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Voices of Belonging: Building Community Among Autistic Adults

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Voices of Belonging: Building Community Among Autistic Adults

DISSERTATION

submitted in partial satisfaction of the requirements
for the degree of
DOCTOR OF PHILOSOPHY

in Anthropology
by
Heather Thomas

Dissertation Committee:
Associate Professor Keith M. Muprhy, Chair
Professor Victoria Bernal
Professor Tom Boellstorff

2018

DEDICATION

To

my mentors, loved ones, and colleagues

"Everyone has his or her own way of learning things," he said to himself. "His way isn't the same as mine, nor mine as his. But we're both in search of our Personal Legends, and I respect him for that."

Paulo Coelho, *The Alchemist*

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Thomas, Heather, "Storying Autism." Composition Forum 39.1 (2018). https://www.compositionforum.com/issue/39/storying.php

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ABSTRACT OF THE DISSERTATION

Voices of Belonging: Building Community Among Autistic Adults

By

Heather Thomas

Doctor of Philosophy in Anthropology

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Professor Keith M. Murphy, Chair

This research project is an ethnographic study of the communication technologies and social practices that enable the formation and maintenance of community among adults with autism, a group that is widely dispersed across online and offline spaces. This study focuses on adults who self-identify as autistic people and explicitly claim membership in an "autistic community." Autistic people are still typically understood to be asocial and socially uncoordinated, making the very notion of a community of autistic people, and efforts to continue its development, a significant challenge to enduring beliefs about what autism is, how it works, and how people with autism operate in the social world. This study employed ethnographic research methods, including participation in online and offline groups and spaces that autistic adults use regularly and interviews, to learn about three key things: First, this research entailed exploring how autistic community and the social practices and communication technologies that facilitate its continued development, both online and offline, demonstrated the ways various forms of expertise on autism interacted with — and were contested by — the lived experience of autism and autisticness. Second, I sought to learn what a "community" of autistic adults looked like and how it might work online and offline. Here, it was important to examine the inclusionary and exclusionary practices of the autistic spaces in which I studied. Finally, this research investigates the ways that sociocultural identity and self-knowing intersect with the ways people resist, transform, and reify the various classifications they are assigned to and accept. This study highlights the ways that cultural discourses of autism, autisticness, and normalcy shape autistic people's interactions with one another and the broader social world.

INTRODUCTION

This dissertation explores the construction and maintenance of autistic identity and community among adults in the United States, in three Southern California social activity and support groups, and online, across three social media and network platforms. In this study, I focused on the social practices and communication technologies that helped my interlocutors develop the sense that they were autistic and belonged to a singular but widely dispersed community of autistic people. I concentrated my research on adults who explicitly self-identified as autistic people and claimed membership in the autistic community, and I explored online and offline groups and spaces where my interlocutors congregated and exchanged with one another.

I was attracted to this study on autistic adults not only because of its timeliness. When I began preliminary research, the American Psychiatric Association was releasing news of its latest revisions to the *Diagnostic and Statistical Manual of Mental Disorders*. These changes entailed a dramatic reformulation of the autism classification and other diagnostic labels that were understood to be closely related in symptomology and etiology. Asperger's syndrome, childhood disintegrative disorder, autistic disorder, and pervasive developmental disorder not otherwise specified were essentially decommissioned, while people who followed the changes were reminded that Rett syndrome was never really part of the autism "spectrum," as psychiatrists once believed. My own experience receiving an Asperger's Syndrome diagnosis in my early twenties, in combination with approximately six years of work in an autism behavior clinic in a southern California public school district also sparked my interest in what it might mean to be an autistic adult. On reflection, I have been involved in the "community" in which I conducted my research for more than ten years. Though my diagnosis was questioned and later removed by my physician toward the end of my research period, I remember feeling confused and fascinated by the 2013 *DSM* changes. I made sure that my interlocutors understood that my research had deep, personal significance and shared with them my diagnostic status and musings on autistic identity and autism classifications often. Interestingly, this transparency was an important "in" when it came to studying the groups that I chose. These offline groups were not always keen on the idea of non-autistics entering the space, especially for the purposes of researching autism. Essentially this project was driven forward not only by academic curiosity, but by my own sense of entanglement. This entanglement was not always easy to manage, particularly after I received news that I might not have been autistic after all. Still, it bolstered my sincere appreciation and deep respect for my interlocutors and friends in the community spaces I selected.

For decades, anthropologists and other social scientists and philosophers have highlighted the significant impact that researchers' positionalities and perceptions have on the kinds of things researchers looks for and sees in the field, and on the kinds of things they are inclined to inquire of in general. With this in mind, I understand that the data and propositions that I present in the following chapters are generated by a combination of innumerable life conditions, social experiences, perspectival blueprints, and observations that I have collected over the years.

RESEARCH PROBLEM

In spite of major changes to the autism diagnostic classification and the rise of neurodiversity rhetoric in autism discourse in the United States and online, many still assume that people with autism are inherently and problematically asocial or socially uncoordinated (American Psychiatric Association 2013; ASHA, n.d.). In fact, this supposed lack of coordination marks the separation between desirable sociality and faulty autistic sociality, and it is the cornerstone of the autism diagnostic criteria. Therefore, the existence of an autistic community and its ongoing developments calls into question popular presuppositions of what autism is, how it works, who counts as legitimately autistic, and how people with autism operate in the social world. Furthermore, having observed a significant increase in adult self-diagnosis of autism spectrum disorder in autistic spaces, I cannot help but wonder what kinds of accommodations autism (as a classification) and autisticness (as a way of being in the world) offer self-diagnosed people that notions of neurosocial normality do not.

Ultimately, I was guided in this investigation by three primary research questions: (1) If autism is inherently a condition that is typified by impaired communication and introversion, how and why do individuals with autism work together to form dynamic and complex groups of autistic adults? How are these diverse online and offline group spaces maintained over time? (2) How are my interlocutors' autistic identities and subjective and intersubjective experiences of autism mutually constituted through their participation in different kinds of autistic spaces? (3) How might my interlocutors' conceptions of expertise on autism shape, guide, or constrain their modes of participating in their autistic groups? How might they influence how they address their target audiences and maintain the sense that they belong to a broader autistic community. Beyond these things, how do these notions of autism expertise and self-knowing inform the kinds of personal narratives that they develop and the ways in which they embark on and reconcile with circumstances that demand narrative revisioning, the sometimes dramatic and surprising reconfigurations of what we relay to ourselves and others as the stories of our lives? In the following chapters, I aim to address these questions by sharing data from my field sites and my analyses of the examples I share.

This research brings into conversation autistic adult and psycho-medical perspectives on autism and the nature of legitimate autisticness, even as it engages with concerns about the sociocultural mediation of intrapersonal and interpersonal communication. By studying adults with autism ethnographically, situated in their own social worlds rather than in the clinic, I wanted to help enhance available models for understanding what autism is and how autistic people understand themselves in relation to pathologizing classification systems that prioritize narrowly bounded notions of normality. In addition, I wanted this study to emphasize the vital importance of rhetoric in shaping my interlocutors' self-concepts, understandings of what it might mean to belong, and approaches to resisting cultural narratives that promote widespread fear and hatred of autism and autistic difference.

BACKGROUND

The American Psychiatric Association (APA) and US Center for Disease Control and Prevention (CDC) categorize autism as a neurodevelopmental disorder and disability that presents with impaired social interaction (APA 2013, CDC 2018). In March 2014, The CDC reported that approximately 1 in 59 young people, more than 50,000 people under the age of 21, are diagnosed with autism. This is a dramatic increase from the 1 in 150 children believed to be autistic in 2000. Importantly, these figures do not account for individuals who have received diagnosis in adulthood, as I did, increased focus on detecting and curing autism, and people who have limited access to diagnostic professionals (as many self-diagnosing adults experience).

Because autism is recognized as a life-long "disorder" that emerges in early childhood, few studies have explored autistic sociality in its own right, seeking to understand the perspectives, needs, and desires of autistic people. Studying adults on the autism spectrum opens up opportunities to explore these things as people in this population have been ardent advocates for autistic acceptance and rethinkings of neurosocial normality, entreating non-autistics to approach atypical neurology and sociality with a sense of wonder rather than fear and condemnation. This project was therefore specifically aimed at investigating the underexplored population of adults with autism, from a non-clinical perspective, to understand their particular practices (e.g., self-advocacy and narrative exchange), needs (e.g., for community participation, senses of belonging, and narrative coherence), and expertise claims (e.g., living as autistics).

This project expands on a small but growing body of social science and humanities literature that examines the ways that autistic people actively participate in their communities and personal relationships (Ochs et al. 2004; Bagatell and Solomon 2010; Eyal 2010; Yergeau 2018). In spite of growing interest in community and identity among adults on the autism spectrum, the majority of social science research on autism is grounded on psychological and biomedical inquiries that seek to root out the causes of autistic failures to communicate and interact with the social and material world in expected ways. Consequently, the bulk of social science literature on autism focuses on the social experiences, cognitive processes, and language use of individual people (usually school age children and teens) with autism and the ways in which we might collectively approach the problem of inclusion and accommodation of autistics in spaces that were not constructed with their needs in mind. Few studies, though the number is growing, explore autistic sociality with the presumption that it is rich, productive, complex, and powerful in its capacity to highlight cultural biases surrounding issues of biomedical expertise and the assumed insufficiency of those pathologized by its implementation.

As my research period came to an end in 2016, I realized that I embarked on this study of autistic identity and community at a remarkable time. Even though most social science research on autism has continued to rely on medical models of the classification, assuming that it is inherently problematic and rooted in dysfunction and incompetence (rather than function and competence) and not what might possibly be a natural expression of neurosocial diversity, I saw a marked increase in the number of scholars toying with the notion of neurodiversity and the implications it could have for our cultural narratives of deviance and disability.

Autistic Fears and Fears of Autism

In the United States, parent advocacy organizations and news media have claimed that the nation is experiencing an autism epidemic and launched a war to conquer and eliminate it. Such claims have contributed to increased federal funding for research on autism, which focuses primarily on studying the genetic and physiological aspects of the condition in order to ascertain its causative genetic and environmental factors. Physician Brian Moench (2014) claimed that the increasing rates of autism diagnosis in the U.S. pose a remarkable problem because the rate of autism diagnosis in Europe has virtually stabilized. Moench (2014) asserted that the issue is rooted in the U.S. population's exposure to increasing levels of environmental toxins. Parent-driven autism organizations (e.g., Autism Speaks, Autism Research Institute, and Defeat Autism Now) are key supporters of research on genetic and environmental factors as well as curative possibilities. Importantly, few gains have been made in isolating the particular endogenous and/or exogenous causes of autism. By and large, the genetic and environmental etiology models demonstrate how complex autism and its symptomology really is (NIH 2017; Whitehouse 2016; Autism Speaks, n.d.)

Since 2006, national autism research and treatment initiatives in the United States have been developed, reinforced, and amended to grow autism research programs and extend the reach of existing and emergent autism support programs for families, as well as adults with autism (McGuire 2016). In California, the Department of Developmental Services (DDS) is partnered with public and private organizations to provide low-to-no cost autism screening services, augmentative and alternative communication devices (AAC), after-school programs, and employment training. Critically, autistic self-advocacy organizations have also worked to provide services for people with autism and their families. Autism Self Advocacy Network (ASAN), the Association of Autistic Women (AAW), and the National Council on Disabilities (NCD) have developed professionalization workshops, self-advocacy training, healthcare and employment opportunity databases, and local social support groups. In addition, these self-advocacy organizations clash online and offline with parent-driven organizations, arguing against continued focus on raising awareness (if it is not accompanied by fiercely advocating for of autism acceptance), determining autism etiology, and curing autism. Autistic activists claim that these foci have been foundational to creating a culture of fear and blame around the condition and fuel eugenic inclinations (Sinclair 1993; Ne'eman 2009; Mead 2017).

For my interlocutors, who were usually born to non-autistic parents and families, finding social connection with and perspective affirmation from others who share similar experiences required that they take decisive actions. These actions entailed creating online and offline spaces and groups for autistic people, sharing personal accounts that would be subject to the scrutinizing eyes of non-autistics, and challenging typical representational modes for autism to expand cultural imaginations of what it means to be on the spectrum. Frequently, my interlocutors took this action within an immediate social world that was full of non-autistic others who explicitly resisted and denied the validity of their lived experiences. In spite of this challenge, they sought to connect with each other however they could, online and offline, fostering a rich and meaningful social life for people who claim membership in the autistic community. Importantly, the richness and meaningfulness of their social life and forms of engagement did not need to be measured against typical forms and assessments to be valid and productive. I hope that the examples and analysis I present in the chapter "Learning to Be Autistic" helps this point show through.

An Overview of Autism in the Diagnostic and Statistical Manual

In the US, autism was first indicated as a distinct diagnostic category in the *Diagnostic and Statistical Manual III* (*DSM*) (1980), which had it labeled "Infantile Autism" (American Psychiatric

Association 1980). The revised edition of the DSM III (1987) renamed the condition "Autistic Disorder," elaborated on the diagnostic criteria and protocol, and linked the category to Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS), which was to be used when the criteria for Autistic Disorder and Schizophrenia or Schizoid Personality Disorder were not met (American Psychiatric Association 1987). With the fourth edition of the *DSM* (1994), Asperger's Syndrome was explicitly linked to autism, and the definition of autism shifted as Pervasive Developmental Disorders (PDDs) were redefined as an umbrella term that contained Autistic Disorder, Rett Disorder, Childhood Disintegrative Disorder, PDD-NOS, and Asperger's Syndrome (American Psychiatric Association 1994). The text revision of the *DSM-IV* (2000) introduced the notion of Autism Spectrum Disorders (ASDs), making it synonymous with PDDs (American Psychiatric Association 2000). Finally, the *DSM 5* (2013) included major changes to the category of ASDs by making it a singular catch-all for PDDs (American Psychiatric Association 2013; DeWeerdt 2011).

An Overview of the History of Autism

The term autism has not always referred to a distinct diagnostic classification. For approximately 50 years, from the 1910s to the 1960s, physicians used the term *autismus* or autism a to describe the apparently asocial behavior of children and adults with known psychiatric and developmental disorders like schizophrenia and intellectual disability (Eyal et al. 2010). It was first used to describe self-isolation in people with schizophrenia. Between 1910 and the 1980s, several psychiatrists and psychologists have influenced the development of autism into a discrete classification in Europe and the United States. These clinicians and researchers include Eugen Bleuler, Leo Kanner, Bruno Bettelheim, Hans Asperger, Lorna Wing, and Uta Frith. The development of autism into a distinct classification links to broader conversations about the relativity of disability, as a physiological condition and social reality that is produced through interrelating social processes. Additionally, this history is relevant to anthropological concerns about the meaning and use of formal classification systems.

In 1910, Swiss psychiatrist Eugen Bleuler coined the term *autismus* to describe the intense social withdrawal of his patients who had schizophrenia (Waltz 2013). Bleuler's use of *autismus* influenced psychiatric research on autistic behavior, and the belief in an autism-schizophrenia connection that pervaded psychiatric research until the 1940s, when alternative theories emerged (Silverman 2012). In the mid-twentieth century, psychologist Bruno Bettelheim, then director of the Orthogenic School at the University of Chicago, determined that autism was caused by disrupted ego development. Ineffectual mothering, Bettelheim suggested, caused this ego dysfunction (Eyal et al. 2010). Bettelheim made the controversial argument that mothers of children exhibiting self-isolating behaviors lacked warmth and affection from their mothers, whom he labeled "refrigerator mothers" (Silverman 2010).

In 1943, United States psychologist Leo Kanner began using the term autism to describe self-isolating behavior in children. Kanner labeled this phenomenon "autistic aloneness" (Capps and Sigman 1996). Since the 1940s, Kanner's notions of autistic self-isolation and autistic aloneness have been most influential in both Europe and the U.S., becoming the hallmark characteristics of the autism classification, which was established in the 1960s when researchers and clinicians determined that the condition was rooted in neurology (Eyal et al. 2010). Between the early 1960s and early 1980s, following the recognition of autism as a separate diagnosis, psychiatric researchers and practitioners developed treatment programs that focused on altering cognitive processing. These programs typically emphasized the use of pain as means of discouraging non-normative behaviors, mood-changing chemicals in order to alter brain chemistry and achieve desired behavioral effects, and electric shock methods intended to alter brain electrical systems that were thought to be imbalanced (Waltz 2013; Silverman 2012). As disability rights activists and parent organizations gained sway in the 1980s and 1990s—and public policies that protected children with disabilities were implemented (i.e., The Education for All Handicapped Children Act of 1975 and the Individuals with Disabilities Education Act of 1990)—autism treatment programs that involved behavioral therapies and social skills training in highly regulated educational environments became popular (Dempsey and Foreman 2001; Silverman 2012).

Asperger's Syndrome, or AS, was not always classified as an autism spectrum disorder. It developed in parallel with Kanner's autism. In 1938, Hans Asperger, a German psychologist used the term "autistic," as a category of emotional disorder, to describe children he described as having "autistic psychopathy" (Molloy and Vasil 2002). In the 1950s and 1960s, German psychiatrist Gerhard Bosch popularized Asperger's Syndrome (AS) in Germany through his referencing of Hans Asperger's studies of young people who experienced difficulty integrating into their social circles. Interestingly, Asperger's Syndrome, which described the psychologist's young patients who experienced difficulty integrating into their social circles, was not conceived of as synonymous with autism as Kanner defined it (Eyal 2010; Frith 2003). In 1981, however, AS was popularized among English speaking physicians by English psychiatrist Lorna Wing, who published findings from her study of children who exhibited behaviors similar to those that Asperger described. One decade later, developmental psychologist Uta Frith published a translation of Asperger's work, bringing AS into U.S. medical discourse. Asperger's Syndrome was incorporated (as a distinct diagnosis) into the tenth edition of the International Classification of Diseases (ICD), the diagnostic manual of the World Health Organization (WHO), in 1992 and the *Diagnostic and Statistical Manual of Mental Disorders* (*DSM*) in 1994. The fifth edition of the *DSM*

(2013) removed Asperger's Syndrome as a distinct diagnostic category and subsumed it under the umbrella category of Autism Spectrum Disorder (Molloy and Vasil 2002; Silverman 2012).

Recent Revisions of Autism Diagnostic Criteria

In the text revision of the *DSM IV* (2000), autistic disorder was defined by "abnormal or impaired development in social interaction and communication and a markedly restricted repertoire of activity and interests" (American Psychiatric Association 2000:70). With this description, an individual was diagnosed with autistic disorder if these three criteria were present: (1) "impairment in social interaction" (i.e., difficulty using nonverbal communication, developing peer relationships, sharing experiences with other people, or communicating mutual interest or feelings with others); (2) "impairments in communication" (i.e., late development or the absence of speech, difficulty opening or continuing conversations, "stereotyped", "repetitive" or "idiosyncratic speech", or difficulty engaging in pretend play); and (3) "repetitive and stereotyped patterns of behavior" (i.e., unusually intense focus on limited "patterns of interest", strict adherence to schedules and patterns of activity, repetitive movement, or preoccupation with particular elements of an item). (American Psychiatric Association 2000:75). Asperger's Syndrome (AS) was diagnosed if the three criteria listed above were present but there was no delay in speech development and no other "delay in cognitive development of...self-help skills, adaptive behavior...and curiosity about the environment (2000:84). While autistic disorder and AS were the two primary labels associated with the autism spectrum, pervasive developmental disorder (or PDD-NOS) was used to describe "atypical autism" in individuals who did not meet all of the criteria for either autistic disorder or AS but exhibited "impairment in either verbal or nonverbal communication" and repetitive behaviors with restricted interests (American Psychiatric Association 2000:84).

The fifth edition of the *Diagnostic and Statistical Manual of Mental Disorders* (2013), redefined autism by bringing autistic disorder, pervasive developmental disorder—not otherwise specified, and Asperger's Syndrome under the single heading of autism spectrum disorder (ASD). The diagnostic criteria for ASD include the following four items: (1) "deficits in social communication and interaction across contexts"; (2) "restricted, repetitive patterns of behavior, interests or activities"; (3) the two main criteria must have been present in early childhood, even if they only became apparent later, when "social demands exceeded limited capacities"; and (4) the "symptoms" must "limit and impair everyday functioning" (Carpenter 2013). The new criteria also require diagnosticians to indicate the "severity" of an individual's condition by accounting for both "communication impairments and restricted repetitive patterns of behavior" (Autism Speaks, n.d.).

Though autism did not begin as part of a formal classification system, it was inducted into the structure of diagnostic manuals and standardized psychiatric testing protocols as people struggled to understand the nature of a set of non-normative behaviors. Formal classification systems, like the *ICD* and the *DSM* are simultaneously material and symbolic, operating as forms of information technology that bring together "experience gained in one time and place with that gained in another" (Bowker and Star 1999:290). These systems, which consist of "stereotypic representations of concept[s]" allow information to be evaluated, stored, applied and communicated across the borders of intellectual professions, times, and even nation-states (Casson 1983:434; Bowker and Star 1999; Pentland 1995). Formal systems of categorization are used to standardize and regulate interpretations of the things that we perceive and the ways that our interpretations are put to work in everyday life. The history of the autism classification demonstrates the malleability of diagnostic classifications as well as the durability of notions of normalcy and abnormality that undergird its existence. The *DSM,* as a formal knowledge system, reinforces the principles of normalcy by rendering the deviant and their supposed abnormalities visible to state institutions, members of families and local communities, and to themselves (Jasanoff 2004; also see Foucault 1989, 1977). These ideas travel through time and are materialized through people's self-regulating behavior, the diagnosis of conditions that simultaneously define normality and the many ways that one might be non-normative, and the close monitoring of those who are deemed unwell.

Arriving at Autism Spectrum Disorder (ASD)

The above discussion shows that autism, as a biomedical spectrum disorder, has a rather short history. Historical documents and folktales show that the people we might label (and who might label themselves) as "autistic" have existed since before the psychiatric classification came into being. Furthermore, people who seemingly fit the diagnostic criteria have been found in cultures across the world and in past centuries (see Benjamin 2012, Randerson 2009, and Burleigh, 2004). However, the existence and acknowledgment of diverse ways of perceiving and interacting with the social and material world has not exactly increased our collective drive to accept these differences or make more pliable rulings on what counts as acceptable ways of being. In our 2017 article on the ways autistic people are rethinking the autism spectrum, Tom Boellstorff and I noted that even though people displaying behaviors and ways of communicating and interacting with the environment may not have been classified under "a single category" across cultures and times, they have been "treated with everything from veneration to benign neglect and even ostracization or violence" (sec. "The Emergence of the Autism Spectrum").

