through the identification of given categories within the blogging culture (Anahita, 2006).

To appreciate culture as a place or site from which social identities emerge and are managed through interaction requires that traditional sociological techniques for data collection and sampling are adapted to a new, virtual environment: the mass social media atmosphere of the blogosphere. Virtual Ethnography provides a platform for the analysis of blog entries as sites for a multiplicity of distinct voices to interact with one another and with the setting concretized of the blog entry itself (Hine, 2000). Virtual Ethnography inherits some of the critical methods utilized in other studies of media and text, while gaining from the ethnographic tradition a respect for cultures and their participants. To get a sense of how such an ethnography can take place, it will be necessary to specify the techniques and step-by-step processes used to analyze blog entries and comments by this study.

D. **Sampling the Autistic blogging world: Trawling**

For this study, data to be analyzed was selected via a two step-process: first, specific blogs were selected and second, particular entries published on these blogs were identified for analysis. For each blog entry was selected, the comments sections was considered as part of the text of the
blog entry to capture the dynamic interaction and negotiation of meaning about Autistic culture occur within the mediated, virtual space of the internet.

In describing the processing of passively observing the blogosphere before analysis, Hookway uses the term “trawling” to describe “a passive phase (in research)” of meandering through lengthy catalogs of blog entries. Long before my work formally called for me to specifically read blogs, my own curiosity as a scholar led me to engage in what I might call a more casual version of Hookway’s “trawling”. Like Hookway, I was first quite dazzled to discover the Autistic blogosphere and became immersed, but also this stage of absentminded browsing led to general and imprecise reading and sampling. First, I was exposed to the Autistic Hoya blog site. Autistic Hoya has introduced many people to the Autistic blogging world in part through her writing that seems to summarize common themes among the Autistic blogging world and through her all-embracing blogrolls (lists of links to Autistic blogs) that help to elevate the voices of her less public and respectable comrades in the Autistic blogosphere. Through clicking on many of the links on Autistic Hoya, it became apparent the number of unusual and distinct voices in the Autistic blogging community.

Using the list of blogs on the blog rolls of Autistic Hoya, it became clear that some blogs were quite popular and had large audiences while others with important content were smaller and less well known. Methodologically, blog selection reflected a process similar to that undertaken by Inahita in which both a popular and lesser known blog were each selected. It is important to note though that the categories of popularity and unknown-ness are situated based on the audience. What is not well known to the mainstream may be extremely popular within a cloistered enclave. This study does its blog selection based on what is known primarily by the mainstream while acknowledging that the choices made take place with an ear to what voices have already been vetted by the Autistic blog community itself. The goal is to cast a wide net that will include both some of
the more common conversation topics and those that are perhaps on the fringe but still a vibrant part of the autistic dynamic in virtual space.

The outcome of the blog selection process has been to select Ballastexistenz and Radical Neurodivergence Speaking. These blogs were selected to allow for a broad set of perspectives on autistic identity and to allow for opportunities for comparison and contrast. Ballastexistenz is a well-known blog that is regularly referenced in the Autistic blogosphere and identified as a site of cultural production in the disability studies literature (Manning, 2009). Radical Neurodivergence Speaking offers commentary on the writer’s experiences without care for finding the correct words. RNS’ work is sometimes profane and littered with swears but always holds people in power accountable, perhaps this is why it is popular within its own community but not well known in the mainstream.

The choice of Radical Neurodivergence Speaking as a less heard blog is motivated by three separate reasons. First, there is a hierarchy of disability that favors the participation of physically or visibly disabled people but silences and marginalizes psychiatrically disabled and mad populations (Charlton, 1998). As an Autistic blogger operating on the intersections of psychiatric, learning and developmental disability, Neurodivergent K becomes particularly unheard because her voice is often judged to be not respectable enough and the presence of or discussion of other impairments (such as epilepsy) as a major topic in her writing only further this. Second, Neurodivergent K flouts the norms of respectable language. Instead of writing about the general disability experience, K sometimes goes into extensive rants about her own interactions, gets heavily biographical, uses profanity and does not always offer suggestions for allies. Third, the overwhelming tone in Ks writing is anger. K is outraged very often, meaning that she lacks the quietly academic explanatory tone that makes Ballastexistenz so popular. Then, this essay justifies its use of blog entries from the prominent Autistic blog ballastexistenz and from Radical Neurodivergence Speaking on the basis of the need to speak to frequently heard arguments within the online autistic community as well as unusual voices and conversations. For the purpose of asserting the ways in which specific blog entries can be
chosen, next we will engage some sampling methods used by other researchers to sort for more specific topics on blog websites.

E. **Sampling the Autistic Blogging World: Filtering**

After selecting the blogs to analyze, the second step was to identify entries on each blog for analysis. To narrow down the analysis to a manageable size, a strategic combination of randomization and certain key criteria was employed. Across both blogs, I began by planning to choose one out of every four blogs within the chronological time frame X and Y. The goal was to capture a wide variety of topics with this sampling mechanism. After the initial selection, this randomization step provide inadequate because both bloggers sometimes authored entries that were not related to the topic of Autistic identity. For example, sometimes Ballastexistenz writes poetry and about the secondary medical characteristics which have caused the writer to be hospitalized. Also, Radical Neurodivergence Speaking sometimes writes blogs about specific arguments she has got into on the internet (such as quarrels with the skeptic community) or writes about her experience of epilepsy. Finally, other issues arise in these blogs, such as the blogger choosing to write an extended series of posts on a given topic or the failure of certain posts to attract comments.