Notice that the origins of the contemporary medical definition of autism date back to only the 1940s and spawned from the clinical psychological studies of child psychiatrists and psychologists Leo Kanner and Hans Asperger (Silverman 2012; Singh 2015). Though these practitioners and researchers were exploring similar phenomena and theorizing about the conditions that produced them at around the same time, they were not collaborators, and it is believed that they came to similar ways of identifying what became known as autistic disorder and Asperger's Syndrome independently. Following their findings, these classifications tended to be formulated as psychological disorders, and for both researchers, efforts were made to differentiate it from other conditions that bore similarities, like childhood schizophrenia (Rapoport et al. 2009). Interestingly, as these differences were being fleshed out, autistic disorder and later Asperger's Syndrome (when it was introduced to United States biomedical culture) were not recognized as related conditions. In fact, they were framed in singular classification terms rather than related classifications that were part of a broader spectrum of psychiatric or psychological disorder. Approaches to diagnosing the conditions were simple, with classification being binary. Children either qualified for the diagnosis or they did not.

Speculations about the etiology of autistic disorder seemed obvious enough following Kanner's "discovery." As a condition of abnormal psychology in children, parenting, and especially poor mothering, was identified as the causative factor. Bruno Bettelheim was an ardent proponent of this idea, helping to formulate the culpable rhetorical character of the "Refrigerator Mother" (Jack 2014). It was not until the late 1970s and early 1980s that the dominant psychological explanations were challenged and other theories (namely environmental, genetic, and neurogenic) about the causes of autism emerged (Singh 2015). These theories of autism etiology continue today, still alongside some suggestions that individual psychology might play a key role in the development of the disorder (Baron-Cohen 2008). This uncertainty poses a critical problem for psychiatry and biomedicine in general. The widespread assumption is that biomedicine's claims to expertise on certain conditions are legitimate because of the belief that what is claimed points to a concrete physiological reality and that its concepts indicate that there is replicability in diagnostic outcomes across clinical settings (Watters 2013, Szasz 1987). As you will read in the chapter "Disidentification," some of my interlocutors struggled to make sense of their broken trust in psychiatry, especially following discovery that they might have been misdiagnosed with autism.

In light of such diagnostic uncertainty, differentiation from other conditions that looked very similar in terms of classification criteria grew increasingly complex. Previously disparate conditions were drawn into conversation with one another and more and more understood as somehow being causally linked. By the time the fourth edition of the *Diagnostic and Statistical Manual* was published in 1994, one decade after autistic disorder was included (in the third edition) and the same year that Asperger's was officially included, notions of a pervasive developmental disability umbrella that held five distinct psychiatric classifications emerged. These conditions were Autistic Disorder, Asperger's Syndrome, Rett Syndrome, Childhood Disintegrative Disorder, and Pervasive Developmental Disorder - Not Otherwise Specified (PDD-NOS). Lorna Wing, an influential medical researcher in the 1970s and parent of an autistic child, advocated for understanding autism as a "spectrum" of conditions (Wing and Gould 1979, Wing 1993, Eyal 2010).

Importantly, all five conditions were understood as having similar underlying causes due to their overlapping symptomology. Physicians and psychologists, however, had no concrete ways of explaining why any of the conditions occurred until 1999, when physician Huda Zoghbi discovered a specific genetic cause for Rett Syndrome (Wright 2017; Rett Syndrome Research Trust, n.d.). This genetic marker was not associated with any of the other four conditions under the PDD umbrella. Rett Syndrome could no longer be considered one of the pervasive developmental disorders. Fourteen years after Zoghbi's discovery, with the publication of the fifth edition of the *DSM*, the remaining four conditions were effectively removed from the diagnostic cannon, subsumed to the singular classification Autism Spectrum Disorder or ASD.

These recent developments have had significant implications for autistic self-advocacy which promotes neurodiversity thinking and discourages presumptions that differences in neurology and social performance be viewed as inherently problematic, even if they pose challenges to traditional conceptions of normality. Autistic self-advocates or activists have largely supported the classification changes following the publication of the *DSM 5*, believing that this new model would supply much needed cohesion to the autistic community and thus bolster collective efforts to protect autistic people from social, political, and economic harm. Within the autistic community, however, many of the people who had been given the Asperger Syndrome label, resisted and feared the changes, believing that their identities and communities were being erased and invalidated. Some, but not all, of these self-described "aspies" considered Autistic Disorder and Asperger Syndrome to be wildly different conditions that should not be seen as so similar that they be given the same, new label of Autism Spectrum Disorder (ASD). The notion of a linear autism spectrum is important here, as the belief that Asperger's Syndrome and "high functioning" autism or "mild" autism are closer to normal than Kanner's autism (i.e., Autistic Disorder) and the other so-called "moderate" to "severe" expressions of autism (i.e., Childhood Disintegrative Disorder, Rett Syndrome, and PDD-NOS) provides the basis for envisioning autism as a problem of unacceptable neurosocial dysfunction. One pole of the spectrum is populated by people whose behavioral and communication problems are recognizable but manageable in a world that treasures normality, while the other pole is occupied by people who are viewed as more obviously divergent from the accepted norm. What I found in my research is that my interlocutors who favored the classification changes regard resistors as "aspie elitists" who believed that their supposedly closer-to-normal communication and cognitive processing styles made them superior to those who had been labeled autistic disorder, childhood disintegrative disorder, and, in some cases, PDD-NOS.

RESEARCH SITES

In this research, I attended to various digital and offline spaces that autistic adults take part in. I used ethnographic research methods in three Southern California social support and activity groups that were created by and for autistic adults. Though these groups have their unique names, to protect the identities of the group members, which might be found online, I have given the groups, their leaders, and members pseudonyms. I have also used these names to protect their precise locations. The North, Mid, and South County groups had hundreds of members collectively, and in the wake of a major, deadly incident that took place during my research period, I was asked to stop all use of video and photography in the groups and their meeting locations. I readily agreed to their new terms. In large part, this was due to the deadly shooting that took place in December 2015, at a disability center in the region. In the wake of the attack, which claimed 14 lives and injured even more, my interlocutors expressed that they feared for the safety of their offline groups (Chan and Katz 2015).

The oldest of my three offline sites, the Mid County group, was launched in 2008, by Adam an autistic man in his thirties who thought of his group as his greatest project. He used his group as a platform for teaching and promoting "high ideals for autistic adults" by showing them how they could defy negative stereotypes. Consequently, the bulk of his teaching and training emphasized the value of both acceptance and learning how to perform "normally" in everyday social interactions. Stephen, founder and leader of the North County group informed me that their group was started in 2010. He and Kyle, leader of the South County group, which was started in 2013 seemed to take inspiration from Adam's approach, though they denied that they were ever in direct communication with one another.

Members of these groups either found about them from friends or family members or from perusing the social networking site, *Meetup*, which allows people wanting to create and promote local groups to post about their mission, recruit members, and organize a meeting schedule. Group meetings took place in all kinds of local venues, including coffee shops, restaurants, disability centers, bowling alleys, roller skating rinks, and libraries conference rooms. Participants convened multiple times per week, generally having no more than three weekly meetings. Overall, the North and Mid County groups had more, regular weekly meetings than the South County one. The groups were organized and managed by autistic people, and they were made to facilitate relationships and activity partnerships between local autistic adults who were interested in participating in coffee meet-ups, excursions to various local destinations (like comedy clubs, movie theaters, malls, and parks), and the occasional self-advocacy events. These groups were ideal sites for this study because they recruited autistic adult participants, were organized and administered by autistic adults, and were focused on enhancing the social lives of people who might otherwise find it difficult to establish peer groups.

My online research was divided into three primary realms, with two social media sites, one social networking site, and an internet-based non-profit autistic self-advocacy organization. In my social media sites, *Tumblr* and *Twitter*, I trained my sights on hypertext spaces, which were driven by participants' uses of a specific hashtag, actuallyautistic. This tag constituted a digital portal that connected users on these two platforms in an arena where people with similar affinities exchanged various kinds of messages and media about autism and autistic life. Though there are no concrete statistics on the number of people using the hashtag actuallyautistic, over the course of my research, I interacted directly with more than 250 autistic people participating in these spaces. Importantly, some of these individuals participated in the actuallyautistic spaces on both *Tumblr* and *Twitter*, while others strongly preferred one platform over the other. Also, important to note is the sometimes fleeting nature of connections forged in these spaces. Being short-form (*Tumblr*) and micro-blogging (*Twitter*) platforms that provide service to millions of people, many come into the spaces, participate for variable lengths of time, and some may suddenly disappear without comment. This did not happen frequently, but when an interlocutor would seem to vanish suddenly, or pop back up on my radar after a period of silence, I found myself learning that social media platforms like these, which allow for a great deal of anonymity, make it easier for people to duck out of or pause social relationships in ways that other interactional formats do not offer.

On *Facebook*, my interlocutors congregated in a large group that was created by and for "adults on the autism spectrum." It differed markedly from my sites on *Tumblr* and *Twitter* largely because interactions between my interlocutors were not mediated by platform users' use of hashtags or their creation of hypertext spaces. My *Facebook* interlocutors could generally expect to have their target audience ready for them by simply clicking the link to the group from their dashboards or profiles. In addition, members of the group were subject to the rules of engagement that were spelled out on the group's "About" page. Our posts and comments in the group were moderated by a handful of autistic adults who could make executive decisions on the appropriateness of participant posts for the group space. On *Tumblr* and *Twitter*, though, my interlocutors created or circulated content by typing into their posts a particular code, either in a specific "tags" field or the content entry field, the hypertext actuallyautistic. Among my interlocutors who were most established in this hypertext space on *Tumblr* (and later *Twitter*), the story follows that a small group of autistic self-advocates on the site decided on this code in the early 2010s.

The *Facebook* group in which I studied was very large, with more than 16,000 users. While it was officially geared toward "high functioning autistics (HFAs) and adults with Asperger's Syndrome(AS)," The vast majority of the group's regular participants were self-identified autistic people. Others in the group chose to identify themselves as "aspies" or "Aspergians." Over the course of my research, group dynamics shifted, initially reflecting tensions between members who supported changes to the *DSM* criteria and those who thought them regrettable. Toward the end of my research period, these tensions seemed to lessen, though not entirely.

I participated in the group by regularly sharing posts about disability and autistic community news, asking general questions of the group that I asked moderators to preapprove, and commenting and engaging group members on other participants' posts. Engaging with the group in this way, I received many friend requests from group members, who were curious about my research, even if they were not particularly keen on sharing their own experiences as autistics and aspies. Even though I assured my interlocutors in this group space that I was taking every precaution to protect their identities in this study and collaborated with participants to create pseudonyms and omit information that might make them identifiable, I imagine that on *Facebook* I faced a group of people far less willing to participate in my study. I believe this was because of the sense of exposure. *Facebook* group participants were usually posting with their real names and had profiles that provided information about employers, academic institutions, and lists of friends and family members. For those who did not want others in their lives to know that they were autistic, or who feared being targeted and harassed for their disability status, engaging me and participating in my study understandably seemed to not be worth the risk. This contrasts with my experience on *Tumblr* and *Twitter*, where the vast majority of my interlocutors usually created profiles that would not relay personal information that would compromise their privacy. In many instances, in fact, my interlocutors had multiple accounts– a primary account with specially selected bits of "real" personal information and secondary accounts with more restricted amounts of information. These secondary accounts would provide just enough information that they would be able to connect with others in their target audiences. In fact, the *Tumblr* platform encourages users to create multiple blogs, with one "main" blog and other "side" blogs that can be tailored to specific interests. With just a few minutes and a few clicks, a person can create multiple blogs, each with a different focus.

Each of these social media and networking platforms, *Tumblr*, *Twitter*, and *Facebook*, that I used in my study allow their users to publish different kinds of media to their blogs and profiles. I selected them for this study because of their popularity among many adults with autism, who moved between blogging and networking platforms. Collectively, the sites enabled me to examine how my interlocutors' autistic identities and self-concepts as well as the groups in which they regularly participated were maintained. Ultimately, these digital domains provided important spaces for autistic adults to receive confirmation of their self-images and understandings of the world, even as they sought and offered guidance to and from one another. The various tools or features that these platforms provided their users elicited different kinds of communication, but also offered channels for inventive approaches to social interaction, self-expression, group gatekeeping, and management of breaches of sometimes loosely defined notions of acceptable conduct.

The most significant features on *Tumblr* and *Twitter* included the ability to: freely use hypertext to access audiences and targeted content; create profile or "about me" pages; upload or link to original or circulated images, videos, and audio files; access follower lists that allowed users on the platform to keep track of the people who were interested in interacting with their content on a regular basis; and exchange private messages with other users. On *Facebook*, in spite of what I deem to be a dizzying and cluttered interface, worthwhile features are present. On the site, users can create private and public groups, personal profiles, and fan pages. They can manage relationships with others by approving or disproving friendship requests; have real-time chats with friends and other users on the site; send private messages, and post original content as well as link to external media. In general, I used all of these features in my study and saw that my interlocutors did too. In this way, I was able to observe information flows and changing currents in autistic community discourse.

For this study, I also participated in and observed some committee programs and board activities within a young internet-based non-profit autistic self-advocacy organization. In this study, I refer to the organization as the Association of Autistic Women and give its founder the pseudonym Daniella. Being a young organization, many of its activities involved branding, advertising and marketing, issuing public statements on social and political issues concerning people with neurodevelopmental disabilities, and developing committees, programs, and small projects that would attract positive attention. I took part in several small projects, some of which were dissolved prematurely because of insufficient funding or the need to redirect the energies of a relatively small band of volunteers toward more generative endeavors, such as book publishing, social media and network profile building, and original content production. I was able to use my connections with AAW, namely my volunteering and researching with them, to develop a sense of accountability and credibility among my interlocutors in other sites, who were at times suspicious that I seemed "too high functioning to actually be autistic" and that I would use my position as a researcher to collect information that would be used to pathologize autistics and sully the names of autistic organizations and their membership.

Having been scrutinized by medical professionals, and having read about the infantilizing, medicalizing, and pathologizing rhetoric that academics frequently use to discuss autism, it was not surprising that my interlocutors sometimes doubted my diagnostic status and wanted to know about not just my contacts within the broader community but my purposes for embarking on such a study. My most wary interlocutors wanted to know the fundamental premises on which my research was grounded. Did I think autism was a disorder? Did I believe in the need for a cure? Ultimately, I found that while my own diagnostic history, helped legitimize my stated aims in the eyes of my interlocutors, being able to say that I was involved with an autistic self-advocacy organization gave me greater credibility. Interestingly enough, this was the case even with those of my interlocutors who were unconvinced about the soundness of autistic acceptance claims. On reflection, I gather that their comfort in interacting with me and participating in my research had more to do with me being who I actually claimed to be. It was sometimes important for them to know that I was volunteering with an organization and participating in a space in which I could be publicly taken to task if I was deceitful. Admittedly, my approved human subjects research documents did not seem to hold as much sway.

METHODS

During my research period, I divided my time between the online sites and offline sites I described above. I used direct observation and participant observation in all of my sites, with the aim that this would allow me to learn how participants in my chosen sites coordinated and interacted with one another to create and maintain their groups. Furthermore, this allowed me to explore the communication strategies that members of these groups employed to express their personal and shared understandings of autism and autisticness.

I was fortunate that my online and offline interlocutors were generally quite willing to allow me to join into their group conversations and get-togethers. With AAW, these activities included board meetings, committee brainstorms, and project management. All of these things were coordinated and managed using various web applications like Skype, Google, and webinar software programs. With the North, Mid, and South County groups, I took part in independent-living workshops, coffee shop gatherings, birthday and holiday parties, and movie and game nights. As participant observer, I documented the structure of group meeting activities and how that structure was connected to the ways my interlocutors participated. In addition, taking part in these groups enabled me to examine how communication practices linked up with identity claims, personal narrative exchanges, and cultural narratives of autism in these spaces of learning and cooperation.

Using direct and participant observation in this study's online sites – *Tumblr*, *Twitter,* and *Facebook* – I created blogs and profiles that relayed detailed information about my research project and positionality. I used these tools to recruit interviewees and communicate with other self-described autistic adults while circulating my research observations and questions. My participation and observation in these sites, especially on *Tumblr* and *Twitter*, allowed me to document the use of hashtags to learn how my interlocutors used them to identify themselves while calling to platform users who were in their target audience. Above all, the tag actuallyautistic was most used and most effective for my interlocutors who wished to reach out to other autistic people. Even though posts using this tag were public, the sheer volume of original and recycled content on these short form and micro blogging social media platforms made it far less likely that untagged posts would be located by the people who might be interested in them. In this way, hypertext opened up spaces that included people who were "in the know" and understood the significance of the actuallyautistic tag. At the same time, it excluded those who did not know about its significance. Furthermore, the tag itself was guarded, unofficially moderated by regular participants in the hypertext space who were willing to protect it from intrusion by non-autistic people who used the tag. Though it was not easy to determine whether or not a person using the actuallautistic tags on *Tumblr* or *Twitter* were in fact autistic people, regular participants in those spaces were quick to announce their suspicions of others who seemed to promote controversial ideas (e.g., the need for autism cures or information about causes) or who harassed other autistics (by "trolling" them). Additionally, it is important to mention that while the vast majority of my online informants resided in the United States, some resided elsewhere in the Anglophone world. The examples I provide in the following chapters include US-based adults on the autism spectrum.

In addition to direct and participant observation in my online and offline field sites, I also conducted interviews. In my formal and informal interviews, I aimed to learn about the following four things: 1) how my interlocutors connected with other autistic adults and why; 2) how their interactions with other autistic adults shaped the way they conceptualized the autism spectrum, their own sense of autistic identity, and their understanding of and participation in the autistic community; 3) the ways personal narrative revision and cohesion shaped my interlocutors ways of participating in their preferred autistic groups; and 4) the various tools and technologies that they used to connect to autistic community and/or engage in self-advocacy. It was fortunate that I learned through personal experience, previous employment in special education, and preliminary research that my interlocutors might have diverse communication abilities and preferences. This enabled me to anticipate their diverse needs in communicating with me so that I could make provisions for interviews and interactions that in video, audio, and text-chat formats.

CHAPTER OVERVIEW

Chapter 1, "Autistic Narrative," explores the ways in which my interlocutors construct and manage their self-concepts by navigating a discursive terrain in which autism and autisticness are assumed to look and perform in particular, stereotypical ways. My interlocutors worked individually and collaboratively to expand the available range of rhetorical characters of autisticness, so that people within the autistic community, who are severely underrepresented might be legitimated in their chosen peer groups. A major challenge for my interlocutors who live at the intersection of various marginalized identity categories is being received as legitimate autistic people. In particular, they faced the scrutiny of autistic and non-autistic others who believed that acceptable forms of autisticness belonged to restricted populations of people who are generally white, middle class, geeky, and male. Autistic people who do not fit this limiting description often expressed the feeling that their needs, desires, and lived realities were ignored or denied.

In chapter 2, "Rhetorical Characters of Autisticness," I discuss the ways my interlocutors used their personal narratives to make sense of their autistic realities. Diagnosis and misdiagnosis accounts, were important tools that they used to make sense of their past experiences, senses of self, and future trajectories in a space of narrative exchange. My interlocutors' narratives were not useful only for those who were telling them, they were supportive of newly diagnosed and "prospective" autistic adults who participated in the digital and offline group spaces in which I studied. People who were unsure of their diagnostic statuses, but who suspected that they might be on the autism spectrum, found these personal narratives to be sources of encouragement and sometimes used them to justify their quests for autism diagnoses. Meanwhile, others found that these narratives unsteadied them in their certainty about their diagnostic statuses. When the narratives that my interlocutors had consumed diverged significantly from their own, they sometimes wondered if they had been misdiagnosed or if they were assuming a false autistic reality for themselves.

The third chapter, "Learning to be Autistic," dissects and interrogates the ways in which participation in the groups in which I studied were structured. While I initially imagined these diverse kinds of groups falling neatly in line with a community of practice framework, where participants learn within a hierarchical group structure how to become central or core participants, I found that these kinds of structures were not so clear cut across the board. In my all of my offline groups, the participant structure followed the community of practice model quite closely. There were designated leaders and followers, teachers and students. This was also the case for participation within the Association of Autistic Women (AAW). In my *Tumblr*, *Twitter*, and *Facebook* sites, similar structures appeared, but they were more vulnerable to challenge and they stood alongside much more lateral participant structures.

The final, fourth chapter of this dissertation deals with the issue of misdiagnosis and autism disidentification. Drawing on my interlocutors' accounts, I argue that the autism classification's instability, uncertainty about its causes and the physiological loci of autism supposed dysfunction, but also a lack of diagnostic precision plays out in their narratives of betrayal, narrative fragmentation, and hesitancy. This chapter shows how adults on the autism spectrum might make sense of the kinds of self-concept disruption that emerge in the wake of misdiagnosis and reclassification. I discuss the ways my interlocutors sometimes rejected the validity of psychiatry or set about reconstituting their relationships with the autism classification and the autistic community.

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AUTISTIC NARRATIVE

In this chapter, I discuss the ways autistic adults use narrative to cultivate and transform their identities and develop a sense of group belonging. In sharing their stories and aiming to discover their autistic selves, my interlocutors found ways to affirm their experiences of autism and their autistic identities as well as renegotiate the terms of their accepted realities in the face of emergent social possibilities. Among my interlocutors, this often involved claiming membership in a large, widely dispersed autistic community and dis-identifying with culturally sanctioned conceptualizations of neurosocial normality (or neurotypicalness).

These narratives often underscored my interlocutors' efforts to make known the extent to which they struggled to accept themselves, receive peer and family acceptance, and make sense of where and with whom they might be accepted. This speaks to the impact of autism pathologization in United States biomedical culture on autistic people who understand that they do not and perhaps cannot meet the expectations and desires of parents, educators, medical practitioners, and peer groups. This medicalization and pathologization have also sponsored a cultural preoccupation with vanquishing the disability, empowering federal and state government, non-profit, educational, and corporate institutions to brazenly declare their commitment to wage war against autism.[1] I propose that my interlocutors' narratives of autistic struggle reflect the powerful tension between their desires for narrative coherence and the internal and external forces that pressure them to concede to notions of autistic inadequacy. Cultural notions of normality and deviance are influential forces that helped shape my

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[1] See Anne Mcguire's (2016) *War on Autism*

interlocutors' social practices and ways of talking about and making sense of autism. Their narratives shine a light on not only the frustrations they felt because of their misalignments with the dominant, accepted modes and codes of "good" social engagement. They also highlight the ways they resisted pejorative representations of abnormality by emphasizing and celebrating the ways they deviated from the norm.

WHAT AUTISTIC NARRATIVES DO FOR AUTISTIC ADULTS

For many of my interlocutors, sharing personal narratives helped provide information about the experience of being autistic to others who were exploring the possibility that they might be on the spectrum. It also helped support parents and caregivers who could benefit from autistic people's experiential knowledge. Furthermore, their narratives were sometimes shared in hopes that they would influence non-autistic people's perceptions of autism and impact public policy. In sharing their stories, my interlocutors worked to develop their autistic identities and grow their senses of belonging in their chosen autistic groups and in an abstract, widely dispersed autistic community.

In my online and offline research sites, it was common to see my interlocutors sharing their stories in order to obtain peer confirmation of their self-diagnoses of autism. Most often these efforts were linked to a lack of access to biomedical care, fear of the social and financial repercussions of a formal autism diagnosis,[2] or mistrust of medical doctors after experiencing poor treatment or a series of conflicting medical judgments and misdiagnoses. I found that those who submitted themselves to be evaluated by their autistic peers did so with varying degrees of success, as the rhetorical boundaries around the validity of self and peer diagnosis within autistic

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[2] Several of my interlocutors, who were "hiding" their diagnoses explained to me that their careers, families, and marriages could fall apart in the wake of such a diagnosis. These interlocutors grappled with how to incorporate autisticness into their individual and collective images and identities

groups was not always clear-cut and was subject to the particular context and audience in which the request for recognition was offered. In spite of the risk that one might share their personal – and sometimes painful – stories without attaining the desired outcome of a positive peer diagnosis of autism, I frequently heard from my interlocutors that contributing in this way was ultimately palliative. It provided opportunities for their incomplete stories – which seemed to fissure, fracture, and bend in awkward and confusing ways – to be crafted and recrafted in more sensible terms. It enabled those who eventually came to self-identify as autistic, and others who found themselves questioning their extant autism diagnoses, to recalibrate to a new, revised temporal flow.

Especially when confirmation was given, my interlocutors reframed their life stories from the beginning. I propose that this is largely influenced by the fact that the diagnostic criteria for autism and the dominant assumption about the disability holds that it is located *somewhere* in the bodies and brains of individuals. Whether the cascade of "abnormal" effects (i.e., symptoms of autism) was produced through endogenous or exogenous material processes, it is thought to be there in the genetic fabric of persons, waiting to be discovered by the trained and discriminating eyes of experts. I found that when an autism diagnosis or the prospect of such a diagnosis entered my adult-age interlocutors' experiences, they reframed even their earliest memories and offered them as acknowledgements of their autistic childhoods. Prior to their awareness of autism and sense of receiving a valid psychiatric diagnosis, their anomalous childhood behavior was framed as simply strange. Following diagnosis, however, that unusual behavior that they displayed, sometimes decades earlier, *became* autistic behavior. Steven, the head of the North County group, for instance, recalled:

> I wasn't diagnosed with AS until I was in my late 20s ... Maybe 28 or 29, I think. So, roughly 12 years ago ... honestly, up to that point things were hazy. I mean, I had doctors

> thinking I had all kinds of things wrong with me ... but I never thought they were getting it, you know? So, I kept trying to get answers until I found one that actually made sense to me and my family ... That was Asperger's Syndrome ultimately. Everything else that had been so confusing finally made sense. All of it ... Why I was a strange infant like my parents would tell me ... why I couldn't make friends. It just explained things *really* well and I couldn't find a good argument against it ... Basically, I stopped looking after the last shrink came up with that diagnosis.

Autistic Me, Autistic Us

In what follows, I propose that my interlocutors' personal narratives worked to cultivate a personal sense of an "autistic me" and a shared sense of an "autistic us," both of which are fundamental to the notion of autistic community. Crucially, these senses of autisticness, which are drawn from tellings and retellings of the self, as one is now and as they were then, also show how Now and Then can be rendered permeable through disclosure and naming. To be diagnosed with autism today, through official or unofficial channels, presumably indicates that one has always been autistic. The ways in which these stories of autism discovery unfold demonstrate how they speak to transformations in my interlocutors' senses of self and group belonging over time, and the ways in which they relate to evolving forms of community participation.

To explore how my interlocutors' personal narratives encapsulate these complex processes and transformations, I first discuss the kinds of work that disability narratives do. Second, I explore the ways narrative figures into the formation and management of autistic identity. Third, I examine how my interlocutors' narratives work as sites wherein group identification and disidentification, as well as notions of membership in an autistic community, are articulated and confirmed. I conclude by discussing autistic adults' personal narrative practices as tools for making sense of not only oneself as an autistic person and a member of an autistic community, but also for making sense of the autism classification(s)[3] itself. Ultimately, I aim to show that autistic adults' personal narratives, as disability narratives, do particular kinds of identity and community building work for those who tell and share in them. I believe the discussion that follows helps illustrate how my interlocutors' personal accounts are tied up in the unstable and rutted discursive landscape of autism, a supposedly pathological psychiatric classification.

DISABILITY NARRATIVES

In the expanding sphere of belonging and intimacy that links up with notions of autistic community, narratives serve as vectors of representation for diverse kinds of embodiment, which are central to processes of identity formation as well as group identification and disidentification. These are also fundamental to formulations of autisticness that aim to legitimate manifestations of neurodevelopmental difference in daily life. These disability narratives fortify key understandings of the ways in which autism (and developmental disabilities in general) becomes socially, culturally, and politically constructed. Since the early 1990s, the increased production and circulation of these "neurodivergent"[4] experiences and insights among broader publics – digital and physical – has supported calls to revamp our conceptions of what constitutes "normal" human sociality, legitimate community participation, and expert knowledge on autism.

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[3] See pediatrician Susan L. Hyman's article on revisions to the pervasive developmental disabilities category (which previously consisted of five distinct but related diagnoses). The umbrella category was effectively consolidated into a singular classification, Autism Spectrum Disorder.

[4] Many of my interlocutors referred to themselves, and others with neurodevelopmental disabilities, cognitive disabilities, or psychiatric illness as "neurodivergent," assuming that all of these categories are linked by physiological distinctions like atypical neurological structures and/or chemical profiles. Importantly, the use of "divergent" in this case is intended to be a point of pride. It served as a way to celebrate neurobiological diversity while also acknowledging that these categories of difference are regarded as unusual.

Within the last decade, we have seen disability studies' increased concern with exploring the narratives of people with cognitive and developmental disabilities such as autism. Three things undergird this development: first, because many autistic and otherwise developmentally disabled people communicate in non-normative or unexpected ways[5], historically, it has been challenging to access the personal accounts of members of this population. That is not to say that autistic adults were unable to share their experiences before the social networking boon of the late nineties. Autistic women like Temple Grandin (writing her first book about "curing" herself in 1986[6]) and Donna Williams (writing her first book in 1992) were two early, influential autistic voices whose memoirs helped open up a path for autistic people who felt called to share their own accounts of their lives through publication. John Elder Robison, Rudy Simone, and Philip Wiley are just three of many other autistic writers to release their autobiographies.

Second, increased scholarly concern with narratives of people having cognitive and developmental disabilities relates to the fact that with the rapid proliferation of digital media and social media platforms there has been a reduction in some of the major barriers to this group's access to opportunities to share personal experiences. Where in-person socializing with non-autistic others who refuse to provide needed accommodations limited social opportunities, digital platforms enabled autistic adults to develop and mobilize community-building resources, making these technologies vital cogs in the wheel of autistic social group formation and the concomitant cultivation of autistic self-concepts that intersect with autistic group identity. These technologies have also facilitated autistic people's abilities to create offline groups by enabling them to speak

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[5] For more information on observed social and communication characteristics of speaking autistic children and adults see Beverly Vicker's (n.d.) article for the Indiana Resource Center for Autism.

[6] This book was co-authored with Margaret M. Scariano.

directly to the autistic adults with whom they wish to connect. Meetup, for instance, is *the* primary platform for advertising offline autistic groups among my interlocutors.

Third, cultural biases against cognitive and developmental disabilities as conditions of inherent unintelligibility reduce even adult "sufferers" capacities to feel, understand, and self-express to that of small children. This infantilization is due at least in part to reliance on notions of standard developmental benchmarks in the human life course and the continued use of intelligence quotients to support ideas of "mental age" (McGuire 2016). These factors have made it exceedingly difficult for non-disabled people to take seriously the reflections of a discredited and disenabled group. Yet autistic people's pronounced rejection of these ideas and beliefs has demanded greater attention to and examination of what autistic and other developmentally disabled people have to say.

With the emergence of the autism spectrum metaphor and the rapid increase in the texts, works of art, video blogs, and self-advocacy organizations that are being produced, promoted, and circulated by autistic people, opportunities to seek out, establish, and nurture social connections amongst peers has increased and enabled forms of autistic community, culture, and identity to emerge and morph. As Joseph Strauss (2013) notes, in this historical moment, with significant transformations in the autism spectrum classification that have expanded and redefined autism, "it has become possible to conceive of people with autism" – no longer understood to be inherently insular and asocial – "as a social group with a distinctive, shared culture" (p. 462). Now, Strauss claims, "we see self-aware people claiming autism as a valued political and social identity and celebrating a shared culture of art and everyday life" (p. 462). At the root of this "autistic culture" and its development is the collaborative exploration of the space of autistic experience. I found that very often, this exploration was led by three fundamental questions: (1) what is autism, really? (2) What does it mean to be autistic? (3) What does it mean to live "a good autistic life?" My interlocutors routinely dug into their life stories to uncover answers to these kinds of questions.

Counterbalancing Cultural Narratives of Autisticness and Disability

The ways in which autistic peoples' accounts work for them, individually and collectively, speak to the ways in which disability life experience is so often shaped by marginality, a sense of misplacement, dislocation, and misrepresentation. In narrating aspects of their lives, disabled people can both represent their own life experience and explore the notion and reality of disability itself, offering "the best-case scenario for revaluation of that condition" (Couser 2013, p. 458). In this way, disability narratives give the teller the chance to express the particularities of their unique life experience and the conditions of their daily lives. But they can also defy our accepted understandings of what it means to be disabled in a cultural context where accepted notions of normality are used to cast those who are deemed abnormal into the realms of freakishness and pitifulness.

Therefore, these personal accounts stand to be powerful refutations of the status quo, as we may find encoded within them important responses to cultural narratives of disability that critique, marginalize, condemn, pathologize, and objectify disabled bodies, brains, and lives.[7] In much the way that the cultural anthropologist aims to make the strange familiar and the familiar strange, the life narratives of disabled people can grant to others (disabled or non-disabled) "access to lives that might otherwise remain opaque or exotic to them" (Couser 2013, p. 458-9). Furthermore, because of the often-intimate relationships between developmentally disabled people in the United States and the biomedical establishment, their personal accounts may be understood as contributing to ongoing conversations about not only problems of access and

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[7] For more on this see G. Thomas Couser (2013).

abuse in medical and non-medical care. They may also contribute to discourse in the realms of philosophies of biomedical science and psychiatry.

Scholars have asked what the production of disabled people's narratives can do for them and their fields of study. Disability studies scholar G. Thomas Couser (2013) has proposed that disability narratives link up to a complex of expressive modes that include, among other things, various forms of media. He claimed that "disability autobiography should be seen ... not as spontaneous 'self-expression' but as a response ... to the traditional misrepresentation of disability in Western culture generally" (p. 456-457).

While Couser (2013) was concerned with how the polished monographs disabled people have produced and continue to produce misunderstandings of what counts as legitimate disability experience, we might also question whether their everyday personal narratives work in similar ways, countering those misrepresentations. I propose that their everyday accounts do in fact constitute such a response. My interlocutors' narratives routinely opened up spaces for inquiring and negotiating the meanings of direct experiences and observations. Telling and interacting with tellings allowed them to test the boundaries of widespread presuppositions about what a person should and should not be and how autisticness should and should not be read. Their accounts of distress, frustration, incapacity, suffering, abuse, and socio-economic limitation illuminated the areas where the accepted interpretive mode failed to serve and satisfy, not only those who were pigeon-holed as abnormal or deviant, but also those "normal" people who loved, cared for, and encountered them in their daily lives.

Misrepresentations of autisticness are inextricably entwined with the how cultural understandings of disability support manifestations of ableism at various scales, from everyday interactions between individual people to the broad scale disenfranchisement and economic marginalization of disabled persons. "The assumption is that I'm unable to do almost *anything* at all," Fabby, a 26-year-old autistic woman, told me in a series of exchanges on *Tumblr*. Fabby had been soliciting financial assistance through crowdfunding websites for four months after she was "let go" from her job.

> I think [my boss] fired me because I'm autistic ... I never told him about my diagnosis, but I overheard my co-worker telling my secret. My supervisor was concerned that I was going to lose it like one of those mass-shooters everyone thinks has Asperger's ... I heard rumors about how scared he was of me after he heard about my diagnosis ... that really hurt a lot. We used to joke around and stuff before then.

Here, Fabby reflects on being forced to answer for cultural representations of Asperger's Syndrome as a condition of a potentially deadly lack of empathy and sociopathy (see McCoy 2014 and Alley et al. 2017). She reflects on the way revelation of her diagnostic status shifted perceptions of her and resulted in her loss of employment. A loss that led to her experience of not merely social rejection, but also massive financial decline and psychological distress. Fabby explained,

> One day, I had an appointment with my psychiatrist, and I made the mistake of telling him I had to visit my shrink ... right after that, when I called to find out my work hours for the next few days, he said to check back in a while. Every time I checked back, he said they had no work for me to do. Eventually, he said that since I hadn't been to work in weeks, I should look for employment elsewhere. I was already broke, so financially and socially, this devastated me. At one point suicide felt like a good idea, but I couldn't do that. I don't know what to do. But the gofundme[8] thing helps a lot.

Fabby's experience of employment discrimination is just one example of how misrepresentations of autistic people, and others with neurodevelopmental and psychiatric diagnoses, exploit fears of abnormality and emphasize their inherent dangerousness to neurotypical others. The consequences of this misrepresentation were severe for Fabby, whose financial welfare was

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[8] *GoFundMe* is a crowdsourcing site that allows its members to petition the public for financial support of projects and causes. Increasingly, social media users who face financial strain turn to the site to raise funds to meet every day needs.

decimated by her boss's acceptance of widespread assumptions that autistic people, by virtue of their supposedly nonexistent empathy, are inherently dangerous and predisposed to violence.

The accepted practice of regarding some prototypical human, defined by their bodily and neurosocial wholeness and normality, as the epitome of goodness has failed us. Disabled people's accounts invite us to ask after how this failure works and who this idol worship is meant to serve? Within autistic groups and the broader disabled community, such questions have produced conflicting interpretations. While some disabled people find that the message to aspire for normality is challenging, it is regarded as natural and essential. Others, however, seek to deconstruct normality, with its revered images of solid and virtually infallible bodies and brains that we are meant to aspire to but will never attain. Sharing personal narratives of autisticness is a key tool used to support this deconstruction and dethroning of normality. "My parents placed me in tons of therapy as a kid and went broke because of it," Fabby explained in a post published in the actuallyautistic hypertext space on *Tumblr,*

> I remember her telling my dad before he left us that I was *supposed* to be different, better. I guess I'm lucky that I wasn't one of those autistic kids smothered in their sleep or drowned in the bathtub ... My parents and everyone else thought I was supposed to be someone who could shoot for the absolute top of the mountain. But ... I was born autistic and like a mile or two underground ... NTs were at least born on the surface of the earth. My life's not even halfway done, probably. How much harder and longer do I have to work just to be seen as having the right to be on this planet with the rest of everyone else? Anti-autism and ableism are so shitty. And, like ... not just for autistics ... but for every parent whose now scared that their kids would come out and be like someone like me.

This post from Fabby was part of a series of neurodiversity themed posts that she published in August 2015. Receiving many likes as well as affirming and sympathizing comments, the posts were well-received by other autistic people who frequented the actuallyautistic space. Fabby, and other autistic activists regarded the concept of neurodiversity as an answer to the image of (neurosocial) impossibility that diminishes the life value of neurodivergent people through rhetorical violence, even as it inspires fear, despair, and sometimes violent displays of bigotry from people who purchase anti-autistic ideology. Neurodiversity, proponents suggest offers an alternative to aspiring to the unattainable ideal image (or set of images). Shattering the mold of the ideal, we begin to recognize a field of plentiful images of neurosocial difference, none of which are good or bad. Driven by the forces of natural evolution and the imperative of biodiversity, different ways of being a person in the world are alright. They *just are*.

Cultural narratives of disability, by subjecting disabled bodies and brains to scrutiny and correction, obligate disabled people to both educate non-disabled people about their social and embodied realities and alleviate any discomfort their assessors may experience. Disabled narratives are powerful because they exist even in a cultural space where the authority to write or talk about one's disabled life is compromised. This complex, violent dynamic has traditionally set up disabled people to have their lives written *for* them as "culture inscribes narratives *on* their bodies, willy nilly" (Couser 2013, p. 458). Therefore, in telling and sharing their narratives, autistic and otherwise disenabled people resist oppression. Though their resistance sometimes calls directly for a full-scale reevaluation of the ideas that demand their total submission to traditional understandings of normality and abnormality, I observed that often, in their everyday narrating, this appeal was indirect.

This has broad implications for our ongoing evaluations of the standards thrust upon our bodies, whether we are disabled or not. Because cultural norms define disabled bodies as corporeal matter that is undesirable in its limitations or excesses, this is the predominant and circulating narrative and legacy of disability in the United States. That the body or brain has been regarded as faulty, leaves disability to be a fearful thing and makes lives shaped by these supposed neurophysiological blunders necessarily unfortunate. Yet disability narratives, and especially those that center on defining, enhancing, or celebrating disabled life check these popular, marginalizing accounts. This was particularly noticeable in instances where my interlocutors actively sought out diagnoses for autism, a condition typically understood to be disabling and thus stigmatized. Rather than being a devastating diagnostic discovery or ascription, in many cases, diagnoses of autism enhanced my interlocutors' senses of satisfaction, meaningfulness, and social connection. Their narratives, therefore, might be seen as counterweighing or reigning in the simultaneously restrictive and immoderate tenor of our physiological and neurosocial cultural norms and the stigmatizing narratives that they produce.

Lisa Capps and Elinor Ochs (1995) explained that the worldviews of persons living with psychiatric disabilities are often subjugated because interactions with United States biomedical culture, and psychiatry in particular, bolster accounts that are widely accepted as representing the "official version" of things (1995, p. 11-12). In part, this is because certified medical practitioners and psychotherapists are heavily influenced by this official narrative, as it was fundamental to their studies of identifying illness and learning how to employ accepted US-centered allopathic and psychology healing modalities. Since 1980, the American Psychiatric Association's *Diagnostic and Statistical Manual of Mental Disorders* has codified the authorized narrative about autism spectrum disorder(s). The assumption that autistic people's embodied knowledge is necessarily inadequate when measured against the explanatory frameworks of the psychiatrist is partially grounded in the denial of autistic people's rationality. This repudiation of autistic rationality is based on the fact that they have been ruled to have psychiatric or neurological deformity.[9] This is significant because it illustrates a crucial misalignment. While

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[9] See Corina L. Becker's (2012) post on the *No Stereotypes Here* blog for a discussion of famed autism psychologist Tony Attwood's interactions with an autistic person who critiqued his portrayal of autistic people.

biomedicalized views of autism may center on the ways in which the "disorder" entails some inherent compromised common sense or rationality, my interlocutors understood themselves to have other, "divergent" ways of seeing and knowing themselves and the world around them. I found that this belief was fundamental to their storytelling as they aimed to discern how their experiences of autistic self and neurotypical other, which were variable in the extent to which they match or controverted expert knowledge, mutually constituted one another in what they saw as sensible ways.

THE SPECTRUM

"Autistic," Aspie," "person with autism," "member of the autistic community," "on the spectrum" – these membership categories often appeared in my interlocutors' narratives and served as tools that positioned them in relation to one another, gave hints about how they conceived of autism and autisticness, and shaped how they engaged with their groups and the notion of a broader autistic community. In identifying with autisticness and the autistic community, these categories worked as sites in which the rhetorical boundaries of "autistic" could be actively negotiated by those who identified with that term or in other similar ways. I observed group members aligning themselves with some of these categories, distancing themselves from others, and redefining them. I found that hashing out these ideas together helped them produce senses of self that were meaningful not just within the context of group interactions but also beyond them.

On a late summer afternoon, I sat in a Mid County restaurant talking with Adam, Lei, and Ned. Just an hour earlier we were roller skating at nearby rink, and now we sat down to enjoy a late lunch. Seated across from Adam, I asked him what he thought about the use of functioning labels in relation to autism. I wanted to know how he and the others in our small group understood the notion of an "autism spectrum" and, perhaps, their places on it. Taking a momentary break from his bowl of hot noodle soup, Adam explained to me that the popular conception of the autism spectrum could be beneficial. Elaborating on how he thought of the spectrum, generally conceived of as a line that measures neurosocial productivity and runs from low to high functioning, severe to mild, he continued: "We choose to interpret these terms negatively and that's pointless." I asked Adam how labels like "low functioning" and "high functioning" might be useful when increasing numbers of autistic activists expressed the stance that they were derogatory. But Ned, who frequently regarded himself as a high functioning aspie, interjected, telling me that "everyone's autism is different."

With a chunk of brioche in her hand, Lei explained her position: "functioning labels have some use. Most of us in the group are high functioning and that's how we can do stuff like go roller skating and take ourselves out to lunch. And some of us, like Steph, are low functioning. It's not like she's any less important, though." Lei appeared to have more to say, but Ned and Adam were surprised by her statement. Adam quickly turned to Lei: "Steph isn't low-functioning ... She drives, works part-time, can have a regular conversation." Ned agreed emphatically with Adam as Lei rolled her eyes and said, "Oh well, whatever, you know what I mean."

This interaction captures a set of debates that were frequently encountered during my fieldwork – and that were coded into my interlocutors' personal narratives of autism and self-diagnosis. In these debates, the autism "spectrum" provided a framework for working out how to effectively become an autistic person and be accepted as one. Because the spectrum metaphor has been used in autism discourse to discuss autism etiology and symptomology across the globe, it is significant to note how it supports diagnostic process, by narrowing the field of possible categories of dysfunction, buttressing assumptions that autism is an objective reality (and social problem), and by assigning a level of intensity to diagnosed peoples observed, dysfunctional traits (see Broderick and Ne'eman 2008). Establishing a hierarchy of functioning or ability, the spectrum, which was once used to draw multiple autism classifications under one umbrella, now helps diagnosticians and non-expert observers alike to access a diagnostic classification that is assumed to be hierarchical in spite of its claimed unitary nature (see Krueger and Bezdjian 2009). In practice, the "spectrum approach entails situating diagnosed patients along a continuum that joins what were multiple but ostensibly related classifications" and "allows for sites of overlap between once disparate classifications" (Thomas and Boellstorff 2017, The Emergence of the Autism Spectrum section, para. 7]; also see Willemsen-Swinkels and Buitelaar 2002).

Though there are many ideas about the validity or invalidity of the autism spectrum metaphor, a couple stand out. On the one hand, some have argued that the spectrum enables medical professionals and their patients to establish common reference points and break through the barriers to understanding that prevailed under the use of a "discrete entities" metaphor of autism (see Lutz 2013). When the discrete entities metaphor dominated the discursive, one was either autistic or they were not. There was no sliding scale of severity. The assertion that the spectrum metaphor continues to be useful, even decades after the dissolution of the discrete entities metaphor in the autism discursive field, now butts up against contentions that determining functioning labels for autistic people is more subjective than scientific and leaves questions as to the precise techniques diagnosticians use to gauge who counts as high functioning or low functioning autistic. This is an important point given that these labels enable people with diagnoses of autism to access various forms of support from their local and state governments and institutions.