Consequently, I used three criteria to evaluate the relevance of the blog entries that were selected into the sample: 1) relevance, 2) stand-alone, and 3) comment number. Relevance is established based on whether the arrived at post discusses autism or the Autistic community. I use the notions of stand-alone vs. series to discuss how some blogs function alone as a single point or argument and other blogs are part of a series on a given issue. While blogs that are part of a series are interesting, it would not be ideal to include a blog in a series in my analysis, because it would be included without the other parts of its series and would lack the context key to its meaning. Finally, all the blogs I’m using have at least 8-10 comments on them. This is an important threshold because 8-10 is an average number for both blog URLs. While the minimum number of comments on a post tends to be between 0 and 3, the maximum tends to be 20-30 comments. As a result, it would not be
ideal to use a post that did not have enough comments, because a major part of this analysis is engaging with interactions that go on among comments. Thus, the only blog posts I select are those that have at least 8 comments. While it is okay to go beyond this number, going below it would mean a lack of content for my research project.

When a blog entry was selected in the sample that did not fit, it was replaced to maintain a consistent number of blogs for analysis. Eight blogs was the number that this paper decided to study, for reason of depth in analysis. Replacements for blogs filtered out were found using the procedure already outlined earlier in this paper. Chronologically, the next blog following the removed one would be looked at and if that did not suffice, another would be found.

Following the sampling process, blog entries were systematically analyzed using the tools of Foucauldian Critical Discourse analysis. Foucauldian critical discourse analysis is crucial in considering how such blogs reflect on both the making of their own communities and on the larger macro-political environment. The coding schemes I use reflect two types of data analysis: Foucauldian critical discourse analysis for the entries themselves and Castellsian social network analysis for the comment sections.

F. **A Framework for Coding Virtual Ethnographic Data**

I code the blog entries according to the categories offered by Foucauldian discourse analysis, which themselves consist of medical knowledge “statements” which unite disciplinary knowledge groupings and counter-memories which reassemble these organizing elements of discourse such that they are widened and brought into continuity with communal experiences of body-history. While the two main categories used here for coding purposes seem to indicate diametric opposition between memory and discipline, these codes are used to assist in centering how Autistic blogs resist against the proliferation of clinical or medical discourses of Autism through parent organization, governmental and nonprofit based sources. While counter-
memories as a code ensconce the critical insights and alterations to dominant discourses of autism, the discourse of autism comes from no singular source but certainly finds its vocabulary in the canons of clinical psychology and psychiatry.

I code the comments according to the work Manuel Castells whose foundational book on information age social movements, *Networks of Outrage and Hope*, speaks to the use of symbolic online spaces for marginalized communal identification practices. I choose to term the communications occurring in the comments sections of these blog entries “networking” in part because of the internet processes going on but also because overwhelmingly, users do not find these comment sections without adding something positive and additionally, bloggers themselves carefully moderate commenting to make their blog conversations conducive to building communities and large followings. These features mean that primarily the comment sections are used for support, agreement, the sharing or evocation of similar stories and for hardening mutual connections. As most of the comments coded are overwhelmingly positive, the descriptions of the comments sections understand them as an Autistic space of openness, but one that is also guarded from the encroachment of co-opting forces.

In seeking to unearth the discursive formations that blog entries from the Autistic blogging sites, Ballastexistenz and Radical Neurodivergence Speaking, ply upon in their work of telling new stories about autism and autistic being, it will be necessary to draw upon some base terms that Foucault has used for the analysis of discourses and the subjugated knowledges that resist them. First among such basic terms is the concept of the statement as a unit for Foucauldian critical discourse analysis. In *Archaeology of Knowledge*, Foucault (2012) writes that:

*The statement is not the direct projection on to the plane of language (langage) of a particular situation or a group of representations. It is not simply the manipulation by a*
speaking subject of a number of elements and linguistic rules…a statement always belongs to a series or a whole, always plays a role among other statements, deriving support from them and distinguishing itself from them: it is always part of a network of statements, in which it has a role, however minimal it may be, to play…There is no statement that does not presuppose others; there is no statement that is not surrounded by a field of coexistences, effects of series and succession, a distribution of functions and roles. If one can speak of a statement, it is because a sentence (a proposition) figures at a definite point, with a specific position, in an enunciative network that extends beyond it. (p. 260)

In defining the statement so as to suggest that it is a legible point at which a network of other statements and co-existences as well as functions and roles manifest, it becomes possible to think of a statement as a key axis in a text. Foucault’s elaboration on the organizing as well as directing potencies of the statement help in that they provide a basis for seeing how a statement as a unit associates a pre-given subject with a set of pre-given qualities, actions and objects. The statement is defined in its discursive capability here such that statements that arrive from the area of therapeutic thought related to the condition of Autism can be excavated for their use and reassembly within Autistic blogs. While the arrival of such statements, out of a wider psycho-medical discourse of Autism will be traced, they will not be traced until after the crucial terminologies at issue in Foucault’s corpus are brought into being in this paper.