My interlocutors frequently questioned whether it was the ability to consistently produce verbal language or the ability to take part in particular forms of self-care or body maintenance that justified placement in one category and not the other. "Could I be high functioning in one area and not in another? Does it change over time? ... The way the spectrum is used is mostly nonsense," Daniella, founder and executive director of the Association of Autistic Women, told me. "If it was meant to be a useful tool, OK, fine. But it's been weaponized now and it's really damaging to autistic people who are told they're useless because they're severely autistic or low functioning." As we can see, Daniella's perspective speaks to arguments that counter claims that the spectrum helps clarify terms for medical professionals and their patients. Instead, she sees the spectrum as a metaphor that represents supposedly "severe" expressions of autisticness as a terror, for both autistic people who are labeled in this way and those who assume that the metaphor captures a concrete reality. For autistic people labeled "mild" or "high functioning," access to needed supports might be harder or nearly impossible to attain.

A common thread in anti-spectrum arguments is that the metaphor harms autistics because of the ways the hierarchy of ability is read and applied. It encourages stigmatization of autistics by reifying the hierarchy and a linear ranking of autistic social value and need. It does not merely subject autistics who are labeled "severe" to intrusive programs that attempt to correct or fix autistic dysfunction at almost any cost. Here correction or fixing is essential to redeem life value. It also sets them in opposition to those autistics on the other end of the pole, who are regarded as "mild." Individuals regarded in this way are also said to require intervention, but not to establish life value. Instead, intervention for "mild" autistic people serves to restore or grow culturally prized capacities and legitimacy within their communities. Significantly, those placed on the mild pole of the autism spectrum are typically understood to need few (or no) supports or interventions, often in spite of indications to the contrary. They can be variously pardoned for their near-normal "quirks," denied assistance, or stigmatized because of their diagnostic link to autistic people "on the other end." Given this dynamic, I suggest that ascribing or assuming autism functioning labels might be regarded as an injurious rhetorical exercise.

In my research sites, the now-defunct classification of "Asperger's syndrome" served as both a clinical diagnosis and term of self-identity, with individuals claiming themselves to be "aspies" or "Aspergians" (Singh 2011). While, technically, Asperger's syndrome is no longer diagnosed; it persists as an informal description for those who were originally diagnosed with the label prior to the changes in 2013, and for those who are self-diagnosing and disregard the validity of claims that autistic disorder and Asperger's syndrome are rooted in the same neurosocial difference. Consequently, some members of social and activity groups for autistic adults, who identify as having Asperger's syndrome or who are prospective aspies, "see the removal of the Asperger's diagnosis as a potential threat to their identity. Many within these groups fear that the positive identity associated with being Asperger's will be overshadowed or stigmatized by the broader definition of ASD" (Sing 2015, p. 27). It is important to note that in these groups, notions of high functioning and low functioning hold significant weight. Being an "Aspergian" and being seen as high functioning can bolster a keen sense of aspie pride, or what many autistic self-advocates regard as "aspie elitism" (e.g., Brown 2013 and The Caffeinated Autistic 2013).

In June 2015, in the *Facebook* group for autistic adults, I encountered a post by Sasha, a young autistic woman who had been diagnosed with Asperger's Syndrome years before. In her post, she discussed how she struggled to interact with extended family members, who she felt diminished her autistic identity and held to outmoded views about autism and autisticness. Sasha had grown frustrated with the way they attempted to correct her when she referred to herself as autistic. In her post, she wrote that her family members repeatedly claimed that she "[didn't] seem autistic" or "just [had] Asperger's and real autism is more severe." Her efforts to explain about "Asperger's inclusion in the autism spectrum," and its being subsumed to the autism spectrum disorder classification, seemed ineffective: "The autism label might suggest that I should be severely debilitated, but that doesn't mean that's how it actually is. I don't look like a stereotypical autistic person ... There's more to autism than 'seeming autistic.'"

Sasha's post shows how her family members understandings of autism and Asperger's Syndrome were shaped by the linear spectrum metaphor and notions of high and low functioning. It also shows how these notions influenced the way she came to understand her own autistic identity. By sharing her account in a space geared toward people who considered themselves to be "on the spectrum," and many seeing themselves as aspies or high functioning autistics, she did a couple of things. First, she expressed her own frustrations, knowing that others might sympathize with her and potentially reinforcing her perspective. Second, through her account, she drew attention to what she regarded as divisive modes of thinking about autisticness and the nature of Asperger's Syndrome. She challenged the assertion that her autistic identity was inauthentic because she was not "severe" enough.

NARRATIVE AND IDENTITY MAKING

Because my interlocutors' narratives focused on exploring their experiences as (potential) autistic people, their personal stories offer opportunities to see into various understandings of autisticness – those psychological and physiological traits and social sensibilities that make someone recognizable as an autistic person. In centering their own experiences and understandings rather than the perspectives of biomedical practitioners, researchers, caregivers, and educators, they help transform an assigned diagnostic classification into an expression of individual and collective experiences of otherness. This was especially noticeable when sharing personal narratives assisted my interlocutors and those in their audiences in bettering their self-understanding and estimation who they *really* are in relation to the classification. When telling their stories focused on an aim to determine their status as autistic or non-autistic, my interlocutors drew from past experiences, current understandings, and future imagined encounters to formulate and reformulate their personal, possibly-autistic identities and develop a sense of coherence across time.

In this process of reflecting and narrating, the idea of a prototypical autistic person seemed to come into view. Though biomedical and psychological sciences have devised complex formulas to know and represent autisticness as a form of dysfunction, for those of my interlocutors who looked outside of official channels to determine whether or not an autism diagnosis "fit," autisticness occupied a space where internal and external evaluations would some time clashed and at other times match. In this process of becoming autistic, the classification was measured against and drawn into the belly of an internal, ever-morphing body of knowledge based on direct experience. For those persons wanting to locate, define, and remedy what they considered a neurological or psychiatric disorder, self-diagnosis preceded their willful subjection to the scrutinizing eye of biomedicine. For others of my interlocutors, self-diagnosis was a necessary process that would allow them to locate, define, and remedy their sense of narrative chaos – the sense that their accounts lacked coherence and was fragmented.

"I think the thing that made me realize that I was autistic was that I was so against it in the 1st place (1)[10] ... I knew sumthing was up when I saw how much I hated myself *and* what autism stood 4 in my mind (2)," Fabby explained to other autistics in *Twitter's* actuallyautistic space. A number of us in the tag were on a movie "date." A frequent actuallyautistic tag participant posted a link to a documentary film and invited us to watch and discuss on a Saturday evening. I watched the film along with self-advocates from the Association of Autistic

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[10] Note that the numbers in parentheses are numbering Fabby's tweets or posts. Because Twitter limited the number of characters its users can include in any one post to 140, users would number their posts and use shorthand so that their followers and other members of their audience could follow their line of logic.

Women and ASAN and unaffiliated others. Fabby continued, posting and numbering each successive tweet in her account:

> I didn't *want* 2 B autistic, and by all accounts, you'd never guess it by looking at me (3) ... The doctors I went to couldn't figure out what my deal was until I finally started asking 4 specific kinds of evaluations (4) ... Some really didn't want 2 respect that I could *know* that I was autistic (5) ... 'That's sumthing only trained docs can diagnose' is sumthing I heard a lot (6) ... Then I started 2 print out DSM criteria from online and check off boxes and remember parts of my life that matched what it said 100% (7) ... Eventually, I found sum1 who heard me out, I got my diagnosis and now feel justified in asking 4 help when I need to (8) ... or speaking up 4 ppl with similar experiences. Especially other adults who can't get diagnoses needed 4 disability support or closure (9).

Fabby's tweets highlight the initial sense of disarray she experienced in her pre-diagnosis life. For her, a sense of opposition to possibly being regarded as autistic clued her into a key area of her life needing resolution. Diagnosis, in this case was understood as the required remedy. In sharing her personal narrative, she contributed to an ongoing dialogue that draws in adults who received late diagnoses from physicians, those who have yet to receive those professional diagnoses, and others still who have opted for self-diagnosis of autism and peer confirmation. Others who were tweeting following the documentary "liked" Fabby's posts and left comments encouraging her continued advocacy and identifying with her story by typing comments like "This sounds like me!" or "Wah, when will docs see that we know way more about ourselves than their little tests can pick up on ... even though we're *gasp* autistic?" It is important to note that there was a detractor who participated in the event and commented on Fabby's series of tweets. This person's profile did not reveal anything about their diagnostic status or identity, but they suggested that she was "presumptuous" for believing that her "knowledge could possibly rival a licensed medical provider's." This perceived attack was swiftly rebuffed by other actuallyautistic *Twitter* users who accused the detractor of being either a "self-loathing autistic" or "an allistic who doesn't belong in the [actuallyautistic] tag anyway."

For many of my interlocutors, sharing personal stories was also a way to explore unrecognized or stifled aspects of themselves. While these stories aimed at finding out who they have really been all along, in telling them, my interlocutors experienced changes in their self-concepts. What was hidden or unknown stood to be unveiled, and inherent autisticness that may have been subdued was understood to be set free. For example, in a short post, *Tumblr* blogger AkitaBaby91, wrote:

> I always rocked myself back and forth as a kid, and when I was excited I remember I would always flap my hands like crazy. I always did this, and I don't remember exactly when I stopped. But I distinctly remember my teachers and mother told me how strange I looked doing that kind of thing. Maybe ... I just wanted to fit in, but I forced myself to stop. I sat on my hands, started biting my nails into nubs. Got into trouble all the time because I couldn't sit still. But I think that because I really didn't know I was autistic until I was like 19, I had no way of knowing I just wasn't wired to sit still like everyone wanted me to! The point is that I've been watching you guys' posts about stimming and being so carefree about being autistic, and it's like I got my autism groove back! LOL. I can rock and flap and it feels good – like I'm being my REAL self.

AkitaBaby91's short personal account highlights how she understood herself to be inherently autistic and ultimately transformed (freed to stim or rock her body back and forth and flap her hands in excitement) by her diagnosis at the age of 19. In her post, we can also see how she tries to understand how her own self-concept was shaped by the unavoidable personal and interpersonal strains that stemmed from ideologies of neurosocial normality and deviance. It was not only abnormal for her to rock her body side to side or flap her arms and hands around, it was disruptive and marked her as deviant in the eyes of her parent and educators. Yet changing her own behavior to align with the expectations and preferences of her caregivers and educators backfired. Her apparently inherent autisticness could not be effectively regulated. These ideologies produce conflict for AkitaBaby91, but also afforded her tools for recognizing autisticness and for identifying with and representing herself as a "fellow Autie."

In their study of lesbian coming-out stories, Kathleen Wood (1999) noted that coming-out narratives were distinct from other accounts of personal transformation because of the ways in which heterosexist ideologies make up such a significant "pool of coherent resources from which a woman constructs herself as sexual, gendered, attractive, and attracted" (p. 52). The self-transformation stories of lesbians in Wood's study drew upon this pool of resources even as they worked as narratives of resistance against sexism and homophobia. This illuminates how heterosexist ideology provided the constraining variables that drew out conflicts in the tellers' lives and afforded the means by which they might recognize themselves as lesbians.

As with the coming-out stories from Wood's study, that were "embedded in heterosexist ideologies, which tellers...invoke and transgress" in reinventing their identities (Wood 1999, p. 52), the stories of autistic persons and those exploring the possibility that they are autistic, are similarly embedded in ableist, medicalizing ideologies that tellers both call upon and contravene. These widespread cultural understandings about acceptable and legitimate neurology and sociality make it possible for non-autistic, "neurotypical" persons to see themselves as normative. It also enables people who identify with the autism classification to conceive of themselves as autistic. In other words, the identities of both groups are "realized in relation to hegemony" (Wood 1999, p.52). Autistic people can recognize themselves as such through the very ideologies that shape the ways in which non-autistic, non-disabled people view and (mis)represent them.

When cultural understandings of what constitutes a "normal" or "neurotypical" person run counter to the autistic person's lived experiences, they might see autisticness as a central component of their identity. The subjective experience of sensory otherness and neurosocial difference prevents them from experiencing social relationships and interactions with the material environment "normally." Consequently, the existing cultural requirements that a person should experience the world and move through it in sanctioned ways is foisted upon the supposedly disordered person and may present them with significant moral dilemmas. If they can subdue their primary interests, tastes, impulses, and desires to perform in a way that aligns with cultural expectations, should they? If so, at what cost? And if they cannot conform and are widely perceived as disruptive, should they resist forms of community reprisal or accept a marginal social position?[11]

Assessing Autisticness through Narrative

Several of my interlocutors found themselves grappling with questions of how to recognize their autisticness in ways that kept them safe. For them, sharing personal stories of their experiences as autistic people was reserved for autistic-only spaces. Autism diagnoses were not disclosed to peers, colleagues, and even family members. Formal diagnostic processes were sometimes halted mid-way when it seemed likely that a diagnosis of autism was on the horizon. Worries about what an "official" or documented diagnosis might mean for a new marriage, employment, and education possibilities, or for parenting undercut desires to know, for certain, who they really were. Similarly, some of my interlocutors who had received formal diagnoses of autism often went to great efforts to conceal their autisticness when in the company of non-autistics or neurotypicals. Some of them explained to me that they took many social skills classes, practiced restraining themselves from moving their bodies in unusual ways, and abstained from social events where they feared they might humiliate themselves in the presence of their peers.

Take for example Matt, a man in his late thirties who works as a computer programmer. I met him at the North County group. When I met Matt, who generally self-identifies as an "aspie," he explained that it is like he is "autistic-adjacent." In an interview, he told me, "I'm *technically* autistic, but not in an obvious way ... Basically, I'm sort of normal but also kind of

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[11] See AC Liang (1999) for more on how marginalized identities are conversationally implicated.

weird." Very often, he spoke to the group about the frustration he felt knowing that he was not very well understood by people he encountered in his everyday life. He talked about his struggle to get along with his colleagues at work, who were unaware of his diagnostic status. While he occasionally requested advice from group members, most of the time, he shared his experiences just to "get something off his chest." That is not to say that group members had little to say in the follow-up to Matt's accounts. Often, he received advice in spite of his proclamation that he was seeking only friendly listening ears. At a Sunday evening group meeting that met at a North County coffee shop, Matt had this to say about the social challenges he continued to face on the job:

> I try to tell myself that it doesn't matter at all, but ... it matters, right? I sit in my office at work all day, and people just sense that I'm different from them. Like, they're all nice and everything, but ... they talk to me like I'm really fragile or a kid or something. And they won't ever invite me to get drinks with them ... I'm just shy and don't think they have the same interests as me ... So maybe it would be better to tell more people that I'm an aspie, but people don't even think that exists anymore. And if I told them I was autistic they might treat me like I'm crazy or stupid or something, and that would really suck ... Like, I was talking to some guy at the grocery store the other day ... and he was telling me about all of these autistic kids that would end up shooting up public places ... Do I want my co-workers to think I'm a threat? No. So I keep my diagnosis to myself ... Just my aspie friends know what's up.

Matt's account brings to light the ways in which cultural ideas of normality and difference interplayed with his self-concept. He found that his perception of himself as an autistic man was butting up against negative cultural evaluations of autism, and assumptions that autism was not just a threat to normality, but also a growing terror (see McGuire 2016). For Matt, this was an acute point of strain that compelled him to keep his Asperger's Syndrome diagnosis and autistic identity a secret.

Unlike Matt, most of my interlocutors were not as concerned about being exposed as autistic. Many of them were openly autistic people and self-proclaimed activists or self-advocates.

For them, the acknowledgment of their autistic identity was fundamental to their practical concerns with resisting ableism and representing autism and other forms of neurosocial diversity (or neurodiversity) in new ways. In particular, publicly claiming autistic identity and unabashedly expressing autisticness in their personal accounts enabled them to claim authority and expertise on autism. Expertise that they believed rivaled or exceeded that of certified biomedical and psychology experts. In coming to know themselves as autistic, their expressed autisticness became a resource that they could use in a way that was responsive to the concerns of a so-called autistic community. As Lindsay explained in a comment in the *Facebook* group for adults on the autism spectrum:

> It's not my job to feel bad about being Autistic. And yes, I'm calling myself Autistic with an uppercase 'A.' If I could run down the street with an Autistic pride flag, I would. I'm that proud of who I am and who all of you are. For every good and great thing that I've ever done in my life, autism was a part of it. It's not that I did any of it *in spite* of autism. I probably did it *because* of autism. Why should I hide this? It's who I am.

Looking at Matt and Lindsay's respective accounts, we can see how attributed and assumed autistic identity might seem to work for one's benefit or to their detriment. Their accounts also help us understand how personal stories and shared self-evaluations help constitute spaces in which people might test out or experiment with identity categories in order to discover a sense of self that is more stable. This stability or coherence is achieved in part through telling their stories, and in the ways in which collaborators (i.e., readers, listeners, and commenters) are recruited in their efforts to argue for, attain, or maintain a intelligible autistic identity.

In April 2016, in a public discussion forum on the website *PsychForums*, I observed a conversation between user kenny_the_legend and several established forum members. Kenny was pursuing an evaluation for autism spectrum disorder, but wanted to know if his suspicions that he is autistic were reasonable. He explained to the group that from early childhood, he had struggled to communicate verbally with his family members, classmates, and school teachers. He could not remember if he engaged in the repetitive and complex body movements that autistic people, caregivers, and medical professionals commonly refer to as "stimming." He wrote: "I liked to order things and line up my toys as a kid, and I do pace a lot now. Does that count?" Though he had already received diagnoses for depression, anxiety, and insomnia, he felt that something else was going on. "The other diagnoses make sense, but I have a gut feeling that something else is probably at the root of it all," he explained. "My psychiatrist didn't want to refer me for the evaluation...he didn't think autism made much sense since I'm an adult and with the meds for my other diagnoses I get along OK. But dammit I really just want to know if I'm autistic or what's really wrong with me. Thoughts?"

Kenny's post in the forum highlights how narrative, when shared with a group of peers and a target audience with which one desires more full alignment, can help allay feelings of being unseen, unheard, and unrecognized in the ways one would prefer to be seen, heard, and recognized. The few people who commented on Kenny's thread shared a variety of opinions. Only one individual, a visitor named SopranoED suggested that his pursuit of a diagnosis was unnecessary: "now ur just getting greedy, dude. trying to add another label? jfc, ever hear the saying 'let sleeping dogs lie.' if ur not suffering what's the point? and nothings f-ing *wrong* with you even if ur autistic." SopranoED's frustrations with the original poster's complaint links up with their own experiences of trying to navigate psychiatric care as "an unemployed person ... relying on government assistance to get by." Crucially, this user revealed in previous conversations that they were unable to access effective psychiatric care due to financial constraints and had been struggling to find answers to their most pressing troubles: sensory disturbances, unemployment, the inability to sustain relationships with family, friends, and romantic partners. In spite of their strong suspicions that autism might be the cause of their differences, SopranoED refused to self-identify as autistic because they did not "have a legit diagnosis, and it would be disingenuous."

But SopranoED was not the only person to leave a comment on the thread. Several other users did, too. Faintofheart, a 51-year-old woman sympathized with him, explaining that "sometimes not knowing causes suffering." She wrote, "I know that my unofficial diagnosis gave me the push I needed in terms of personal development. My marriage of 22 years has never been stronger." Of the six responses to Kenny's initial post, five read like the one that faintofheart posted. One user commented that they "didn't necessarily know how detrimental it was to not know until diagnosis finally happened." Another wrote: "That sounds pretty autistic to me, mate! Good luck with the evaluation. They don't always get it right, so keep your head up even if the assessment says you're not [autistic]." Still, another commenter suggested that kenny_the_legend could do their own study of autism and explore groups made by and for autistic people to see if the label was "a proper fit." This way, Kenny might make like-minded friends and find his "people" without the hassle that a documented disability might bring.

Though Kenny's brief personal account and the short conversation that followed highlight a number of important issues related to access to affordable psychiatric care and the role of the patient in the evaluation process, it is notable that just knowing one's status as autistic or not, as a way to make "proper" sense of things, was understood to be key. Save for the comment left by SopranoED, Kenny's pursuit was seen as reasonable, and he was encouraged by several of his audience members to press on either in the diagnostic process or in general self-guided study of autism and possible self-diagnosis. For those commenters, the answer to the question "am I autistic or not?" had edifying power, so pursuing it was understandable and justified. Kathleen Wood (1999) wrote that "the coherence of stories is created by inferences, shared assumptions, and subsequent presuppositions that underlie the discourses of a community" (p. 47). In sharing his story in the presence of those he identified with, Kenny enabled his audience members to become his collaborators in the task of establishing the rhetorical boundaries of acceptableness with regard to his reported self-evaluation, choice to pursue diagnosis, and prior and current experiences of neurosocial difference. The troublesome absence of an autism diagnosis, for Kenny, stood to be resolved (or at least partially alleviated) with his autistic collaborators' assurances that his suspicions were not merely defensible. They were also accepted and celebrated.

The conversation between kenny_the_legend and others who participated in the forum also show the significant amounts of power that psychiatric diagnosticians – by virtue of their claimed expertise, widely recognized certifications, and the presumed validity of their foundational premises – have, and are frequently given, to bridge perceived gaps in their patients' life stories. For some of my self-diagnosed interlocutors, giving that kind of authority to biomedicine was not an option. For many them this was because of the financial burden that psychiatric care can entail. They felt "pushed" to come up with answers on their own and be satisfied with the conclusions that they came to, even though those conclusions would not be officially recognized. For others, the decision to self-diagnose with autism was a form of protest against biomedicine's, and especially psychiatry's, claims to expertise on autism. In particular, because autism was seen as being "mishandled" by biomedicine, they assumed responsibility for the ways they would interact with the diagnostic classification. Following a string of posts from disheartened diagnosis seekers, Lindsay, my interlocutor from the above interaction in the *Facebook* group, had this to say about the validity of self-diagnosis of autism:

> First, autism is not a psychiatric illness ... it's a disability. You can't medicate it away or talk therapy it away. Second, it's not a neurological disorder ... it's not that chemicals are off or injuries or deformities made us the way we are. We literally just have different

> brains. We don't need to be fixed or 'treated,' we need more people to think about how they can accommodate more kinds of people.

While the members of the group were divided in their views of the validity of self-diagnosis of autism or Asperger's syndrome, more than 200 members expressed their appreciation for Lindsay's post. Two comments that demonstrated gratitude for the post, for instance, said, "This makes me feel so much better about my self-dx, the [doctors] wouldn't even hear me out" and "I never thought of [it] this way before, but I think you just changed my mind about self-diagnosis."

It is important to note that Lindsay was not self-diagnosed. She was diagnosed by a psychiatrist nearly seventeen years earlier, at eleven years of age. It is also important to note that there is a crucial point of tension in Lindsay's post, which diminished psychiatrists' knowledge, capacities, and discernment in the diagnostic process. This tension shows up in other such anti-psychiatry proclamations. While disregarding biomedical expertise on autism and the exclusivity of diagnosticians' authority to determine who is or is not autistic, self-diagnosis proponents like Lindsay do encourage "deep study of the diagnostic criteria." "Do your due diligence," said Pili, a self-diagnosed autistic woman and member of the *Facebook* group,

> Doctors really don't know everything and they get it wrong all of the time. Remember they still don't know what actually *causes* autism, but everyone knows it's NOT an illness. YET it's in the DSM. Every week it's something new that causes autism. You're probably better equipped to decide if you're autistic or not. Just study the DSM and check in with other autistics ... In general, if you think you're autistic, you probably are.

Self-diagnosis accounts and arguments for and against the practice underscore a critical tension between prioritizing self-knowledge and assessment and the cultural assumption that lay people should submit to biomedical knowledge and testing. It also highlights how people might use personal narrative to work out, resolve, and work around problems of diagnostic integrity or legitimacy.

Ongoing debate and uncertainty about the causes of autism and the continued war against the disability fueled some of my interlocutors' distrust of psychiatry, as they regarded it as an institution given unqualified charge of the autism classification. Along these lines, it is also interesting to note that my interlocutors who supported self-diagnosis in lieu of official diagnosis emphasized the importance of "study" and learning about autism through exploration of the American Psychiatric Association's *Diagnostic and Statistical Manual of Mental Illnesses*. This highlights how, in spite of distrust of psychiatry, as a practice, there remained the presumption that the diagnostic label pointed to something real in the world and that the diagnostic criteria provided a tool that could help people identify the essential truth of autism and autisticness in their lives.

A central problem in my interlocutors' projects of self-diagnosing autism and exploring how they might fit within the autistic community and their chosen autistic groups was finding relief for the sense of dissonance between how they experienced themselves as autistics and the ways they were regarded by their chosen peers. To face this challenge my interlocutors sought out other narratives that would complement their own and buttress their claims about who they were and the labels they assumed for themselves. Similar to the ways that we recall and retell the stories and perspectives of our parents and grandparents, friends, and mentors, my interlocutors embedded others' stories of autisticness into their own "creating footings that are not general but particular" (Gordon 2007, p.154). Cynthia Gordon (2007) asserts that within the family context, shared experiences and "prior texts" support the creation and re-creation of our "footings and identities in everyday interactions" (p.154). Within the contexts of our everyday narratives, these retellings can pinpoint who we identify or disidentify with and why. By quoting another member of the autistic community or retelling another's personal stories as part of their own, my interlocutors, highlighted for those in their audience, the likeness they shared with the autistic people from whom they learned and took inspiration. Writing to the actuallyautistic tag on *Tumblr*, Fatimah wrote:

> I don't have access to official diagnosis, BUT I do have access to all of your wonderful selves. If it wasn't for you all I wouldn't know myself to be the strong autistic woman badass I am today. Stephen Shore, Rudy Simone, Donna Williams, Melanie Yergeau ... all of them had complicated diagnosis stories and people doubt them because they're so "high functioning." When Rudy wrote about people thinking she couldn't be Aspergian because she was an expressive woman and NOT your standard awkward aspie geek, I squealed. That's me, too! If you have doubts about your diagnosis because you think you ... don't seem autistic enough. Just remember, there's no one way to be autistic. And in the words of Mr. Shore, "if you've met one autistic person, you've met just one autistic person.

Through the process of identification, which entailed aligning themselves with autism, dissociating from the category of normality, and regularly participating in groups of autistic adults that were similarly aligned, my interlocutors produced and reproduced autistic identity and community. Their personal stories, which were central to this process helped form a basis for their group memberships. This was particularly visible when I observed those who were selective contributors in the groups I studied. Early on, many of them liked and retweeted, reblogged, or reposted published accounts from others rather than offering accounts of their own. Several of these interlocutors described themselves as feeling "unsure of [their] diagnoses," fearful of "coming out," and worried about being "called out" for misidentifying themselves. They wanted to be certain that when they expressed themselves as autistics they would not feel compelled to equivocate because of harsh criticism from the potential friends with whom they desired to connect. As these participants who sought legitimation for their senses of autisticness grew more resolute in their claims of being autistic, their participation within their groups habituated them to the act of claiming autistic identity and community membership, even as it opened up spaces for them to elaborate on their ongoing performances of what they increasingly understood as legitimate autisticness.

I found that self-diagnosed autistics' conceptions of authentic autisticness were centered on not only the ways these participants learned to tell their own stories, consume and interact with those of others, and navigate the physical and digital groups that accepted them as members. They were also rooted in how cultural models of disability and normality provided them with techniques of interpreting and applying embodied and biomedical information into the context of their newly discovered autistic lives and emerging autistic identities. As my interlocutors moved from feelings of uncertainty to certainty about their autisticness, telling their stories and retelling them, they developed the abilities to "create, improvise, criticize, or struggle against" (Agar 1994, p. 236, cf. Wood 1999, p. 49) visions of who they were, were not, or should be. In cultivating this creative potential, those who came to identify with autisticness and autistic community, became protective voices that shaped community debates about incorporating more inclusive perspectives on self-diagnosis and expansive views of what constitutes legitimate autisticness.

GROUP IDENTIFICATION AND DISIDENTIFICATION

Sharing personal stories with others did not just help my interlocutors develop their autistic identities. This involved identifying and disidentifying with social groups. For my interlocutors who were seeking out autism diagnoses, sharing their accounts provided a field in which they might cultivate a coherent sense of self and explore new and unrecognized social and sensory possibilities. In this field of exploration and disclosure, my interlocutors' narratives supported their identification with autisticness and disability and their disidentification with normality and non-disability. Sharing their stories also drew out social links between them, could-be autistic persons, and their target peer group, individuals who already knew themselves to be autistic. When my interlocutors aimed to recruit peers as co-assessors in their self-diagnoses they were often careful about where in the digital environment they shared their narratives. In particular, they were careful to tag their posts appropriately, using the hypertext markers that would identify their target audience (i.e. actuallyautistic).

This was a supportive move for two reasons. On the one hand, tagging their posts in this way increased the likelihood that it would be encountered by a population of autistics who were more apt to accept self-diagnosis. People who participated in this hypertext space were typically proud to claim their autistic identity and membership in the autistic community. On the other hand, tagging in this way discouraged detractors who might feel inclined to confront prospective autistics with disparaging commentary. Detractors who commented on actuallyautistic posts could be countered by more supportive others, and might open themselves up to receiving critical direct messages and even posts warning actuallyautistic participants on the site about their supposed bigotry. For instance, in December 2014, in response to a detractors' comment on *Tumblr* that discouraged a participant in the space who had chosen self-diagnosis over official diagnosis, Fatimah composed and circulated a post for actuallyautistic participants. She wrote:

> Just an FYI, everyone, 3MealCabal is an ableist and bigot. They honestly think that being autistic means you can't know who you are and that *everyone* has the time AND money to get good, *quality* psychiatric care and evaluations for autism. And that getting an official diagnosis is always a good idea for everyone ... For some of us, it's a risk to our families and livelihoods to have the official documentation. *sigh* I just don't have the time and patience for this anymore. Their posts might be triggering for you if you're struggling to accept that you're autistic. I'm blocking them ... I suggest you do that too.

Fatimah's post was liked, commented on, and circulated for several days in the actuallyautistic space, and it accumulated almost 150 notes in about four days. While the impact her post had on 3MealCabal was unclear, her actions show how the actuallyautistic space could be guarded by people who participated in it. It also shows how the space was made to constitute an affirmative narrative arena, as many of the tag's participants assumed that prospective autistics were already "actual autistics" who had yet to be convicted of their own autistic realities. By pointing their content to the actuallyautistic hyptertext space, which was generally affirming of self-diagnosis and peer confirmation, self-diagnosers made themselves available to connecting with their preferred autistic peers and opened up avenues up for developing, legitimating, and maintaining their autistic selves and membership in an autistic group.

The above interactions demonstrate that personal narratives of autisticness are not isolated forms of communication. The ways in which my interlocutors developed their accounts were influenced by their chosen modes of relay, the content of the stories, and the generally agreed upon purposes of the social spaces in which they were embedded. In my research, I encountered diagnosis, self-exploration, and, ultimately, self-transformation stories in both physical and virtual spaces that were (1) created for casual conversation, (2) used strategically by autistic people to form and develop groups of autistic peers, and (3) routinely used as sites of information that could be mined for their ability to highlight points of conflict within autism discourse and expounded upon in future personal stories.

The ways in which my interlocutors' personal stories, when linked up with requests for peer assessment or diagnosis, seemed to be handled differently depending on whether the conversation took place online or offline. In the offline groups, such requests were often rebuffed and authority of diagnosis was expressly given to biomedical professionals. Conversations with group leaders about this observation generally landed on concerns about possible legal ramifications of confirming an erroneous self-diagnosis. "A lot of the members look up to me," said Adam, leader of the Mid County group.

> I'm not really opposed to self-diagnosis, but I don't consider myself a doctor, and I don't think anyone in our group is at the level where they can say anyone is autistic and be 100% sure ... I don't allow [peer diagnosis or confirmation] in my group, and if I see or hear it, I cut that conversation off *immediately*.

I saw this play out one Saturday afternoon in the summer of 2015, when Sam, a 58-year-old woman, visited the Mid County support and activity group meeting with her friend, Anna. The group was seated for a day of board games and laid-back conversation when the two visitors entered the room. In introducing themselves to the group, Anna explained that she was not autistic. She was only there to support Sam, whose "lifetime of intense struggle" with the social and sensory demands of work, friends, and family so exasperated her that she was “damn ready to give up completely.” Sam, we learned was experiencing situational mutism and could not speak in that moment. Anna told us that Sam only learned about autism recently, understanding that “it was that kids’ disease ... when she first heard about it on the news a couple of years ago."

More recently, Sam had learned from an online message board for people suffering from major depressive disorder that adults could also be diagnosed with autism spectrum disorders. When Sam was suddenly able to speak, she chimed in with a rough, quaky voice, “I had no idea. I was curious because the young lady on the board had Asperger Disorder and she was telling us about her mental health issues and it was like she was telling my whole life story ... I had no idea why I've been how I am, and I was learning, and I’m *still* learning ... Maybe I have autism or Asperger Disorder, too.” Anna finished their introduction telling the group, “That’s actually why we’re here...Do y’all think Sam has autism?”

Lei, a regular member of the group, quickly chimed in: "I think she probably does. Like, most people who think they're autistic probably are, I assume." Before she could say much more, Adam terminated the conversation, saying, "No, guys, we can't do that. This isn't that kind of group." He explained to the two visitors that while they were welcome to take part in the group's fun, no one in attendance was in the business of "playing diagnosis games." He suggested that the guests "ask questions, compare notes–that's fine. But I think it would be best if you didn't ask us what we think your diagnosis should be. You have to figure that out with a doctor or do your own research."

The above interaction is representative of the ways I observed my interlocutors interacting with others' personal narratives and navigating requests for peer diagnosis during my research. Although in offline sites, within the contexts of social support and activity groups, I found that my interlocutors were generally reluctant to respond to such appeals, in online sites, responses to these stories and appeals were variable and seemed to depend on the hyptertextual space to which the conversation was targeted. Fatima's post about 3MealCabal illustrates that dynamic. Most of my interlocutors, whether online or offline, refrained from explicitly diagnosing those who searched for answers, and the degrees of peer involvement on blogging sites like *Tumblr* and *Twitter*, or in autism discussion forums on sites like *WrongPlanet* or *PsychForums*, where the risk of legal consequence or exposed identity are much less severe, showed how modes of engagement shaped perceptions of the tellers' accounts of confusion and curiosity in the self-diagnosis process. Where some refused to offer their recommendations, many others offered resources and advice, made referrals to established autistic self-advocates, responded with their own personal stories as tools of comparison, or put forward questions and issues that provoked further thought and investigation. Some others offered no resources but would routinely check in on their new acquaintances to learn how they were coming along in their self-inquiry.

As demonstrated in the above interactions, throughout my research, I found that my interlocutors' social bonds with one another were cultivated through narrative telling, which enabled them to share in practices of sympathizing, consoling, theorizing, and debating one another. Engaging in these practices as part of their casual discourse helped draw together these people from sometimes vastly different life experiences and support them in discovering some shared ways of behaving, seeing, and understanding themselves and others. I found that this was key in helping my interlocutors foster the sense that they belonged to a community of autistic people (see Ochs and Capps 2001). For those who sought out answers to questions about why they felt "out of place" or "on the wrong planet," being drawn into a group of peers meant becoming a proficient participant in those virtual and physical autistic spaces in which they hoped to take part.

Offline, in social and activity groups, this meant using similar language to describe oneself, one's sensory experiences or interactions with non-autistic others. It also meant moving one's body more freely or learning new ways to move. This is largely because "stimming" is so often stigmatized by non-autistic people, and in these designated spaces of autistic expression, stimming was known as not just an autistic way of moving the body. It was a way of expressing comfort and belonging in the presence of friends. Online, this sometimes meant posting a video or GIF (an animated image) of stimming, expressing pride in one's autistic identity, using similar language to describe autistic and non-autistic people, and using hypertext (in particular the actuallyautistic tag) and links in ways that were consistent with how others in the community used them.

Online, engaging in these practices on a regular basis, afforded new group participants the opportunity to build rapport with individual group members as well as grab the attention of their larger target audience. Building up this audience, increased the potential for highly collaborative interactions. That is not to say that sharing in this way was without risk. For my interlocutors, telling their stories before a rather large virtual audience could mean that their voices were going to be lost in a flurry of social activities or taken in unexpected directions and derailed. Yet, I observed that my interlocutors and others in these spaces were more likely to have a sense that the narratives they were receiving were familiar. These participants were often most responsive and willing to give advice, and if needed, protection or defense. While those who felt unsure about their autistic identity were less likely to offer possible solutions, they were frequently eager to commiserate, respond with their own anecdotes, and follow along as their new friends' stories developed and their senses of self were transformed.

CONCLUSION

The accounts that I have discussed in this chapter demonstrate how personal narratives worked for my interlocutors, serving as both a means of discovering their autistic nature and managing autistic identity and community belonging. Narrative, therefore, served as the connective tissue between the widely circulated, unstable notion of an "autistic us" for which many reach and the intimate, direct, and often painful experience of uncovering an "autistic me." In general, sharing their experiences allowed my interlocutors to receive encouragement from autistic others who tended to support their efforts to recast their life histories by "fitting them into a shared and collective standard master narrative" of autisticness (Ayometzi 2007, p. 45).

Narrative scholars have proposed that our lives emerge as we work to tell our stories and make sense of them. Across my online and offline research sites, I found that while verbally relayed narratives that took place in-person and over the phone differed in form from those that were text-based and published in the online blogosphere or in discussion forums, the episodic forms they took were similar. Though the narratives were different in terms of the modes of communication and surrounding interactional conventions, they were similar in a key way: they were seldom fluid, seamless, and comprehensive. The incompleteness of these narratives resonates with our current understanding of autism and autisticness today. Even as US biomedical culture struggles to define autism and relentlessly works in pursuit of the goal of finding its causes and cures, for those who self-identify as autistic, or who think they might be, the inquiry doesn't stop even after diagnosis. And while it was seldom discussed within the groups within which I researched, there are many who understand that diagnoses are not fool proof–a person can be incorrectly classified or outgrow the particularities of the classification.

For example, Myles, a 26-year-old Black woman from North County had struggled to express within her chosen autistic spaces what it meant for her to be undiagnosed with autism. "I was autistic until I wasn't. I was on the spectrum for seven years and thought that I knew what that meant." For Myles, race was a central part of her autistic identity. As a Black autistic woman, she envisioned herself as one who forced the issue of intersectionality in the disability spaces in which she participated. This work became a central part of how she understood herself and her purpose. "Finding out I was autistic in high school was hard. I was a wreck until I graduated. Then I got more involved in self-advocacy and they taught me that I was autistic with a big 'A', so that's who I was." [12] As Myle's pursued answers to her frequent panic attacks and depression, however, she found that her new therapist, a psychologist specializing in mental health issues faced by members of the African diaspora, was keen to second guess her autism diagnosis and propose an alternative–PTSD. When asked why she opted to consult with a doctor with this specialty, she told me that he came as a strong recommendation from a family member. Telling me about her reaction to his suggestion that she had never been autistic, she said, "I was so mad at first ... I was like, 'they're just ableist and don't want Blackness to be associated with autism,' but I was curious about PTSD and I heard them out ... And it started to make sense." For Myles, autistic identity and the sense that she was autistic unraveled as she learned to more effectively manage her anxiety and past trauma. "When I was autistic, I was *so* autistic," she told me, "but right now, I'm OK just being Myles and not *autistic Myles*...I'm working through my anxiety and my PTSD every single day."

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[12] This way of conceiving of autism and autisticness is not unlike the d/Deaf distinction within Deaf culture and community.

While Myles's account was unusual, I find that it demonstrates how our identities and the ways we identify with different groups might change with time and circumstance. This is not unlike the ways that the diagnostic classifications that we might identify with transform. Autism, like all other psychiatric classifications that are subject to revision or removal from the classification manual, remains unstable. It has been unstable from its inception as new information pours in, methods of evaluation develop and approaches to categorizing wellness and debility come to the fore and fall by the wayside. The apparent sturdiness of the autism classification (and all psychiatric classifications) mirrors the apparent sturdiness of the institution that has been charged to tend to it. Because institutional integrity is essential to garnering the consistent support of a public that regards itself as beholden to the white coat,[13] the American Psychiatric Association's claims to scientific knowledge–which is generally deemed incontrovertible–are received in full. This is not to diminish the significance of the diagnostic classifications developed by the APA but to highlight a key area of incongruence. The seeming finality of a diagnostic protocol and ascribed medicalized identity can be quickly overwritten by an alternative (and arguably more convincing) approach. Everyday accounts of identity and group membership shifts (especially around the now defunct Asperger's syndrome classification) shine a light on the ways this sort of unsteadiness serves as an impetus for major narrative revisioning at the level of the individual and group.

Crucially, this instability, which speaks to broad concerns within the philosophy of psychiatry regarding the validity of contemporary diagnostic processes and US psychiatry's claims about mental health, illness, and disability, underlays a social arena where senses of self and notions of community and belonging are being produced, reproduced, and revised. Autism

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[13] Social science scholars like Salhi (2016), Wind (2008), and Levi-Strauss (2016) have discussed the effect the doctor's white coat has on interactions with patients and lay people writ large.

occupies a rutted discursive terrain, and within this arena that my interlocutors' disclosures, inquiries, and conversations, show how they manage to identify autism and autistic community as solidly real in their experience. The subjective nature of autistic narratives brings into view the power of everyday theory making, the senses of identity, belonging, healing, and hope that are often borne out of the practice of putting words to experience and ways of seeing the world.

Throughout my research, I found that my interlocutors' stories were sparked by the fruitful friction between the sense that they wished to uncover a seamless and coherent central plot for their life stories and the desire to explore and describe the nuances of their experiences, modes of questioning, and understandings of their position in the world. Scholars have shown that the desire completeness and consistency in one's narratives makes good sense (see Ochs and Capps 2001, Wood 1999, Ayometzi 2007). Linearity and coherence support a sense of unity and help tellers identify the particular pivot points around which the pressures and possibilities of everyday life are organized. In working to make connections across the gaps that seem to form and reveal themselves over time, there comes the opportunity to not only reformulate understandings and recast recalled events, but also to create a sense of immediacy that might displace senses of disconnectedness and remoteness, resonate with one's self-concept, and bring together what is misunderstood and dislocated into a coherent flow.

Autistic narratives are not significant just because they serve as a form of life telling and writing like most others. It is particularly powerful because encoded in its expressions are explorations of what it can mean to occupy sites of contrast in the context of biomedical pathologization and the celebration of marginalized disability identity. Importantly, the cultural norms thrust upon all bodies make it so that disability cannot be welcomed or thoroughly accommodated because of its "deviant" nature. Disability is frequently pushed to the fringes of social consciousness and physical world spaces in the hopes that it will soon disappear.

Otherwise, it is targeted as a great enemy to war against.[14] Disability's disruptiveness of cultural assumptions about normal bodies and brains indicates, therefore, indicates a major conceptual misalignment between cultural desires for the complete melding of society to the ideal or norm and the actuality of biological and sociality diversity.

The reality that the cultural mandate attempts to produce – ordinariness in our form and comportment–shone through my interlocutors' narratives. They understood themselves to stand opposed to culturally sanctioned images of normality, even as they celebrated denigrated or ignored ways of experiencing the world. Therefore, these accounts, even when exchanged in private between peers, might to be seen as forms resistance against pressures to be sedimented beneath cultural narratives of disabled people as pitiable and ineffectual members of our communities. In telling the stories of their lives, my interlocutors have developed tools for crafting, sustaining, and revolutionizing their communities and past, present, and future selves.

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[14] McGuire's (2016) War on Autism explores how cultural narratives of autistic difference and deviance sponsor violence against autistic people.

2

RHETORICAL CHARACTERS OF AUTISTICNESS

In this chapter, I explore how autistic adults interact with, create, and circulate stock characters of autisticness to strengthen their autistic identities and senses of group and community belonging. Centering autistic conceptualizations of autisticness and the ways they interact with autism stereotypes highlights how autistic adults understand how their lived realities align with popular portrayals of autistics and biomedical theories. As the population of self-identifying autistic adults diversifies and increasing numbers of autistics of various gender, sexuality, racial, and even functioning level identities use their platforms to speak about their experiences, a broader view of autism (as a classification) and autisticness (as ways of being autistic) emerges. Additionally, I suggest that this diversification supports the autistic community's continued effort to pivot away from assumptions that autistic people must occupy a disempowered rhetorical position in relation to certified medical experts who have not only dominated autism discourse but configured rhetorical characters of autisticness in pejorative terms.

This chapter also explores how stock characters of autisticness emerge from and become incorporated into autistic adults' multifaceted self-concepts. I propose that the emergence of new, increasingly varied characters points to an expansion in the autistic imagination of autistic possibility, helping them accommodate and incorporate new and established community members with evolving understandings of who they, as autistic people, could (rather than should) be. I found that my interlocutors senses of autistic selfhood were produced through dialogic processes that were critical to their projects of satisfying a desire to become drawn into and entangled in, to varying extents, their chosen groups. These projects of becoming one who could belong were shaped by the way autism and autisticness were understood, and they were protected by informal group or organization-based gatekeeping practices. These practices aimed to design particular kinds of relational spaces that attracted some autistics and repelled others. These projects of becoming were also grounded in repeated intrapersonal assessments that motivated my interlocutors to test group and community tolerance levels for revised personal narratives of autisticness. This was particularly important for my self-diagnosed interlocutors.

With these foci, this chapter explores how my interlocutors' affinities for different imaginings of autism supplied a much desired sense of legitimization and sponsored experiences of belonging to a group and/or community of autistic people. Therefore, this exploration is rooted in the assumption that foregrounding intrapersonal evaluations of autistic possibilities (which may be represented by the stock characters of autisticness that are in circulation today) is one way to grow our understandings of how group identification works and how this identification enables increased entanglements with a group. I found that these entanglements and obligations to group were fundamental to maintaining a "legitimate" autistic identity and peer confirmed connection to a broader, more abstract autistic community.