The next concept that will be brought into play will be Foucault’s notion of “subjugated knowledge”. In describing, and in turn, defining the concept of subjugated knowledge, Foucault says that he refers to “a whole series of knowledges that have been disqualified as nonconceptual knowledges, as insufficiently elaborated knowledges: naïve knowledges, hierarchically inferior knowledges, knowledges that are below the required level of erudition or scientificity” (Foucault, 2012, p. 264). I use this as a major code for the discourses of Autistic blogs instead of Foucault’s parallel concepts of counter-memory and counter-history.

The concepts of counter-memory and counter-history do not allow for the subjective histories of the body or allow for the unique channels of institutional experience. In these
Foucauldian concepts aimed squarely at a collective past, a continuity of maligned experience is ignored. “Subjugated knowledge” as a concept is more open and continuous as well as capable of addressing the ongoing occurrence of knowledge and experiences that run counter to institutionally certified knowledge systems. “Subjugated knowledge” is used then as a term to address the arrival of many recognized truths that would alter the meaning and constitution of Autism discourse.

Examples of these kinds of knowledges include disruptions to medical knowledge as well as disruptions to the political discussions of the political Autistic self-advocacy movement. In that the Autism discourse begins with a medical definition of the terms of Autism but that other organizations claim their authority based on relating to that initial definition, either through being diagnosed with it in some form, intervening against the impairments it describes, having to live with the burden of its subjects or attempting to cure it.

To close, it will be necessary to carry Foucault’s own mantra for discourse analysis as the chief command of the work going forward. Foucault says that what genealogy (and to me this is instructive for discourse analysis as well) should be is “a way of playing local, discontinuous, disqualified or non-legitimized knowledge off against the unitary instances that claims to be able to filter them” (2012, p. 253). This method of reading the blogs highlights how subjugated knowledges deconstruct the things that try to limit or doubt them. In engaging with discursive formations through their reassembly, it becomes possible to see how the setting for the building of networks is sculpted for shared senses of resistance and shared battles against conventional categories that is composed in due part by claims to oppression, self-descriptions and claims of community.
As this study is analyzing eight blog entries, four from the blogger Ballastexistenz and four from the blogger Radical Neurodivergence Speaking, there is a sharp divide in results, but what can be established is that all of the official statements that are cited by such bloggers originate from scientific expertise and official clinical designs that described autism but in that some of the cases described, the repetition of official logics in the discourse of autism are the result of further repetitions or extensions of the official discursive formation into areas such as family, political being, interpersonal presence and care of the body. Largely, however, the posts are split in either reacting to different assumptions about the limitations of Autistic social impairment or discussing how the personal pathology concept of autism eschews equality of citizenship. That the Autistic blogs randomly selected for this study contain content about either communication or functioning is instructive of how the hybridity of the category is comprised of a mix of periodic stigmas and permanent devaluation. Most of the chatter about Autism is concerned with communicative accessibility or with permanent devaluations of functioning, this proves in many ways that Autism is a hybrid between constructions of developmental and psychiatric disability. To deeply grasp these discourses and how they relate to institutional definitions of what makes an Autistic, the two sets of propositions will be analyzed in one section for each of the themes that will start with the statements hidden in the blogs but will excavate the official assumptions hidden within those invoked descriptions.
IV. ANALYSIS SECTION

Engagement with the discourses embedded across the Autistic blogs used here has led to the discovery of four distinct themes. The mercurial characteristic in networked spaces mean that identity contestations in the blogosphere are ongoing social processes, and are actions tied to community building. Blogging manifests a series of discursive moves wherein identity is negotiated and (re)stored. Specifically the blogs function to: 1) claim Autistic lives formerly dominated by psychology; 2) rearticulate the meaning of autism to a wider society; 3) redefine internal thinking on self-identity; and 4) realign notions of community to reflect Autistic norms and values.

A. **(Re) Claiming Autistic Communication and Autistic Experiences**

...the current theories of autism all involve us being terrible at nonverbal communication.

  - A Bunch of Stuff That Needed Saying, *Ballastexistenz*, April 2013

> You've heard that eye contact is about sharing and social referencing and subtle messages and cues being sent among communicative partners. That's not what this is at all...this is the safeword... When I was a very small little child, the first thing they tried to get me to do was "look at me". Now, if I was a small child now they'd be still coercing looking at them.

  - Forced Eye-contact *Radical Neurodivergence Speaking*, March 2014

Half of the blog entries analyzed were focused on grasping the dissonance between the mass societal conceptions of Autism (as isolation) and the Neurodiversity Movement’s¹ local knowledge of Autistic communication. The authors of both blogs wrote responses to specific public manifestations of ableistnormative conceptions of Autistic communication as

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¹ Neurodiversity is an extension of biodiversity which acknowledges that multiple different neuro-minorities might add to the evolutionary and cultural richness of humanity.

categorically deficient. This analysis highlights the discursive resistance to hegemonic conceptions of Autism within a clinical knowledge tradition extending all the way back to Bruno Bettelheim. In using clinical evaluations as their focus, Autistic blogs help to reverse the isolation claim hurled at Autistic people through arguing in effect, that it is the clinical view which has become removed from the actual realities of Autistic communication. In the displacement of deficient labeling, bloggers reclaim the communicative expressions otherwise rendered oblique.