CHARACTERIZING AUTISTICNESS

In using the notion of rhetorical characters of autisticness, I refer to blueprints or patterns of possible selves that represent assumedly legitimate or acceptable embodiments of autism. These rhetorical artifacts play prominently in the broader field of autism discourse, which is distinguished from autistic discourse because of its inclusion of people who may not be autistic but have something they would like to say or do about autism. These individuals and their contributions to autism discourse have significant influence within autistic community, which self-identified autistic people understand to constitute an autistic-only domain. In this broad, widely dispersed community, autistic adults interact with one another across digital and physical world locales, celebrating in the "safe spaces" of offline and online groups and hypertext spaces shared affinities for idealized ways of defining autism and autisticness writ large. Such celebrations, when recognized as legitimate by autistic others, were powerful because they allowed many of my interlocutors to find redress for their often subordinated identities.

In presenting data from my various field sites in this chapter, I move from the understanding that my interlocutors' choices for their preferred autistic groups were a product of interactions between their self-concepts and their objectives in becoming involved with a particular group. For my interlocutors, becoming involved with their chosen groups and attaining recognized membership in them enabled them to fortify their sense of being authentically autistic. Senses of belonging and/or peer validation were also important drivers in their processes of discovering resonance between themselves and extant and emergent rhetorical characters of autisticness. Importantly, my interlocutors' desires for social belonging and connection challenged still-pervasive cultural assumptions about autisticness as asociality (see Yergeau 2018, Organization for Autism Research 2016, University of California-Davis 2018).

My interlocutors demonstrated that ways of conceiving of their autistic selves through "image" or "character" were measured against, and recalibrated in light of, the perceived images or characters of their target collectives. Essentially, my interlocutors sought out similar others who might reflect to them more robust portraits of themselves through their interactions with them (Goffman 1959). In this way, seeing their autistic selves in a group of autistic others, my interlocutors expressed, autisticness was made real and validation was keenly felt. Efforts to sustain that connection through continued group participation and professed membership grew to be key expressive modes that supported their self-images. Stephen, a co-moderator of a public *Facebook* group people with Asperger's syndrome explained it like this:

> I still identify as an Aspie even though they don't diagnose it anymore. That's the diagnosed I was given a long time ago, so it's the one that feels most natural to me. It took me some time to come to terms with the diagnosis when I realized what it was. I dealt with all the negative stereotypes for years before anyone was talking about merging all the labels into one. I identify as autistic and most of the people do here, I believe, but that's like a very general label ... ASD as a diagnosis does *not* resonate. I can't identify with non-speaking autistics children and adults even though I respect them and think they deserve the best. This group is really a nice place because it tells people who have this diagnosis ... that their *identity* is still valid even though the diagnosis went bye-bye.

Following the 2013 changes to the *Diagnostic and Statistical Manual of Mental Disorders* that eliminated the Asperger's syndrome diagnostic classification, many Aspergian's experienced panic, believing that a vital part of their personal identity and the connective tissue for many of their social relationships would be eviscerated. By continuing to participate in groups that welcomed people who still identified with the Asperger's label, like the one on *Facebook*, autistic adults who self-identified as aspies or Aspergians could maintain a key part of their identity, maintain the integrity of their personal narratives, and sustain their relationships to other self-identified autistics who held fiercely onto their aspie identities.

PROSPECTIVE MEMBERS' GOALS

Shortly after his diagnosis at age 39, I met Roland, an “old autie” from southern California. It was the summer of 2013 and I was attending a meeting for SCAA (Southern California Autistic Activists), a short lived group near the Mid County group in which I studied. I sat beside Roland at that meeting, which was held on a weeknight, in a large conference room in the basement of one of the area’s public libraries. It was Roland's second time attending the group, and in later conversations, he explained to me that he had some trouble choosing a group to commit to: “I wasn’t sure which one I would call home,” he told me. He wanted to have fun, but more important, he determined, was his aim to be an effective self-advocate. Because he had limited free time due to his busy schedule as a self-employed computer specialist, he felt that he could choose just one group to focus on and devote his time and energy.

> When I commit to something, I put my everything into it. That's why I had to make sure the group I said 'I do' to would work out, or at least work with my personal goals. If it didn't do that, it would be a total waste of time ... I'm successful in business because I make my goals match my activities. That's true for my hobbies and my social life, too.

Roland told me that this branch of SCAA "fit the bill" because he would "get to hang around other autistic people who are open minded" *and* be part of an organization that's explicitly dedicated to "bold" autistic activism, "the kind that makes waves in the convo ... That's the kind of person I am, in general, so it works well with how I see myself moving forward ... as an autistic activist."

Roland's example shows how positive identification with a group or organization corresponds to the belief that the group or organization's actions are in alignment with its claimed collective identity. This example also shows that these groups were attractive because they spoke to aspects of (prospective) members' self-images that were durable, and they could accommodate personal growth and development. Seeing himself as an activist in the making, even when he had yet to *do* activism, was enough to motivate his connection to the group and desire to increase his involvement with it. This demonstrates that when my interlocutors perceived an alignment between their self-concepts and a group's image, they were encouraged to take stock of their beliefs about what "defined the organizations" and imagine how they might participate in it in a way that supported both their projected visions of themselves and the continued development of the group (Dutton, Dukerich, and Harquail 1994, p. 243). In the examples that follow in this chapter, we will see more of how this worked in my online and offline field sites.

DIVERSIFYING THE AUTISTIC CAST

Following Jack's (2014) claims that the autism community is populated by participants who buy into and perform stock characters of motherhood, fatherhood, medical expert, and Aspie geek, I argue that *autistic* communities are similarly constituted, through the rendering and complicating of a set of prototypical autistic characters, including Jack's (2014) "aspie geek." Autistic groups' commitments to expanding the range of available characters (and consequently their membership) figure into their group images (as sorts of brands). In this way, they attract a more diverse cast of autistic "kinds." These group images are primary attractors that represent for potential members possible spaces of belonging but also make available a set of membership-approved ways of being legitimate autistics and expressing shared identities and affinities. I propose that these group images work with and alongside the stock rhetorical characters of autisticness that autistic adults draw into their individual self-concepts and personal narratives.

Though autistic self-advocacy is not new, the emergence and proliferation of various forms of social media platforms since the early 1990s, especially in terms of short and long-form blogs and web forums, supported the circulation of autistic people's personal narratives and critiques of the narrow range of rhetorical characters of autisticness that circulated in autism discourse (Sinclair 2010). Importantly, these understandings might never have seen the light of day or been circulated without an increasing range of accessible platforms. Before these digital platforms came about, smaller groups of self-advocates networked and communicated via pen pal lists and meetings at yearly parent-driven autism and developmental disability conferences (Sinclair 2010). With such limited reach, self-advocate peer groups remained small and with narrower conceptions of what constituted "real" autisticness. Consequently, in those earlier self-advocate groups, images and characters of autisticness reflected the limited imagination of what constituted autistic possibility (Robison 2009, Hughes 2016, Heilker 2012).

It is important to note that these limits were predominantly set by biomedicine and who the diagnostician deemed to be reasonable candidates for certain diagnostic classifications. For example, before 2010, in spite of the popularity of autistic women like Donna Williams, Liane Holliday Willey, and Temple Grandin, girls and women were generally understood to be poorly suited to the pervasive developmental disorders. Rett syndrome, which was thought to be a condition related to autistic disorder at the time of the publication of the fourth edition of the *Diagnostic and Statistical Manual of Mental Disorders*, posed an exception. It was the only autism-related classification that was given almost exclusively to girls. It stood, therefore, in stark contrast to the other pervasive developmental disorders, which were most commonly ascribed to white male children. In 1999, five years after the publication of the *DSM-IV* (1994), the syndrome was discovered to be the consequence of a genetic brain disorder that is carried on the X chromosome, explaining why medical professionals associated the condition to girls.

Autistic Social Justice Warriors

Digital media has afforded a much broader reach for autistic self-advocates, so that groups of autistic adults are increasing in member diversity and have incorporated more ways of representing autisticness across gender, racial, ethnic, age, and sexuality categories. It is largely in and through digital media platforms (i.e., short and long form blogs, social networking sites, web forums, and group management and event coordination platforms) that my interlocutors and others within the broader autistic community have determined that it is their right and responsibility to participate in autism discourse and to make and take part in designated autistic spaces. Stock characters of autisticness are an important mediator in these kinds of engagement, serving as icons or symbols of possibility that supported autistic people, whether they were professionally diagnosed with autism, self-diagnosed, or still exploring their diagnostic options.

For my interlocutors, these characters supplied much needed focal points as they attempted to establish, define, and come to terms with the ways their autistic experiences measured up against self-advocate evaluations of autistic distinction, rhetorical and material marginality, debility, and medicalization. Through this assessment work, they identified gaps in representations of autistics and determined that such absences should be remedied. My interlocutor Seva, for example, explained to me that they struggled for a long time to find a group to which they belonged. As an intersex autistic person, they attempted and failed to find community in offline autistic groups in their hometown outside of Nashville, Tennessee. "If you meet me in person, you'd see that I don't look like your stereotypical man or woman, which can be confusing for people," they recounted.

> I went to a couple of small groups that I found on *Facebook* and *Meetup.* Both times I was basically traumatized because I was treated like a monster ... It was horrifying because I expected autistic people to behave differently since we are put down as a group so much ... I went to the first group, and it was the first autistic group I ever went to ... I felt rejected right away because I was ignored by everyone and they looked at me like they were disgusted. Then, I went to the next one, and it was even worse because they looked at me like they were grossed out ... some of the autistics there whispered to each other about me, and a couple of them had the nerve to tell me that I looked 'strange.' They called me names and asked me what I was doing there ... I mean, it was an *open* group for autistics ... They even tried to use the Bible on me and called me a sinner. I was like, 'honey, I *am* a Christian and you're the one sinning right now ... I didn't feel safe so I left right away.

After their experience with the second group, Seva stopped attending offline groups and decided that they would focus on online groups instead. "I have a relatively small but growing following on *Tumblr*," they told me.

> I sometimes get hate messages in my DMs, but usually people are pretty nice and circulate my posts about intersex acceptance in autistic community ... For the most part, the autistic people on the site who are freaked out by intersex people don't bother me and

> if they did, I bet other autistics would tear them apart, even if they don't usually care about intersex issues specifically. There's a better checks and balances of haters and social justice warriors on [*Tumblr*].

Seva's account presents an example of how particular kinds of groups afford greater opportunities for belonging. The members of the smaller offline groups that they attempted to partake in possessed a limited set of acceptable options for not only the kinds of autistics who belonged in their group but for the kinds of people they were willing to tolerate in general. While this dynamic does not hold true for all offline groups, it does speak to how the size (and arguably the location) of a group could present a constraining factor for prospective members, impacting the likelihood that one who occupies multiple marginal identities will be received as a member and protected. On *Tumblr*, thousands of people use the actuallyautistic hypertext space and interact with one another. In this "group," as Seva shows, it is far more likely to find members who will readily accept them, no questions asked, and even come to their defense if others there behave in bullish and bigoted ways.

In my research, I saw that there was tension between the established characters of autistic absence that came out of the medical model of disability and self-advocate-composed characters of autistic possibility. In autistic spaces both sorts of characters vie for playtime in autistic narratives and self-concepts. As my interlocutors attempted to sort out which character or combinations of characters were most relevant to them, they dealt with questions about whether or not they were truly autistic, autistic enough, or the “right kind” of autistic. These questions helped them determine which autistic groups they wanted to become involved with and, sometimes, which groups they could no longer stand to participate in. In the above example, taking part in a group that had a strong affinity for social justice was critical for Seva. In gauging the suitability of different groups online or offline, my interlocutors identified and highlighted the autistic traits and affinities they possessed and that were valued by their target groups.

When group images and my interlocutors' self-images intersected they offered a validated portrait of autistic possibility and a potential space of belonging. I found that my interlocutors used those portraits to assess their forms of autisticness and determine that they were recognizable as people who were "actually autistic." Autistic organizations like the Association of Autistic Woman (AAW) and the Autistic Self-Advocacy Network (ASAN)[15], woo members through their promotional materials and because of their reputation amongst members of the broader autistic community. For instance, on ASAN's official website, they include in their policy statements a declaration of their commitment to being inclusive and respectful of all autistic people in their activism. They assure autistics from diverse backgrounds that they see them as part of the autistic community regardless of the ways in which they fit or diverge from the stereotypical images of autisticness and the myths about autistic inadequacy that still dominate autism discourse today. "We view the Autistic community as one community," they write, and state that "In the interest of ensuring for everyone the rights of communication and self-determination," they are working "to change public perceptions of autism ... that have led to discrimination and abuse" (ASAN, "Position Statements"). In addition to statements about community services and public funding, employment discrimination, inclusive education, and the rights of autistic people (and other disabled persons) to resist forced sterilization and have families, they refer to the "Autistic Community" as inclusive of "people who have been identified

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[15] The Autistic Self-Advocacy Network (ASAN) was founded by two autistic men, Ari Ne'eman and Scott Michael Robertson, in fall of 2006. The non-profit organization has 501 status and has asserted itself as a key player in representing the autistic community in public policy conversations related to autism.

by professionals as being on the autism spectrum and to those who are self-identified" (ASAN, "Position Statements").

They add that it is the organizations stance that the reasons why people pursue professional (or "official") diagnoses are a part of the self-determination that they value and desire all autistic community members realize. Furthermore, they acknowledge various barriers to accessing professional psychiatric diagnosis, including

> financial constraints, scarcity of diagnosticians specializing in autism spectrum disorder in the adult population, desires to maintain informality in seeking accommodations in education or on the job, and importantly, the "political view that our community should not have professionals as its gatekeepers. (ASAN, "Position Statements")

ASAN's position statements highlight efforts to break the molds presented by biomedical stereotypes about autism. In doing so, they present themselves as opposed to the kinds of rhetorical characters that pervade autism discourse. Yet, I argue, they present a rhetorical character that they, as an organization, define, embody in their diverse staff and extensive social media presence, and enact in their political advocacy, and that they invite their supporters to "wear" and perform as a particular kind of autistic self-advocate. This stock character of the autistic self-advocate who is vigilant in their commitment to preserving the integrity of all autistic people and who has a greatly expanded conception of who counts as autistic is seemingly portrayed as the anti-character character that the autistic community needs to effectively proclaim and issue forth vital socio-political reforms for autistic people. While all of my interlocutors did not support ASAN, all did know about their work. "Who are they to decide what the autistic community should be," expressed Corey, an Aspergian man who rejected the validity of self-diagnosis of autism spectrum disorders. "They're making it so autism doesn't mean anything at all." Those of my interlocutors who did support the organization, either financially or in spirit, commended its efforts to open up the autistic community to groups of people (especially gender, racial, sexuality, and ethnicity minorities) who had been presumed unsuited to the diagnostic label.

Stock characters of autisticness, like ASAN's, which involve ways of characterizing both the autism diagnostic classification (as open to the interpretation of self-diagnosers) and the social and physiological reality of autisticness (as unique and worthy of celebration) show how autistic self-evaluation and self-reporting operate as "forms of constitutive rhetoric” (Jack 2014, p. 130). These characters do not just describe neurobiological actualities that exist in the world. They also help legitimize those autistic people who have been diagnostically marked because of their supposedly pathological behavioral and cognitive dispositions. As a consequence, they open up new possibilities for self-recognition and belonging.

Intersectional Self-Diagnosed Autistics

I met Vic, a 24-year-old, self-diagnosed autistic person through a common friend on *Facebook*. Over the course of several interviews, they told me about how they circumvented psychiatric diagnostic protocols by committing to deep study of autism symptomology and acquiring for themselves peer and parent confirmation of their self-diagnosis of autism spectrum disorder. Vic "felt" that they had “severe limitations" to becoming part of an autistic group, because of the apprehension they felt about coming out as both autistic and genderqueer. Because they understood both their autistic and queer identities to be central to their self-concept and image, the possibility that they might join a group and become involved in it, only to be rebuffed after coming out prevented them from seeking out offline groups and left them watching online interactions between autistic people from the sidelines. They told me,

> When I self-diagnosed I hadn’t come out as genderqueer and I identified as a woman ... but I think I was just afraid to come out at that particular time. I thought it would be too much. People would be all like, ‘oh, she’s autistic and now she’s genderqueer, too?

> Bullshit, she's crazy, that's what she is. I didn't want people to mix up autism and gender identity and say that autism is like a risk factor of gender identity issues. Even though that's something people are trying to argue now ... I ended up sticking to my couple of [neurotypical] friends from school. They're super dorky so they got it, but I would go online and see all these fun conversations but feel like it wasn't my place to take part. I felt like a wanna-be autistic.

Vic heard of AAW a couple of years before our conversation, when the organization's content seemed more exclusive to self-identifying autistic women and girls.

> I hadn't come out as genderqueer but I knew that about myself, so it was just a matter of timing when I would come out. I heard some good things about AAW but still felt isolated except for a few of the forums I would post on here and there. I didn't really interact with other autistics much, partly because I was ashamed that I didn't have that official diagnosis ... Well, at some point, I saw on Facebook and Tumblr that they had some committees doing work on gender, so I got curious, started to read up on them. I wasn't sold right away, but I still preferred their message to the main autistic self-advocacy organization [ASAN] ... because the main mouthpiece wasn't a dude.

Though Vic feared interacting with peers in a less structured online autistic space, like in the actuallyautistic hashtag on *Tumblr* or in groups on *Facebook*, they were willing to take part in a non-profit organization like AAW. I suggest that this is because the organization, with its structured ways of interacting (between volunteers, committee chairs, executive board members was protective. Given the organizations stated priorities and reliance on public support, they were more likely to intervene in instances of conflict between organization participants and make needed accommodations. Furthermore, because the nature of interactions between participants and organization leadership were task and project oriented, there was less emphasis on collecting and assessing the details of Vic's personal identity. This buffer enabled them to participate as they wished on projects they were interested and divulge as much information about themselves as they preferred. As Vic explained,

> In a weird way, they were my link to the [autistic] community ... But once all the different committees and blog posts and organization alliances between AAW and LGBTQIAA friendly groups popped up and queer people who were in the org started coming out, I

> was so freakin' excited. I was like, 'where do I sign up?' I liked that it was becoming slightly less focused on just women and girls and more focused on gender minorities in general. So far, I've volunteered for a couple of their projects and spread the word about things they have going on...They just seem so open minded about all of it, and everyone there is SO nice. It makes me feel like I can be a part of the autistic community without being afraid that people are going to say that I'm giving it a bad name because I'm queer too! ... they're my anchor, if you. Even though it's mainly about autistic women, I don't think that's all they care about ... I ... consider myself a member ... and since I've been spreading the word about their stuff, I've been forced to interact more with people in different parts of the [autistic] community, and ... that's been a huge gain for me in terms of feeling more and more legit as an autistic.

Vic's account highlights how significant a role the sense of freedom to express one's worldview, multifaceted identity, values, and opinions within a space of support can play in their group identification process. For Vic and many of my interlocutors, this sense of freedom to express themselves was inextricably tied to a group's being (or openness to becoming) welcoming of a more expansive range of expressions of autisticness. When they perceived that their "kind" of autism was recognized and that they would have the freedom to express themselves, their identification with that group was bolstered. Organizational studies scholars Dutton, Dukerich, and Harquail (1994) explained that "People are drawn to organizations that allow them to exhibit more of themselves and to enact a fuller range of characteristics and values in their self-concept" (p. 244). In the above quote, Vic shows how impactful a perceived lack of room to expressing their racial, gender, and sexual identity was for them, as they wanted to belong to their preferred autistic groups and feel that they were part of the autistic community in general.

A lack of representation of diverse expressions of autisticness can contribute to feelings that it is not safe to be self-expressive, and groups that even unwittingly represent a limited range of autistic characters may be perceived as unwelcoming and restrictive, likely to prohibit free or full expression. Vic mentioned, for example, that she was uninterested in taking part in ASAN primarily because the organization's founder and primary spokesperson is a man. It is not surprising, then, that in social contexts like business organizations, social support and activity groups, or even in social media networks, prospective, new, and established members are drawn to opportunities to "accentuate their own distinctiveness" through their group association. (Dutton, Dukerich, and Harquail 1994, p. 246; also see Fajans 2006, Johnstone 2000).

Intersectional Autistic Parents

I met Dani, a 35-year-old self-described "multiethnic autistic woman" from northern California in the *Facebook* group for adults with on the spectrum. Dani is also parent to a young, brown, "neurodiverse" boy. In late 2015, I commented on one of her group updates, which shared a blog post from the Association of Autistic Women (AAW). The AAW blog post that Dani linked to and commented on issued a statement in support of Black Lives Matter (BLM) and grieved the widely publicized police brutality that Black Americans have faced. The blog post, she wrote to the Facebook group, sold her on the organization's commitment to drawing into autistic discourse issues facing people sitting at the intersections of multiple marginal social categories.

That was her first and last post in the group. In subsequent chats on *Facebook*, using the private messaging function on the platform, I learned that she joined the group because it popped up on her *Facebook* timeline as a recommended social space for her and she was curious. She quickly left the group because she felt that it was "too tied up in the whole 'high functioning/Aspie thing.'" Having AAW as one of my research sites, I used *Facebook's* private messaging function to aske Dani about her involvement and interest in AAW. She wrote to me:

> I was first onto them after this post they had about racial profiling on black autistics. 2014, I think. I looked and saw that the main people in charge weren't black, and didn't even look mixed, and that's something that always made me feel like an outsider as an autistic. The only autistic people who seemed to care about brown and black people are brown and black autistic people. So talking to groups of autistics can be frustrating, because I'm supposed to choose. Like in autistic spaces only autistic things matter ... But

> I'm an autistic woman and then on top of that, I'm not white. So it felt like there wasn't that much space available for me ... Most of the autistics I knew of ... were mostly white and young, didn't even have to think about some of the things that I had to think about. And ... when I'd bring something up about being Brown, I'd be brushed off, like, 'we all have that kind of issue' or 'this shouldn't be about race' ... I always felt like even more of an outsider because before anything I'm Brown.

This quote from Dani points to the ways in which responses to intersectional subject positions can complicate relationships between individuals and groups. This conflict highlights neglect of people occupying multiple marginal positions and the desires of those multiply marginalized people to connect and be received by their preferred groups because, rather than in spite, of their unique contributions to group dynamics. Dani continued, telling me,

> I poked around on the [AAW] site after the profiling blog post maybe because I was just hopeful that I found something legit ... That profiling post and the one about Michael Brown had me crying ... sad tears but also happy ones. Autistic activists were actually talking about the stuff that I wanted to talk about as an autistic ... and it was these people I wouldn't necessarily expect to put themselves on the line and say something publicly.

In subsequent conversations, Dani explained to me that she had "'been autistic for 12 years," an interesting way of describing the fact that she was diagnosed in adulthood rather than childhood. Unlike many of my other autistic interlocutors, she did not consistently express her diagnosis as a moment that revealed some truth about all of her preceding life experiences. Most of the time, however, she acknowledged that she possessed something akin to an essential autistic core that was neurophysiological. To be autistic, she told me, was "more about claiming a self-advocate attitude. I could say that I'm a 'person with autism,' but it's part of my activism to own this difference by saying outright that I'm autistic.