1. **Isolation**

   Across the blog entries, the authors identify and react to essentialized, institutional definitions of Autistic communication, offering personal stories to illustrate the inappropriate “fit” of these concepts of autism with the lives of Austistics. As illustrated above, Radical Neurodivergence Speaking (RNS) reveals how the absolutist belief about the need to wrench the Autistic from isolation through mandatory eye contact have taught the antithetical lesson that eye contact does not mean friendship. Through this example she illustrates how the normative communication ideals on which these therapies are based are used to discipline, and in fact, punish Autistics such that the lessons learned are in fact counter to those stated goals of these therapies.

   Some of the institutionally held reductionisms revealed in the above statement include ideas conflating eye contact with communication and assumption of eye contact as the ideal result, no matter how it is achieved. This paper advocates for describing situations such as the one above as **equivalences**. In this context, equivalence refers to social situations in which dissimilar discursive objects are made to refer to similar meanings. Across cultural, national, and institutional divides, specificities in meaning secure the stability of various ideologies and set of
Equivalence becomes a frame within Foucauldian discourse analysis, to capture the invisible coercive work enacted upon bodies, minds and groups to erase the differences in perspective meaning and experience of objects or ideas in a favor of false unity. Identifying such moments is a central practice of Foucauldian discourse analysis, because they rediscover space where previous meanings have been ignored elided or buried.

2. **I/literacy**

Ballastexistenz’ (BE) offers another example of equivalence in her discussion of how assumptions about Autistic communication result in the erasure of uniquely Autistic forms of nonverbal communication. They reference how this occurs and then notes that it is predominant among Autistic activists calling for political change to “…(be) bad at nonverbal communication…” argues, “…their experience gets seen as applying to all of us”. BE disowns in this case, the work of ASAN and organizations like it that purport to represent Autistic political interests here. BE pushes back against the representational claim made by activists to knowledge and surrogacy for an Autistic counter public. In excavating the insability of representation inherent to Autistic communication, BE opens up the possibility that it is merely a series of gaps in flexibility between broader society and gaps in self acknowledgment by Autistic people. Consequently, Autistics are imagined to inhabit a unique form of communicative misunderstanding what we call here, *Autistic I/literacy*. In this form of I/literacy, real differences in communicative comfort and ability are conflated and misinterpreted as a unitary signifier for complete cultural, social, behavioral, and cognitive isolation. Autistic I/literacy functions to erase the specific differences of the communicative performances of individual

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2 Amanda Baggs is referred to as they because they have publicly indicated that they prefer the “they” singular pronoun to correctly gender them according to their genderqueer self-concept
Autistics. Instead it replaces these with an idealized Autistic person (representative of all Autistic people) whose communicative deficiency invalidates the right to self-expression, representation, determination, evaluation, and identification.

3. **Institutionalization**

One of the parts of Autistic extension, communication that is missing in the dominant paradigm is the shadowy threat and or spectre of the institution as it looms large in the individual and collective lives of Autistics. There are two ways in which this plays out in the blog entries in this analysis: 1) the link between reciprocity and friendship; and 2) the hierarchy-building around experiences of institutional abuse.

First, the normative social assumptions of reciprocity as a key ingredient of friendship cause some friends to be mad at individuals when they fail to have the energy to respond. Ballastexistenz summarizes their frustrations writing “it’s hard to deal with this in a world where people measure how much you care by how much you think about someone and stay in touch with them.” This problem implicates the clinical history of autism in the understanding of uneven communicative performances. Consequently, two hidden equivalences become manifest: 1) friendship as two-way communication; and 2) friendship as consisting of certain representative signs e.g. responsiveness, ritualistic greetings. Friendship takes on equivalent meanings when it is enforced upon Autistics that would seem to be counter to its idealized and normal meaning, but those new meanings are not in major defiance of the themes already present within it. While considering friendship strictly as two-way exchanges or as representative gestures perhaps would not occur to those within normate contexts, these meanings are not alien from those contexts either. As noted earlier, the threat of institutionalization that is attached to improper communication perpetually threatens the Autistic. Friendliness that is latently
omnipresent and expressed through very specific instances is perpetually deemed inscrutable within a normative set of expectations. The clinical history of Autism and the resulting construct of Autistic illiteracy stand in striking contrast to the ways that Autistic people express latent or subtle forms of friendliness.

A final statement that illustrates how Autistic social capabilities have been reduced within the dominant scientific discourse comes from Ballastexistenz’ post about experiences of institutionalization and harm. Discussions of institutionalization prioritize accounts of physical injury over the more quiet degradation. In the blog post, Ballastexistenz explains “…I’ve seen disabled people who compete with each other about things like this. They say that they, unlike so-and-so, had experience with real institutions. Or they, unlike so-and-so, had real bad experiences.” Even among disability advocates, the hierarchy of disability leads to the discounting or reduction of social experiences of devaluation and an emphasis on (often physical) qualification for claims true of oppression. This too is an example of clinical or medical assumptions (physical over mental/psychological and measurable over subtle) being repeated to the detrimental effect of atomizing and essentializing the complex interpersonal and social character of Autistic communication.

B. (Re) Framing the Autistic Body and Autistic Function

... of course people are again coming out of the woodwork to demand those of us who say "down with that sort of thing" walk in her shoes. They seem unaware that we, too, have shoes.
- Here, Try On Some Of My Shoes, Radical Neurodivergence Speaking, November 2013

When I was nineteen years old, my psychologist told me that I was not a real adult. He told me that by virtue of being in the system I would always be a child. And that this was actually true legally so he and my parents would always have control over me.
The dominant discourses of autism rely on antiquated notions of “idiocy” and more contemporary understandings of familial burden to erase the subjectivity of Autistics, resulting in an objectification and dehumanization of Autistic peoples. Furthermore, by virtue of being part of a class of people that is institutionalized (or at risk for institutionalization) Autistics are demoted to a lifelong, devalued status and autism is equated with permanent dependency legitimated by the state, educational systems, and biomedicine.

A number of the blog posts address the ways in which Autistic existence is actively devalued, beyond communication, but more generally on the basis of an assumption of inferior intellectual or social functioning. For an Autistic writer who is self-aware, the immense dissonance between normate plans for aging, normative assumptions about intelligence (such as its assumption of existing equally in academic and lifeskills), normative assumptions about familial identification as well as about life-meaning (such as its reliance connection with others instead of an obsessed about object) can be extremely overwhelming. Writing on this experience functions within the wider discourse of autism, to challenge those normate conceptions that invalidate Autistic embodiment throughout its every day manifestation.

1. **Autistic Shoes**

The quotation from Radical Neurodivergence Speaking, out of a blog entry dedicated to telling the disabled life-narrative of the writer, says in so many words, that Autistics are worth identifying with and parents who commit violent acts may not be worth feeling for. The quotation is a call to imagine an unusual life where the conditions of one’s situation are misunderstood and the lives beyond the walls of normative culture have a yet unexpressed value and meaning as well as continuity. Taking upon itself the goal of having public others identify with Autistic existence is to ask for a peculiar sort of empathy. This is the call that Radical
Neurodivergence Speaking makes, a call to identify with Autistics and against the acceptability and rationality of their death.

The positionality invoked within this argument resists the overbearing assumption written into the dominant bio/psycho/socio/medical framing of Autism: inevitable, perpetual loss. RNS reframes the argument about trying on another’s shoes by reminding the audience that, as an Autistic they too have shoes. Literally, the author is reminding readers that Autistics who were killed by their parents had bodies, experiences, perspectives and thoughts worth considering in the context of these cases and more broadly. RNS highlights how these deaths are emblematic of the cultural devaluation of Autistic bodies and lives, so that when those who are supposed to love and care (i.e., parents) instead execute, the killer’s perspective overwrites that of the killed. In her work, “shoes” then become a way to reclaim not only her own life by the collective communal life of Autistics that are under attack – these shoes are tools of resistance and reclamation.

2. **Autistics speaking for self and community**

Beyond recounting experiences from their own biographies, the authors also provided critique and response to the leaders of organizations about autism that are not for or by Autistics. These organizations develop and circulate ideas that devalue Autistic individuals – in part as a way to raise money for “cure” and “treatment”. This effort is led by family members and silences the voices of Autistics themselves and is most clearly portrayed in the violence of Autism Speaks. What the bloggers identify as “hatemongering”, are hegemonic biomedical narratives of the need to cure and normalize autistic impairment that are justified by continuing epidemic discourses that construct the emerging tide of Autistic children as a threat to normate society.
Rhetoric, such as that of Suzanne Wright’s, portrays Autism as a mysterious plague haunting the family. As a consequence, one that Autistic bloggers are highly precise in recognizing, Autism Speaks and Suzanne Wright are capable of only understanding Autism’s presence in the family as a two-dimensional problem, instead of as a set of experiences that could enrich family settings. Autism Speaks tries to turn a fairly neutral event in family structures (especially those in which multiple members have Autistic tendencies) into a threat to an imagined platonic ideal of the family unit. Radical Neurodivergence Speaking’s post is meaningful because it notes this equivalence of household instances of misbehavior with disorder and of local inconveniences with global epidemics.

The devaluation of Autistic bodies occurs at multiple levels including the level of semiotics in which attempts to refer to oneself through language are policed remediated and normalized so neurotypicals can make sense of autistics, separate from their own expressed reasoning for self-identification. “And not a day goes by that some parent or professional doesn't read the responses and say "put the person first! Person first language! Person living with autism!" The equation here is of Autism as a thing exterior to one’s selfhood and of the need to use language that separate’s one’s personhood from disability words, lest the selfhood be damaged. In this correction there is a deep irony, that an exterior voice uses the expectation of personhood’s expression according to certain norms to devalue the power of Autistic self-definition. Autistic as a self-identifier has a specific meaning for Autistic people, as it approaches the ways in which Autism inflects everything about the person, from their movement, to their health, to their communication, to their interests, and finally in regard to their thinking on selfhood.
C. **(Re)Phrasing Autistic Subjectivity and Community**

...Someone who understands intuitively... is worth their weight in something way more valuable than gold.

- What Autism Really Is, Radical Neurodivergence Speaking, November 18, 2013

...I was already involved in the autistic community. People in that community helped me (with a lot of help from my family) get onto SSI and move into my own apartment. They literally kept me alive by painstakingly helping me eat enough that even if I was starving I wasn’t dying. And when after several months of starvation and other ugly stuff I applied for developmental disability services they helped me and my family through that process as well.