In spite of her perspective on acknowledging her autisticness as a form of self-advocacy, she spent years feel disconnected from the autistic community. Being "multiracial but mainly Latino and Black" and having a dark skinned, Afro-Caribbean husband and dark skinned son, who had not yet been diagnosed with autism though "he shows signs of neurodivergence," she grew frantic about the increasing media coverage of black men and boys being killed by "trigger happy police officers." She passes as "ambiguously ethnic," she says, so her concern was less for herself and more for her husband and child. She was especially concerned for her husband and son, who "really, really look black." AAW's demonstrated interest in the concerns of racial and ethnic minorities in the US, presented an image of autisticness that was, like ASAN, concerned with broadening the scope of concern and inclusion. The racial, ethnic, gender, and sexuality diversity of its staff in combination with the content it circulated on its website was arguably a more pointed demonstration of inclusiveness. Dani was not sure of how she learned about AAW, interestingly, though she suspects that she was connected to someone who was involved or liked the organization:

> They popped up on my feed a few times, and then I finally started checking up on [the organization] and talking to the people in charge. I've ended up donating money more regularly. Besides that I wouldn't say that I'm actively involved in their projects, but I talk about it like I am and I share their posts on Twitter, Facebook, and Tumblr all the time...I appreciate that this org helped me feel more connected to autistic community because now there's a space for me here as an autistic woman of color … and as an autistic parent of a black child. Like, these people talked about parenting as an autistic woman!!!! No one ever, ever talks about that ... They talk about NTs parenting autistic kids ... Like, I exist, and I know that autistic parents are a thing, but now other people know that too. They're doing really amazing work, and I like being a part of it and supporting them.

Dani's account highlights how identification with autistic community is not diagnostically determined. It is also not easily realized. For her, and several of my interlocutors living at the intersections of multiple marginal identities, a threshold of compelling subjective alignments was required before the feeling of inclusion in a group was attained. These alignments constituted measures of mutuality that were established by my interlocutors who drew on salient features of their personal history, bodily experiences of gender and sexuality, race and ethnicity, preferences or distastes for their projected and ascribed self-images, imagined future trajectories, and social relationships to assess how neatly they fit with diagnostically similar others. Because these features are dynamic (see Rappaport 1993, Capps and Ochs 1995, Garro and Mattingly 2000), positive identification with autistic community, and with autisticness itself, was an emergent and continual process of assessing and reassessing themselves and other autistics against an array of available and newly developing characters of autisticness who were able to convincingly capture the realities of their marginal identities.

Seeing representations of autistics that resonated deeply with her subjective experience as an autistic woman of color and parent of a black neurdivergent child supported a growing affinity with a new face of autisticness, the intersectional autistic parent. Seeing this seemingly new character, Dani could reimagine herself as a legitimate and accounted-for member of autistic community. AAW worked as the key vector for this reimagining by not simply presenting autism as a broad category of neurobiological possibilities rather than as a restricted domain of expressed social and cognitive dysfunction that manifested in stereotypical ways. They brought into discursive circulation conversations about racialized autistics and autistic parenting that had been largely unacknowledged.

The examples that I have presented thus far show how my interlocutors' ways of identifying and becoming involved in their chosen groups was part of a wooing process that hinged on the establishment of a sense of mutuality. This wooing was most explicit in individual-organization relations, wherein the organization, under the leadership of a board and marketing team, understood that its self-image must be affirmed by a substantial group of individuals in order to be sustained. They then had inspire the members that they attracted to believe that the organization and others within it perceived them positively. This positive evaluation supported a bolstered "a more positive evaluation of self" (Dutton,Dukerich, and Harquail 1994, p. 246). Online, this wooing occurred as well, as Seva's example demonstrates. Knowing that more autistic participants than not in the actuallyautistic tag space on *Tumblr* would defend from them anti-intersex bigotry made it an attractive space to invest in through their continued participation.

When Vic and Dani determined that autistics like them were wanted and recognized by AAW, they experienced excitement and relief. In connecting to an organization that mirrored their qualities and represented them favorably their self-concepts and senses of connection to autistic community were elevated. The organization spoke to who they were–and could be–in the world and that corresponded to the degree to which the "content" of their self-images aligned with the group's stated aims and how their activities matched those goals. "When organizational identification is strong," Dutton, Dukerich, and Harquail (1994) suggested, "the organization-based content of a member's self-concept is salient and central" (p. 242). This potentially causes other modes of identifying oneself (e.g., as being insufficiently autistic or unaccounted for in autistic discourse) to fall increasingly to the background, making the organizational or group membership–be it in an abstract and widely dispersed autistic community or in more specific groups or organization for autistic adults–a more "central and frequently used basis for identification" (Dutton, Dukerich, and Harquail 1994, p. 242).

Aspie Elite & Ambivalent Autistics

I first met Dustin, a self-identified "aspie" man in his mid-30s, at a North County coffee house meet-up. It was the first week of February, a Thursday evening, and it was the first time I had seen him at one of this group's meetings. I met him before, one afternoon the previous fall, at a South County meeting. There, group members were impressed that Dustin traveled so far just to hang out and have coffee with them. I later learned that the North County group is much closer to his home and workplace. Dustin, an older group member said, “took the cake,” having traveled nearly 100 miles and bearing through the brunt of rush hour traffic to join them. He seemed to hit it off with just about everyone who was in attendance that afternoon in South County, he expressed how excited he was about being there with his “new friends,” and he was quick to assure all in attendance that he would be there at the coming weeks’ get-togethers. In fact, he RSVP'd to future meetings on the *Meetup* website where general information about the group and its meetings were posted for members of the site. Following that meeting, and for the remainder of my research period, Dustin didn’t show up to any more of the South County group’s events. I learned that this was typical. “That’s not unusual,” Kyle, the group organizer said.

> People see our group online and want to stop by. They try it out and maybe like it or ... pretend they do. They promise they’ll be at the next event ... promise they’ll be at your birthday party! And then the day comes, and they don’t bother to show or even make up an excuse for why they’re bailing.

Kyle's observation, as the group's organizer and leader, invites questions as to what makes a person become a prospective group member, and what makes a prospective member a bonafide one. As Dustin and the other examples my interlocutors provided show, diagnosis is not determinative of one's membership in a group. Membership is processual, supported by a critical assessment process wherein the prospective assesses self and other, testing for fit. As Dustin's example will show, the testing involves looking for image alignment. The prospective, in general, wants their self-image to match as closely as possible with the collective image of the group. I propose that these images are constituted by embodied expressions of autisticness, personal and social goals, interests, and other subject positions.

Following the North County meeting, it was a couple of months before I saw Dustin again. This time we were at a Mid-County coffee shop meet-up. His attendance As weeks passed, he became a more regular presence at those meetings, settling into a routine, and attending the groups' events almost weekly. His preferred ways of interacting with the group were particular to his tastes: he usually skipped events like game nights, birthday parties, or an evening at the movies in favor of shorter late afternoon and evening chats at quiet restaurants and coffee houses. Dustin took an interest in me and my research each time we crossed paths. Eager to chat, he readily shared the dramas of his work day and the "traffic hell" he endured to make it to each of the meetings he attended. When I asked him why he started going to autistic meet-ups and how he determined which ones to return to, he explained:

> Honestly? I come to these things because I don't have friends otherwise. I like people but it always seems to be a one way street…Like, I ended up working with a bunch of people but not being cool with them as buddies. They go places together but don't invite me along, or ... have secrets and inside jokes that I'm not aware of .... I've worked at this place for almost 5 years, not one friend … So, I come here for friends ... I found this group from Meetup. I can't remember why I even looked, actually, or how I found it.

Dustin's motivation to participate in offline groups related to his desire for social connection or friendship. Recounting the social dynamics of his work situation, he expressed a sense of being deprived of a desirable social experience. My interlocutors demonstrated repeatedly that they are invested in the quest to identify a group of people with whom they can regularly connect, even for short periods of time, whether they were focusing their attention on digital or in-person spaces. Identifying groups, might be thrilling as several of my interlocutors explained, but determining fit involves careful reflection. Dustin explained his process, saying

> I found the [South County] *Meetup* page and stalked it for a few weeks, and then I showed up one Sunday for brunch. It was ... awkward at first, but then it was actually fun. But then when I got home, I realized I didn't actually like it *that* much ... At least not enough to drive all that way to South County every few days ... I liked the structure of it...and a few of the people there were nice. But I felt like the people there for the most part were maybe a little lower on the scale than I am, so the kind of conversation wasn't like this one *we're* having, you know? I couldn't talk to them about anything that really mattered to me, nothing deep ... I would get caught up in the excitement of the moment at these meetings and then sorta promise that I'd be there on Saturday or Wednesday, but then

> the day would come and I'd sit on my couch and think ... They just seemed a little more awkward or severe than I am.

Dustin's account shows that even though transportation and time constraints posed concerns for him as he assessed group fit, he also took his self-image the character of autisticness (higher on the "scale") to which he most related into consideration. He saw himself embodying a different sort of autism and, therefore, he was not be satisfied with a peer group that did not have members who were aligned with him. This highlights how the objects of assessment, Dustin, the South County group as a collective, and his forecasting of an "awkward" social dynamic between himself and the group members were set in relation to one another. It also brings to light how popular, ableist conceptions of the autism spectrum (as constituted by a linear model of function) influence his evaluation, playing into his preferences, and ultimately helping establish for him limits of acceptability in selecting his peer group.

Importantly, while Dustin's senses of being uncomfortable in and poorly matched to the South County group were sincerely felt, they are neither original to him, nor innocuous. A number of my interlocutors expressed similar concerns about taking part in groups with autistics having functioning labels different from their own. Importantly, the sense of distaste for establishing and maintaining social connections in the midst of these misaligned functioning labels was expressed exclusively by my interlocutors who, in spite of self-identifying as autistic, also used the labels "high functioning" or "aspie" to describe their autism. They routinely expressed their feelings of being too out of step with those "lower on the scale" to be open to producing meaningful relationships with them.

On the one hand, this seems to be a matter of taste. As Dustin noted, his experience told him that he could have only certain kinds of conversations with people who were more like him. On the other hand, these feelings of discomfort speak to a constriction of imagination with regard to what was allowed to constitute meaningful and rich interactions and social connections. This limitation often appeared in anti-autism diatribes that accused the condition of robbing parents of meaningful relationships with their children and framed autistic difference in terms of insufficient capacities to contribute to local communities and social networks in significant ways.

Furthermore, I found that it was no coincidence that many of the people expressing views like this self-identify as aspies *and* as high functioning. While some of my interlocutors defended their choices to continue calling themselves aspies, even after the classification was made essentially defunct following the 2013 *DSM* revisions, because they were established in it and found community through the label, others used the label to separate themselves, almost as if in protest of the 2013 changes, from autistics who are deemed "low functioning." Because the Asperger's classification and the other three classifications under the pervasive developmental disorder classification were effectively subsumed to the broader Autism Spectrum Disorder classification, people within these once-distinct classifications were forced to reconcile with the idea that they were ascribed a label that seemed to put them at a greater distance from normality. The preference for so-called “high functioning” and “Aspergian” type autistic people, who are seen as sometimes straddling the line between non-autisticness and autisticness, is key to sustaining the war on autism rhetoric (McGuire 2016). In particular, this preference can be a key motivator for parents of autistic children who are non-speaking and/or require intensive supports to press for a cure or therapy that will lessen the appearance of their children’s' autisticness and allow them to occupy the end of the spectrum more proximate to normality.

In the US, widespread preoccupations with defeating autism materialize as awareness and cure campaigns that feature images of non-speaking autistic people (the "severely" autistic character) who may need intensive physical and social supports as inferior objects of repulsion and terror. This representation is most often taken for granted, though it is a powerful form of symbolic violence that runs parallel to, and arguably inspires, physical violence against autistic bodies (McGuire 2016, Yergeau 2018). While Dustin, and my interlocutors who held similar views never indicated that they held violent thoughts about or ill-will for so-called "low functioning" autistics, the insidiousness of popular ways of conceiving of and talking about people with supposedly "severe" autism people makes it easy to mistake deeply entrenched, ableist, anti-autistic modes of thought for personal preferences and sensibilities. As Dustin told me,

> It's sounds harsh maybe, but I'm an Aspie, and even though that's not popular to say anymore, I think there's a real difference there ... And sometimes even high functioning autistic people aren't quite there, you know what I mean? That's why I like that place in Mid-County. At the other groups sometimes it's just like the conversation doesn't go that far or it's about gaming stuff and bullshit things that don't *really* matter ... I want to talk about deeper things and *this* is a group that does that better. If I'm going to make a habit of going anywhere, I have to feel like I belong ... at least a little, and that maybe the group was *made* for someone like me, an Aspie who is in touch with his emotions and can talk about more than just gamer nonsense.

The above quote illustrates the interplay between various elements: autism diagnosis, conceptualizations of high and low-functioning autism, autistic self-concept formation, and group selection and identification. It highlights how the limited range of standard or approved stock autistic characters (particularly the near-normal high functioning autistic and aspie elite) that are widely circulated might become favorable or aspirational images of autisticness. Dustin, seeing in himself a level of cognitive and social proficiency objected to the prospect of investing time and energy in cultivating friendships with groups of autistic others who did not match the image of autism that he held in esteem. The "high functioning" autistic character that Dustin most readily related to, the "aspie elite," helped him identify a range of interpersonal behaviors and cognitive tendencies that he deemed ideal for his chosen associates by foregrounding that which he perceived to be unattractive – ways of being autistic that are most frequently stigmatized and framed as alien.

Those who had been identified as people with an autism spectrum disorder and are self-identifying as autistic persons could find that they did not match, either outwardly in comportment or internally in self-concept, the predominant images of autisticness that circulated within groups of autistic adults. Even amongst self-identifying autistic people, within the broader autistic community or in local activity and support groups, some autistics felt unsuited to the spaces that were on their face meant to be for all autistic people. Take the experience of one of my interlocutors, Cal, a 33-year-old man from North County, who told me in an interview,

> I *know* I'm autistic...but I don't really feel like it most of the time. I go to these group meetings to test the waters and just feel like an outsider, like maybe I'm not autistic enough in some areas ... or maybe *way* too autistic in others.

Cal struggled for a few years to establish himself as a member of local autism groups with no success. His conflicting senses of being autistic but not autistic enough presents an important example of how an insufficient cast of characters of autisticness, produced by restricted understandings of what autism is and who qualifies to be autistic shape the ways autistic people experiencing similar conflicts choose peer groups and manage their relationships. A number of my interlocutors from offline groups spoke about their first contacts with self-advocate groups as "testing the waters." In this testing, my interlocutors showed that positive identification with an autistic community involved evaluations of what made a group's collective identity, stated aim, and ultimately their inventory of stock autistic characters appear attractive, sincere, and accessible. For Dustin, there was a disconnect between the North County group's stated aim — providing a social space for autistic adults across the spectrum and his self-concept and expectations for what autistics in his social groups should and should not be like.

For both Dustin and Cal, members of the groups to which would claim membership needed to meet a subjective threshold of distinctiveness that worked harmoniously with the traits that they saw as central and enduring in their own expressions of autisticness. Though in the above quote, Cal had not succeeded in identifying with an autistic group and becoming a member of it, in general, when my interlocutors saw in themselves and others in the groups that they attended similar distinctive, essential, and abiding traits, they more readily engaged in group activities, investing their time, energy, and resources in the shared project of creating and maintaining an autistic group. We saw this with Dustin's determination that the Mid County group, which he saw as having more autistic people who were "higher functioning."

Crucially, this provides insights about how autistic adults understand and interact with autism's "external image," a concept I am borrowing from organizational studies scholars Dutton, Dukerich, and Harquail (1994). The way non-autistics and society writ large perceive autistics (based largely on biomedical notions and anti-autism rhetoric) and use their understanding to define the boundaries of good or legitimate autisticness influences group selection. In subsequent conversations with Cal, I found that when he was seeking a group that would suit him, he wanted to be sure that he was aligning with a more desirable image of autism. "Some of the groups," he told me, "are full of these guys who won't talk, or maybe they can't talk, I'm not sure. That's not me, and the one time I went and hung out with these guys, I felt like other people thought I was like them, you know?" Being keenly aware of the seemingly negative evaluation of non-autistic people in the area was an important indicator of fit for him:

> It was stressful, and I know that's not PC … but I've made huge strides over the years and as sweet as those guys are, that's not how my autism is, and it doesn't make any sense whatsoever for me to pretend that I'm on the same level they are.

Ultimately, Cal found a local group of non-autistic men. He described what attracted him to the group and inspired him to regularly participate in it, saying, "We're basically all self-proclaimed gamers, computer geeks, and nerds in general ... A lot of them are probably autistic but don’t know or think of themselves that way, and I guess I really do prefer that. It’s freeing somehow.” Finding this group and becoming involved with them supported not only his image of himself, but afforded him the comfort of being perceived by non-group members in the surrounding area in a way that he found acceptable:

> We go bowling and go for drinks ... it’s no big deal, really. The guys know about my diagnosis ... but don’t sweat it, which immediately made me feel accepted. We barely even talk about our problems or hang ups like we would in an autistic group, you know? Well, except for dating and girls, but that’s standard guy talk. People wouldn’t assume any of us are autistic at all, probably ... Maybe just nerdy or geeky.

Cal’s example, and those of my other interlocutors discussed in this chapter, shows how a self-identified autistic person might feel attracted to and seek out groups that they perceive to be seen in a positive light by outsiders. To do this successfully and become a member of these desirable groups would allow them to “bask in the reflected glory” (Cialdini et al., 1976, p. 366). For Cal, in particular, associating with other “basically normal” men proved most satisfying and comfortable, for he would not be required to reconcile disparate conceptions of what autism and autisticness could or should be. By associating himself with normality, however geeky the "normal" men might be, he presented an image of himself that was more in line with an aspirational image of autisticness. Cal, therefore, got to be comfortable associating himself with autisticness more generally, even while perceiving displays of stereotyped autisticness as unrelatable and unsavory:

> It doesn’t bother me to identify as autistic, basically ... I used to say that I’m an Aspie or Aspergian, but that’s kind of put down now. With a couple friends, I still use 'aspie' and they don’t mind, but I can’t say stuff like that on the Internet because then I’ll get torn a new one, which is stupid ... because I was an aspie way before a lot of these newbies, but, like, now “autistic” can mean almost *anything*, so I don’t think it’s a problem to be calling myself that even though it’s really weird sometimes to be lumped in with autistic people who are very different than me, and they’re *literally* disabled.

Although Dustin and Cal were unwilling to continue their participation in groups that they felt were poorly suited to them and had undesirable images, by the time I concluded my research period, they had maintained regular participation in their preferred groups, with Cal even taking on the role of co-organizer for several events. This cultivation of membership through increased involvement in group activities and decision making lines up with what organizational studies scholars Dutton, Dukerich, and Harquail (1994) have suggested: "stronger organization identification may translate into desirable outcomes" for group leaders and membership, "such as intra-organizational cooperation or citizenship behaviors," which are key to sustaining the group across time and space (Dutton Dukerich Harquail 1994, p. 240). In contrast, Cal's moves away from groups they deemed unsuitable indexed their perception that those groups had negative external images as well as a membership that threatened to cause him to be associated with negative, stereotypical traits of autism. These perceptions underpinned his withdrawal from the group's and rejection of further invitations to take part in their activities.

CREATING AN INTERSECTIONAL SPACE

Lei, a 24-year-old woman, and Jazz, a 27-year-old woman, had been members of the Mid County autism support and activities group for two years before they suggested forming a smaller branch dedicated to women on the spectrum. This new grew took shape just months before the end of my research period. Their group was similar to the main group in terms of structure, centering on multiple weekly meetings that focused on game-based activities, social skills workshops, and group outings. However, it differed in terms of demographic makeup and tone and focused almost exclusively on soft skills training to support the particular interests of the membership. These interests related to member concerns with developing and maintaining social relationships (especially romantic relationships), increasing financial independence, self-confidence, fashion sense, and personal safety. On occasion, the group ventured out, leaving the Independent Living Center board room that they routinely used for meetings, to have lunch and discussion at local restaurants, shop at the nearby mall, or stroll through the area's outdoor art district.

While out at the mall one spring Sunday, I talked with Lei, Jazz, and two other members about how and why the group got started. I wanted to know what having a group exclusively for women on the autism spectrum meant to them. Lei offered:

> The idea is that a autism is a boys condition and so a lot of autistic girls don't *think* they can be girly, I think. Not that this group is about being feminine for everyone that comes. But it's part of it, and that's how I envisioned it ... Just girls getting together and doing stuff *we* like to do – talking about dating and boys, and sometimes sex, and maybe how to flirt and dress well and all that ... Practical stuff too, though, you know, because we can't talk about autistic women dating without talking about how to be safe ... So it's a lot of things to me … Plus, we have ladies here who have lots of experience with all kinds of things and some of them are a little older … and give plenty of advice.

In the above quote, Lei demonstrates that autistic women's spaces are scarce in part because of how few women receive autism diagnoses. I observed in my research that there were no other offline spaces for autistic women in driving distance from the North, Mid County, and South County groups that I focused on in my study. With a small population of women who were wanting to, and willing to, gather together to celebrate autisticness, learn, and discuss, it was a challenge for the women to build the momentum needed to launch the group. "I wanted a group like this for a while," said Jazz, "I just didn't know that Lei or anyone else in the area would be interested so I kept it to myself." Growing up with women, and feeling "girly enough," she wasn't concerned with "getting in touch with her femininity" like Lei was. For her, creating a women's group related to more practical concerns:

> In the main group, we do social skills stuff that's pretty useful. But I wanted to focus more on things that no one bothers to teach us about relationships and sex and money ... Remember how at that one workshop when we talked about getting to be independent

> and planning ahead in case our parents die or something, and I freaked out? ... It was an important conversation but it really scared me. But when I think back on it, it was really changing my mind about the future.

Lei responded to Jazz's comment, saying "I bet you a million bucks a conversation like that would never happen in them main group ... The guys usually like to keep things lighter mood-wise." Hoping that Lei would tell me more about how the group had impacted her, I asked how she sees and interacts with the other women in the group. She explained:

> I'm definitely used to being around guys ... I was in Special Ed, and I didn't have many friends ... girls were really catty with me, so I felt defensive around women during my teen years ... But the *one* friend I had as a kid was a boy ... and the odds were that I would have guy friends since there were *so* many boys in my classes and less girls. My mom *hated* it because I was so tomboy-ish already and she wanted me to be more girly, and ... I wanted to feel girly like that too, but I didn't know how, and she worked a lot so I didn't really get to have that present feminine role model. I've learned the most from the older ladies and the others who have more experience in relationships with men ... I tell them about my dates and get tips sometimes.