- On (Not) Having A Guardian, Ballastexistenz, March 1, 2012

The broadest argument contained in the work of Autistic bloggers is has nothing to do with being high functioning or needing rights, but rather describes alternate ways of living, knowing and communicating. From this perspective, being happy is grounded in a self-aware and nuanced, firsthand knowledge of Autism rather than broad medical overtures of deficit and pathology. Consequently, Autistic bloggers begin to outline a definition of disabled life through disabled community; Autistic bloggers both define *personal life* through community and *community life* through personal experience. The duality expressed in this writing forms two interrelated parts of a chain-like connection between group identity and personal identification. The work of Autistic self-definition is nearly exclusively an effort of confiding hidden impairments and abuses previously inflicted while discussing how these experiences offer an altered social world. Admitting these difficulties without accepting them as “tragedies of selfhood” but rather reframing them as structural violence is an important process in shaping the narrative of Autistic selfhood. Additionally, by controlling the narrative the authors are able to identify how these experiences are made worse by communal silence, lack of structures and veritable dearth of publicly expressed solidarity. These, in turn, become motivations for the
stories they tell about their experience, both as interpersonal liberation and public modeling and community building.

1. **Sharing experiences to create community/space**

   As an example, in Radical Neurodivergence Speaking’s “conditioned eyecontact”, Neurodivergent K mentions how “One of the deepest conditioned things I have is "eye contact is giving in…This is irrational…It's deep, though, as the first …of the wrestling matches I had with adults as a small child.” In telling this story in the context of interpersonal normalizing practices intended to produce a fixed or rehabilitated Autistic person, K places her personal vulnerabilities as a consequence of conventional systems and assumptions about socializing made by the clinical majority.

   Another example of this description of clarity problems in regard to the majority reaction can be found in BE’ “my worst social trait”. In their blog, they note that they often cannot maintain communication with people throughout long periods of time, but that this is not strictly a problem for only the writer to deal with in themselves but an issue remedied by “some very tolerant friends… who [don’t] take such lapses in contact personally”. In laying out the problems of Autistic impairment as not strictly bodily, but socially created, both BE and K lay out the potential for another world. K offers the possibility of a world where Autistic aversion to eye contact (in part as a result of cultural normalizing procedures and therapeutic programs) is not punished and Baggs, one where aversion or inconsistency of communication is not unexpected, but can yield to a sense of latent caring. In another of the posts located here, Baggs takes a different approach, noting that living in the community, as person that has multiple impairments is the result of her relation to the disability community.
2. **Community interdependence supports autonomy**

In describing their situation of having self-ownership and independence because of a strong community, Baggs illustrates that the description of personal difficulties as communal is different than merely blaming one’s problems on inaccessibility. Personal difficulties can be a route to interfacing with community and reliance on community support can be a path to autonomy. Baggs description of the community response to a personal problem allows us to imagine that even a dedicated digital group that shares information effectively can replace traditional social services. In reimagining gaps in individual support in terms of the interdependence of disabled social groups, it becomes possible to imagine a more collective and less atomized future.

D. **(Re)aligning Notions of Autism and Community**

*These are the shoes I wear to go help other Autistic people. ... These are the shoes I wear to go do things so my mind doesn't crack under the hopelessness of it all. ... These shoes are falling apart at the seams, but they're mine.*
- Here, Try on Some of My Shoes, Radical Neurodivergence Speaking, September 8, 2013

*I was writing about my favorite communication ever, my video chats with AnneC ...I can see the patterns of movement in other people, including cats, whether or not I see them well in the usual forms of visual perception. And those patterns of movement tell me more than any word ever could.*
- A Bunch of Stuff That Needed Saying, Ballastexistenz, April 18, 2013

In seeking the validation of community, the goal for Autistic activists is essentially to disprove the anti-social thesis of autism, to prove that community and interpersonal relationships are possible between Autistics as well as between Autistics and non-Autistics. Further than just disproving over-emphasized pathology claims, the drive to Autistic community is also a drive toward political power. In this drive toward community, a crucial goal is the redefinition of the personal using that community power. In contradiction to the ways in which personal experience
is used to redefine community, Autistics also use community to reshape how individuals exist in the world.

One of the first examples of this knowledge process that will be brought up in Neurodivergent K’s entry “What Autism really is”. In this post, K writes: “Autism is friendship, the kind you can only have when you meet someone who is like you… Autistic people know how special that is, because it is rare.” In writing such, K opens up a definition of Autism that charts an Autistic life in terms of the practice of seeking rare examples of people who share like traits. The personal becomes much less tragic and doomed in this theorization, but more about elusive moments of happiness. Further explanations of this description of Autistic personalism in terms of rare intuitive connection happen in K’s post favoring what has been called identity-first language. In the simple call for those listening to end their arrogance and listen to an “us” that was heretofore not in existence. In doing so, K uses the credibility of the group identification with being Autistic (instead of “with autism”) as a motivator to listen the loud particulars who are very often casually ignored. In asserting a multi-person “I” and a group “us”, K invokes histories of identity based politics to increase the validity of isolated Autistic positions and opinions.

While K commits to the work of making Autistic community through claims of identification, solidarity and unity, Ballastexistenz tends toward a more critical position in regard to even officially claimed Autistic ways of knowing and being. In asserting a self both within and obscured by the mainstream of Autistic political rights conversation, Baggs helps to illustrate how community can represent simultaneously new openings and new disruptions.

For example, RNS shows the arguments of the community can cover personal differences, especially in the case of the Autistic community. Instead of affirming their part of
the Autistic community, Baggs critiques the Autistic communities argument that “many people who are thought not to be able to use or understand language, actually are”, instead embracing identification with developmentally disabled community and the idea that “There’s entire subgroups of autistic people out there — not just my own — who rely on nonverbal means of understanding the world, and nonverbal means of communication.” In revealing specifically the sub-communities pushed out by the mainstream and contributing an alternative perspective, Baggs shows that the notion of what is community is dynamic. The Autistic community need not rely on respectability oriented simplifications of Autistic experience; Autistic activist politics can move toward conceiving of its community as comprising multiple overlapping sub-groups whose needs and political voice shift.

In a final critique, BE once more shows how community representation cannot speak the truths of the particular, instead admitting that “Nobody will ever be able to pinpoint the institution that inflicts the worst of this sort of damage on its inmates, because this sort of damage is, by its very nature, secretive, even from the person it’s being inflicted upon.” In such a critique of the tendency in the Autistic community toward overwrought accounts details the harms of specific institutions and therapeutic practices, Baggs reaches out to a notion of community as not always about what can be known or said, but as a hidden alliance made of unspeakable experiences. Reaching toward the quiet traumas of the institution as they are present in the lives of disabled people, BE seems to emphasize the subtle epistemic and ontological weight of the institution---an effect that cannot be accessed through sensationalist claims about specific practices, but may be better captured through reference to the loss of agency present in the threat of institutionalization itself as well as the void of agency experienced in the throes of
an institutional architecture where the day-to-day must consist of silent compliance and surveillance.

In redefining the personal based on what can or can’t be known through community, RNS and BS not only disprove the isolation thesis of Autism but show how even the metanarratives of political rights agendas around autism can correctly and mistakenly shape the individuality of Autistics.

In concluding the Foucauldian discourse analysis of Autistic blogs, it will be important to emphasize how the blogs themselves are based in a rupture between official discourses and counter-narratives that allow the public a space of open identification. In setting the terms of the Autistic blogging space through a series of conflicts with dominant discourses of Autism and community, Autistic bloggers’ BE and RNS actualize an invitational rhetoric of open identification, deconstructing the labels and stereotypes normatively attached to Autism and offering the possibility for the commenting community to share experiences without necessarily sharing exact diagnoses.
V. DISCUSSION SECTION

This paper relied on a Foucauldian discourse analysis method and disability studies perspectives to examine positional texts of Autistic people mediated through the blogosphere. In part, this research was out of necessity – this is where these conversations are happening – and in part, it was meant to be instructive, to incorporate these previously unheard conversations into the official records of academia. The new concepts, which have needed to be synthesized to ease the translation of these blogs into the academic context, reflect the realities of Autistic people in the contemporary time. The first concept, which must exist to justify the method of this thesis, is that of the blog as a prosthetic element for the Autistic. I have referred to this idea in my note earlier in this essay when I mentioned the advancement of networked technologies in parallelism with the appearance and presence of Autistic people. Another concept, Autistic I/lliteracy refers to the ease of communication between Autistic people that is often misunderstood as clinical deficiency by non-Autistics and professionals. The final concept, Equivalence, approaches how symptom terminology can be attached to Autistic bodies and acquires new meanings through that attachment. In explaining these new concepts, the hope is to offer some insights produced in this paper that may be valuable for later research.

A. Blog As Prosthetic: Alternative formats of engagement

An important contribution made in this paper in the methods section is the argument that Autistic (and likely other disability) cultures can be located on the information or communication networks instead of in physical places. It is important to emphasize the ways in which information technologies that have seemingly developed parallel with the institutional science and politics of Autism have liberatory possibilities and applications to extend Autistic abilities to communicate in novel, alternate ways that create community identity and support self-
identification as Autistic. While Autistic in-person meetings do occur, internet and other types of communication networks provide a way to establish a place for such individuals to interact without worrying as much about violating subtle interpersonal rules and structures underlying communication. The blog form is uniquely suited to the Autistic cultural form known as the “info-dump” or the rant. It can be thus argued that the digital Autistic community supplements a real omnipresent lack of in-person community in Autistic lives, not only because of impairment, but because of the continuous misunderstandings between Autistic and non-Autistic people.

**B. Autistic I/literacy: Double Misunderstanding and Self Knowledge**

Autistic I/literacy with its slash is utilized to bracket out the ways in which even deficits in communication on the part of the normate and Autistic subjects imply specific or situated knowledges (Haraway, 1988). The double un-knowing of Autistic I/literacy seeks to question the lack of knowledge on the part of Autistics around non-Autistic communicative norms and on the other side, the lack of knowledge on the part of non-Autistic people about Autistic communication norms. However, each of these gaps in understanding implies a certain kind of knowledge of the other side of those gaps. Autistic people display exceptional literacy about their own ways of communicating, this is why the “I” in illiteracy is separated from the other parts of the word.

The doubling of misunderstanding as well as self-understandings is then at the core of the concept i/literacy. While Autism is sometimes portrayed through a deficit model, i/literacy places the communication problem largely in an intercultural misunderstanding between Autistic types of communication and neurotypical or neuronormative communicative forms. Ballastexistenz and Radical Neurodivergence Speaking emphasize the gaps in normative understandings of how Autistics should communicate as well as failures of representation of the
complexity of the Autistic community by Autistic activists themselves. While some psychologists might attribute these problems to pathology alone, pathology fails to explain why the blogger’s studied here also highlight moments in which Autistic people are better able to advocate for their own communicative needs than their supposed allies who are non-Autistic.

A large part of the work done by Autistic activists has been to invent a context for Autistic communicative culture to be displayed. This is why Ballastexistenz is revolutionary when they highlight Autistic nonverbal communication as an unrecorded real thing and this is additionally Radical Neurodivergence Speaking’s articulation of an Autistic “I” is so needed. The critique of Autistic activist misrepresentation of Autistic communicative competencies and variety is a critique inherently of the integrationist tendency in the political rights model used by Autistic Self-Advocates. In making Autism a more simple thing as well as in encouraging the savant stereotype through references to hyperlexic savantism over developmentally, intellectually or psychiatrically disabled and limited existences, disability rights activists have aimed to cleanse the popular media image of the Autistic to fit their agenda of respectability and in doing so have marginalized certain impaired members of their movement. Autistic I/literacy is a cultural gap but also a gap caused by the broadness of diagnosis and the diasporic nature of Autism as well as the tendency toward self-identification with normative communicative tropes by Autistic people. In using social scientific as well as cultural studies methods to locate a cultural gap in communication between neuronormative and Autistic people, the goal here is challenge the often one sided approach often used to think about disabled ways of communicating.

C. **Equivalence: Referential Exchange Among a Communicative Minority**

Equivalency uses Foucault’s theory present in Archaeology of Knowledge of how a single statement elicits a series of other words in reverse. A series of other words equate to a single
statement and a single statement in its widening to those other words must make several stops along the way. In slowing down Foucault’s history of ideas such that it must linger on single terms, one of the purposes of the writing here is to reconnect discursive thought with its semiotic and linguistic histories. Equivalence also draws upon Baudrillard’s theory of symbolic exchange, but somewhat more selectively, implying that within Autistic cultural contexts, words take on meanings that they may not elsewhere in accordance with the moves made to define and redefine subjects politically. It can be seen that the equivalency discussed here refers to how subjectifying discourses, once embedded in the bodies of a given type of political subject (such as the Autistic subject), gain other meanings through the specificities of their historical and bodily contexts. The equivalence being spoken of here is then quite different from Baudrillard’s because it is an ontological equivalence that moves through historically re-occurring bodies and bodily positions. Baudrillard in his magnum opus *Symbolic Exchange and Death* describes equivalence as “the regulated exchange of a referential content” (1993). Discourses are equivalent as they co-mingle with one another. Baudrillard’s formulation assumes all equivalence occurs on a horizontal or equal plane. Equivalency in the context of a communicative minority involves the reclamation of language to fit a more minor end. In this sense, it gets at how aspects of the wider socio-political scientific world become part of Autistic cultural conversations, but only through being translatable to those situations and their uses. Autistic I/lliteracy and Equivalency mediate one another to the extent that I/lliteracy prevents an overload of signs and communications, but equivalency allows some drawing upon the outside world and its concepts. Equivalency is thus the discursive pattern by which extra-Autistic community things and terms take more local meanings. The meaning of equivalency is also strengthened by a realization of the prosthetic function of networking for the Autistic community. As noted earlier, Autistic communities
utilize digital spaces instead of in-person communication to close gaps left by isolating sensory and communicative spaces.

This overall project’s investigation of Autistic blogs through virtual ethnography has without doubt yielded many truths long hidden by the tendency of scholars to eschew the blogosphere for its lack of formalism. Processes of Autistic identification and group formation in resistance to normalizing institutions arrive plainly when they are observed in the language of Autistic bloggers. Likewise, from observing this source, important ideas in thinking about Autistic identity have been presented. Some of these ideas include equivalence, Autistic i/literacy, blog as prosthetic. Some of these concepts should introduce a new conceptual language for thinking about the development of disability culture in networked society. This study concludes with the hope that more research projects will take on the blogosphere as a site for the transmission of disability culture and community.
WORK CITED


VITA

Education

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Publications

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Presentations

“Intersectionalities in Autistic Culture(s): A Discussion Instigated by This Posse of Autistics and Friends” discussant at Society for Disability Studies Conference, Orlando, 2013

“(De)Stabilizing Crip Theory: Anti-Normative Intersections in Anarchist, Marxian, Disability, and Queer Theories” Co-presented with Matt Eichler at Society for Disability Studies Conference, Orlando, 2013

“Narrating the Neuroqueer: On the queer politics of disability culture” co-presented with Elizabeth Grace, Elizabeth Hassler and Melanie Yergeau at Queer Places, Practices and Lives Symposium, May 16-17 2014, The Ohio State University, Columbus Ohio


“The Discursive and Cultural Implications of the Popular Use of the Term ‘Crippling,’” PCA/ACA National Conference, Boston, MA 2012.