Because autistic women, and disabled women more generally, are understood to occupy especially precarious positions, as likely victims of bullying and sexual assault, social skills and safety training for autistic girls is viewed as vitally important. Unfortunately much of this training is geared to girls with disabilities, while women on the spectrum are seldom considered. Even so, the trainings and manuals that are available to girls and women often focus on embracing the "unique gifts" bestowed upon autistic women (usually those identified as “high functioning” and feminine) and becoming datable, softer, more feminine, and empathetic (Rozsa 2016, Simone 2010, 2012, Marshall 2015).

During one Friday evening meeting with eight members of the women's group, Jazz shined as the go-to person for advice on dating. She gave tips on flirting, scheduling dates, and arranging transportation. I asked why she thought she became the person to consult on these matters. Having been involved in a romantic relationship before, apparently an unusual occurrence for women in the group, she became a trusted advisor on matters related to men and romantic relationships:

> I was dating someone for a year or so, and a couple of the girls were *really* interested in how I did that ... How I got a guy to be interested in me and what sex was like. And, like I told them, 'I don't *know* how I got him interested in me and I don't actually know what sex is like.' I have to beat him off with a bat every time we get together ... Because, you know, I'm a Christian girl and my parents would slaughter me and him if we ever, you know … But the ladies had questions and I didn't mind dishing! ... I don't really give advice, but ... they call everything I say advice ... I just tell the group my experience and tell what I think about things and give ideas. I tell them about the stuff that happens with me ... so, like, if there was a problem or something with my boyfriend, I'll tell them how we worked through it and some of the ladies think that is helpful. Other times, I tell them the stories about me and him because *I* actually need advice.

Jazz's statement above highlights the way the women's group created a flexible workshop structure that could accommodate their particular needs while allowing for members to keep abreast of each other's' life updates. While the North, Mid County, and South County groups held social skills workshops, their structure was more rigid and hierarchical, with the respective leaders of the groups, or their invited speaker, being the person who directed the conversation virtually every stage of the event.

The group did not only provide a way for members to learn about dating and independent living from fellow autistic women and a "special guest," a woman named Amber, who having ADHD, experienced many of the neurosocial challenges autistic women in the group did. Amber was invited to attend and participate from time to time, and was generally very willing to share her "lessons from [her] good steps and missteps" to help members of the women's group. The group also provided some reprieve for the women who continued to participate in the main Mid County group. For Lei and Jazz, the main group was so dominated by "male energy" that they would "really end up feeling out of place." Lei told me:

> The guys sometimes say things that are so inappropriate and embarrassing that I have to grit my teeth because I wanted to lose it on them ... It just feels really unfair. And even

> after Adam made rules about 'good conduct,' [guys] would still screw up and nothing would happen ... It's just really inappropriate sometimes and I needed something to balance that out. I still go to almost all of the main group meets ... you've seen me there almost every time you're there … Jazz stopped going completely. But this women's group is really special, because we are usually all really polite and careful about hurting others feelings in the group ... if there's something wrong we try to work through it right away. Usually it's just a misunderstanding that's fixed fast.

I noted that on several occasions, during the main group meetings, Lei's grew very frustrated with men in the group. On Friday night, a group of men were gathered together in a corner of the Independent Living Center where the event was held. Talking loudly about what made a woman sexually attractive or unattractive, they spoke with great detail about how they imagined their ideal woman would "perform during sex." Lei spoke out, trying to compel the men to change their topic of conversation. Her admonitions, however, seemed to encourage them to share louder, more graphic descriptions of their dream tryst. I was not sure whether Adam, the group organizer and leader, was fully aware of the illicit nature of their conversation. He had been moving in and out of the event space. Lei's discomfort and frustration, however, were apparent.

In effect, the women's group provided another key testing ground for autistic women in Mid County. Being the only self-advocate group in the area that focused exclusively on autistic women, those who once believed there were no group spaces available for them now had the opportunity to become members of a group of women who shared some similar interests and life experiences. Kyla, one of the group's members regularly attended group events. She explained to me that she decided refrain from visiting the Mid County group, even though the women's group was an offshoot of it:

> I heard about the main group and I went to one meeting a few months ago for the first time. But then I didn't go back ... Then on Meetup, I found out there was a women's group and I didn't even know it was connected to that group, and it's good that I didn't know because if I did, I wouldn't have tried to come, and I would be missing out ... I really hated how many boys were in that group and how it felt when they would say inappropriate things. It felt like a men's group with just a couple of girls visiting ... the

> games were so competitive and harsh, and some of the games were just really uninteresting ... This [group] is more relaxing, and I actually get to know people in a comfortable place. Plus it's good to have girl friends. I never had girl friends before as a kid and a teen ... Now that I'm in college, and I'm, like, an actual woman, it's cool to have a bunch of ladies to talk to about what it's like to be Aspie ladies.[16]

In the above examples, Lei, Jazz, and Kyla all show how autistic adults' gender identities can shape preferred modes of interacting with other autistic people. Because the main Mid County group's agenda spoke primarily to the interests of the approximately 83% documented male-identifying membership, several autistic women explained that the co-ed group meetings left them feeling "out of place" or like "targets for the guys who wanted to get a rise out of us." For them, a women's group would allow them to escape this discomfort and enable them to include in their agenda a activities that spoke to the preferences, goals, and interests of women in the group. Lei and Jazz's aim to create a separate space for autistic women, and especially "higher functioning autistic women," spoke to their goals of being part of a local and "close-knit group of autistic women." For them, creating that separate space allowed for joint experiences of belonging among attendees and determinations that the group provided some added value to its participants' lives. In the three months that I researched with the new women's group, membership grew from four members to over forty, most of whom expressed interest on Meetup and planned to attend future events. On a weekly basis, there were between four and nine members who attended events. These members were active participants in the group's weekly activities and even made time and energy investments in the group by co-organizing events, and/or contributing monetarily to cover expenses for outings, pizza dinners, and other materials fees.

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[16] It bears mentioning that none of the other women's group members referred to themselves as 'aspies' in my hearing. By and large, they all referred to themselves as autistics. They did, however, made distinctions according to functioning level.

The drive to create a space for autistic women shines a light on how my interlocutors' conceptions of themselves, as autistic women, whose needs, interests, priorities, and desires differed markedly from those of autistic men, draws on a broader cultural inventory of intermingling concepts of gender, neurodivergence, and debility and evaluation techniques that support the construction of a shared identity and group image (see Hogg and Abrams 1998). This shows how, as Dutton, Dukerich, and Harquail (1994) explained, my interlocutors' self-concepts operated as "an interpretive structure that mediates how [they] behave and feel in a social context" (p. 242). Importantly, these interpretive frameworks, which are subjectively employed, engaging their rationalities, beliefs, and preferences, allowed for the possibility that their self-concepts could draw on that inventory of intermingling concepts of gender and autisticness. In so doing, they came to similar conclusions about what made a group an appropriate fit for them.

The Mid County women's group example suggests that the strength of my interlocutors' senses of identification with an autistic group corresponded to the extent to which they routinely engage with its members and how those interactions played out. While the central group that Lei and Jazz branched off of laid claim to a much larger membership of just over 300 people (at least on its social networking account on *Meetup*) during my research period, its core group of participants was comparatively small, consisting of about eighteen people (fourteen self-identified autistic men and three self-identified autistic women). These core participants attended almost every week.

Yet the brunt of the organizing and leadership responsibilities tended to fall on (or be enthusiastically assumed by) the group's founder, Adam. This may be chocked up to the extent to which Adam was amenable to group members directing activities. On just a few occasions during my research period, while Adam was either out of town on self-advocacy business or under the weather, he "allowed" group members that had gained his favor and confidence to work together to develop programs for the weekly gathering. The weeks of his absence, group members in attendance responded with similar enthusiasm and interest when these stand-ins ran the show. However, the sense of structure in the predetermined programs were ultimately diminished, and intragroup conflicts over acceptable conduct were much more common and slower to resolve. This could be seen in the interaction between Lei and the group of men at the Friday evening meet up.

CONCLUSION

Self-images and rhetorical characters of autisticness play into perceptions of group belonging or of being out of place. It speaks to domains of autistic possibility and impossibility, where autisticness can and cannot be recognized (see Yergeau 2018). The body is a central site where this tension plays out. Popular representations of autisticness as a childhood condition that impacts white families and male bodies inhibits recognition of those not fitting the accepted pattern.[17] This misalignment calls for us to rethink our habituated ways of seeing and talking about autism and autisticness.

For my interlocutors, domains of autistic impossibility were those group and organizational spaces where there was not only an absence of characters that looked like them, but a seeming reluctance to expand conceptions of autism and representational conventions to invite and accommodate an more diverse membership. Encounters with these kinds of groups lead to withdrawals from group spaces and reassessments of self-concepts. Rhetorical characters of autisticness, being constituted by dynamic clusters of characteristics – physiological, social, and intrapersonal – were important mediators in my interlocutors' abilities to relate to autistic others

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[17] Yergeau (2018) and Jack (2014) both discuss the gender and racial aspects of diagnosis and misdiagnosis of autism spectrum disorder and autism research

who could show them their recognized or validated autisticness. Crucially, examining ways of understanding absences of characters of autisticness in group spaces supports critical thinking about how select combinations of characteristics make up culturally sanctioned autistic characters. Many of the most recognizable rhetorical characters of autisticness have been produced and reproduced not for autistic people but as tools of thought that support non-autistics in arguing for the need to protect ever-unsteady bounds of normality. They have been used to promote a living image of the social dangers that autistic deviance engenders. In light of this, we might begin to look at character (and characteristic) absence as invitations to learn how the most pervasive stock characters of autisticness have proven most useful to national and institutional projects committed to defining and protecting biomedical conceptions normality.

For my interlocutors, especially those who stood at the crossroads of multiple marginal categories, defining and identifying with rhetorical characters of autisticness, by conceiving of new ways of defining autistic possibility, distanced themselves from stigmatizing (or nonexistent) conceptions of intersectional autisticnessness and clung to their belief in their legitimate autistic selves. This supported them in establishing modes of relating to and belonging with other adults on the spectrum. Where an organization might emphasize its image through its brand, many of my interlocutors expressed their autisticness by defining their "kind" of autism – the rhetorical character of autisticness for which they had affinity and resemblance. Saul, a 46-year-old autistic man recently transplanted from Northern California, explained to me his understanding of "kinds" of autism:

> If your diagnosis is who you are in the doctor's office, your kind of autism is, like, who you are to your autistic friends ... It's being autistic in the real world. My psychiatrist would say that I have X, Y, and Z social and communication problems, but my friends always just say that I'm your stereotypical Aspie-like autistic. White, male, gamer geek, awkward, and piss poor with women ... That's pretty much your standard Aspie guy … basically everyone recognizes that one.

Saul explained to me that his best friend, Kia, a woman he met through *Tumblr's* "actually autistic" hashtag did not have a "kind" until she began posting to her *Tumblr* blog. He told me

> She posted to the hashtag but went general and called herself an ND [neurodivergent or neurodiverse] woman instead of autistic, Now she's involved with autistic women's concerns ... She has a kid, and she's what one would call very high-functioning if they knew she had the diagnosis … But there isn't very much out there about being a mom and an autie unless you get on the forums and blogs. Then you find your kind … or ... it finds you.

My interlocutors' "kinds" of autisticness served as legitimating devices that worked as connective tissues that linked assumedly genuine autisticness to various categories of difference, including diagnostic label, age of diagnosis, race, gender identity, sexuality, parenthood, and even hobbies. When my interlocutors' "kinds" went unrecognized in a space they recognized as possibly supportive of their sense of belonging, there were sometimes crises of self-knowing experienced, where doubts about the validity of their autism diagnosis sprang up, or where a sense of disconnect from the broader autistic community marred their relationship to the diagnostic category. Crucially, this highlights the ways proliferation and diversification of these available rhetorical characters of autisticness bolster and sustain individuals' autistic identity and helps maintain autistic community writ large. If not for these expanding notions of what it means to be autistic, assertions that autism is a condition proving neurodiversity as a biological fact might fall flat, dragging into oblivion arguments for autism acceptance and celebration.

My interlocutors' self-images or the ways in which they envisioned themselves and wanted to be perceived by others was a significant catalyst for their organizational or group identification. With the examples of Lei and Jazz's women's group, for example, Seva's induction into the hypertext space of actuallyautistic on *Tumblr*, and Dani's rapid connection to AAW, we see that affirming marginalized or underrepresented autistic identities can spark an autistic person's attraction to a group or community and encourage their increased involvements and positive identifications with their groups. Crucially, groups' affirmations of my interlocutors' already-realized personal identities were not the only inducements to their becoming increasingly involved and identified with them.

These diverse rhetorical characters of autisticness serve as an important means of intentional self-concept transformation and community building and fortification. Crucially, this process is generative, and not limited to autistic spaces. These ideas about expanding notions of autistic possibility show up in conversations amongst physicians, researchers, and parents (see Harmon 2004; Gensic 2018; and Cascio 2012), inviting re-conceptualizations of the limits of acceptableness when it comes to diverse and "divergent" neurobiologies across multiple axes of personal and social identity (e.g., gender identity, socioeconomic status, race, ethnicity, or sexual orientation). With the expansion of available rhetorical characters, what might we ultimately see, in terms of our multiple, shifting, and interacting notions of what constitutes legitimate autisticness? Perhaps we will find a broadening of the scope of acceptability for autistic people – and those with other, similar diagnostic labels – and the application of the lessons of our continued cogitations on the affirmative impacts of acceptance, inclusiveness and accommodation-centered frameworks.

3

LEARNING IN AUTISTIC SPACES

Jean Lave and Etienne Wenger's (1991) *Situated Learning: Legitimate Peripheral Participation* outlined the concept of "legitimate peripheral participation," which offered a holistic framework for understanding how we learn, emphasizing that learning is inherently social in nature. With a focus on how people participate in various learning contexts, Lave and Wenger (1991) demonstrated that learning takes place through not only active and sustained engagement with others who are recognized as more expert, but also through learners' willingness submit to playing the role of the "status subordinate," "learning practitioner," or "aspiring expert" (p. 23). The assumption is that engagement with a community of others that has a core of experts and members with a particular, shared interest or aim will increase student-participants' proficiency or skills in their area of concern. Lave and Wenger (1991) highlighted the temporal significance of this work. The aspiring expert has sustained engagement with proficient others in a context that is conducive to skill and knowledge acquisition, and over time, their increasing competency draws them in toward a core of more authoritative others. Eventually, they may find themselves qualified to be "masters" to newcomers, novices, or apprentices.

Education scholars and disability scholars have mobilized the concept of legitimate peripheral participation (LLP) to sort out how tried-and-true and newfangled inclusionary tactics might bolster participation of autistic children in various primary and secondary school settings (Milton and Wood 2017), increase d/Deaf and hard of hearing (HOH) people's involvement in STEM disciplines (Elliot et al. 2015), and recognize and address obstacles to inclusive education for children with intellectual disabilities (Reddington and Price 2018; Mortier 2018; Goodley et al. 2017). Importantly, the vast majority of studies exploring disability through (or with) an LLP framework hinge their arguments and concerns on their aims to increase the seamlessness with which disabled people are drawn into non-disabled spaces. While this framework is seemingly well-suited to this mission, it can also shed light on how exclusive autistic spaces take shape and help constitute autistic people's self-concepts and, increasingly, how cultural understandings of autisticness seep into cross-cutting domains of autistic social life.

In attempting to understand how autistic adults construct and sustain an autistic community across digital and geospatial domains, I have found it useful to ask what sort of community is being constituted. How are participants learning to be legitimate autistic adults and recognize legitimate autisticness? And how does learning this enable them to participate in the groups that they wish to be a part of? How might this acquisition of knowledge, explicit and tacit, work across different kinds of sites, and what kinds of relationships between participants are enabled or disenabled in the process? For autistic adults, learning is central to *becoming* autistic or, perhaps, coming to the realization that one has always *been* autistic. Whether one is newly diagnosed with autism spectrum disorder (ASD) or has been diagnosed from early childhood, being autistic entails learning not only about the diagnostic classification and its correspondences to lived experience. It also involves learning by direct experience and by proxy – through the experience of autistic others – how to move through time and space with a psychiatric distinction that is most often understood in the most pejorative terms. Autistic adults, like non-autistics in general, engage in and learn from the biomedical and psychiatric contexts they have been drawn into, even as they learn from the broader social milieu in which notions of autistic and neurodevelopmental difference are produced, assessed, and debated. This multi-pronged engagement, I propose, is a central part of learning how to be autistic and how to belong to autistic community in its varied manifestations.

Early on, I imagined that the legitimate peripheral participation framework captured effectively the group dynamics I was observing across my field sites. On closer examination, however, I found that it captured only part of the picture. My online interlocutors, in particular, had some important differences in the ways they related to and learned from one another. Sometimes, learning was not about receiving answers to pressing questions, troubleshooting complex life problems, or even getting a "talking-to" when stepping out of line, though these ways of interacting with each other were common. Learning was often produced through gestures of acknowledgment, commiserations, and affirmations that one's lived experience and modes of reckoning with it were valid. A simple, "Yep, I hear you" counted. These gestures and comments were no less powerful. They were part of my interlocutors' ways of "negotiating meanings" (Wenger 1998) in their group spaces, and these practices supported them in drilling down into the foundations of their narrative-making processes, helping them either "blow the shit up," as Myles liked to say, or make needed reinforcements. As I aim to show, these lateral forms of relating, sharing, and building knowledge also played an important part in maintaining and problematizing understandings of what it meant to be autistic.

My interlocutors congregated in spaces that they created for themselves, as almost refuge-like places where they retreated when feeling isolated and misunderstood around non-autistics. These spaces also served as key knowledge sharing environments where seminars, trainings, and workshops were developed to teach autistics how to navigate what Adam called “a world that’s obviously unkind to the autistic neurotype.” Beyond constituting a “safe space” and training space, my interlocutors’ engagements with one another in their local support and activity groups shone as emblematic of the kind of engagement that a legitimate peripheral participation framework allows us to map out. Being physically co-present with one another sharpened, through continued interaction, a teacher-student dynamic in the local groups in which I observed and participated. The very clear distinction between group leaders and organizers, without which the groups themselves might not exist or would not continue, made "expert" autistics recognizable. All others were noticeably differentiated as likely students, or at least as people who willingly deferred to a greater, more knowledgeable authority. In the South County group, in fact, the founder and organizer, planning to step down from their role as group leader, began training and instructing two other group members who reluctantly responded to calls for people who might be willing to assume the not-so-coveted role. That is not to say that lateral relationships were scarce in these offline groups. Instead, I am proposing that in my offline groups, there seemed to be a primary, hierarchical structure that shaped participation and the kinds of interactions members had with group leaders and with one another.

AUTISTIC TEACHERS & AUTISTIC STUDENTS

North County Group

Over the course of my research period, a couple of the leaders of the local groups I studied asked me to attend and lead workshops on a variety of so-called “social intelligence” and independent living skills topics. In general, these invitations were rarely offered, and the leaders of their respective groups took charge of the workshop schedule, content development, and content delivery. Even long-time attendees and members of the groups were seldom invited to lead these discussions and were ostensibly understood to be in the student or novice role in perpetuity. This was the case even when members wished to increase their involvement and responsibilities within the group, offering to help organize events and making suggestion for changes to the group format. It bears mentioning, that more often than not, these offers and suggestion were "taken under advisement" and never really discussed again. I learned from my interlocutors in the groups that the occasional guest teachers and trainers were usually brought into the groups through the leaders' personal contacts or from recommendations that they received from personnel at nearby independent living facilities and even parent-driven autism associations. When the trainers were autistic, they were regarded as more knowledgeable and more adept at living successfully as people on the autism spectrum, and by and large, these positive assessments were well-received. These experts either positioned themselves as such or welcomed the assumption that they could serve in that capacity.

One Sunday in late 2015, I received a phone call from Steven, the leader of the North County group. He was working on updating the social skills lessons he delivered every Thursday to interested group members. I was curious about these Thursday meetings, which I learned took place at a nearby diner. I had been participating in the North County group consistently for almost five months and had not heard about these gatherings before that phone call. Stephen explained that he had not mentioned the meetings because he “felt insecure about having an academic show up and … grade him on his teaching abilities.” This was the case even though I had an autism diagnosis and identified as autistic. It was not only his teaching, however, that served as a point of insecurity. Steven worried that his information was not “up to snuff” because of his “limited social experiences” and self-described introversion. He worried that what I might say would challenge or invalidate his previous lessons. Still, assuming that I could serve as an expert on social competency and independent living, determined that it was “in [the group's] best interest” to hear what a “high functioning” doctoral student had to offer in terms of strategies for successful living. The group members in attendance wanted to know as much as I was willing to share about employment, higher education, family life, and money management. More than any of these things, they wanted to know what advice I could offer with regard to dating and sex.

I assured Steven that his guidance and teaching were very likely "right on point," and that I did not feel very equipped to offer the group advice on intimate relationships. Ultimately, I chose to decline his offer to serve as the sole leader of the Thursday meetings for the remainder of my research period, realizing that it could negatively impact my relationships with Steven and the members of the group. I was concerned that assuming this kind of leadership role in the group might inspire feelings of discomfort for Steven or unwarranted adulation or scrutiny from the group. Previously, in my conversations with group members, I noticed some contentions. In casual conversations, my interlocutors would often discuss positive and negative tensions between themselves and either "know-it-all" or "ultra-wise" group leaders.

I understood that my role as researcher, in addition to my gender and racial identities, set me apart from the group of mostly white autistic men.[18] Consequently, I suggested an alternative. If he was willing, I would share the floor with Steven and we would develop workshop agendas and talking points together. He enthusiastically agreed. Each week, Steven and I chatted over the phone or met at a local coffee shop to nail down our workshop agendas. When it came time to deliver our lessons, I shared personal insights, experiences, and tips on things like dating, navigating higher education, reducing stress, and creating and managing a budget. Steven shared information he gathered from scouring the internet and self-help books for step-by-step guides on how to impress women, appear confident, manage time, and dress stylishly. The group members told me each week that they appreciated hearing a woman's perspective on the subjects we covered.

Importantly, my aim to maintain my position as group member rather than leader was compromised even though I was sure to decline invitations to hold the stage and direct the flow of conversations at these events. The laid-back conversations that I had been allowed to take part in were less available to me, as group members increasingly assumed that I was judging them for

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[18] The demographics of the offline groups nearly matched with that purported by the US Centers for Disease Control and Prevention (CDC).

their lack of know-how. For example, after helping Steven lead a workshop one January evening, I approached a group of my interlocutors who were chatting about dating failures and embarrassments, a favorite topic of discussion among my interlocutors in all three groups. Even though we had all chatted repeatedly about our respective relationship "catastrophes" before I started helping at the workshops, they began to withdraw from these kinds of conversations in my presence. Catching himself describing how he "went in for the kiss" before being "totally sure" that his date was interested in receiving his affection, Zach grew silent and told me in a serious tone that he was sure that I "thought he was a complete idiot for being so dense with girls." I assured him that this was not the case, and that I had surely made my share of dating blunders. The other men in the group teased him and one another, exclaiming that they should not "make *any* moves at all with the ladies" without consulting with me first.

My interlocutors within the group grew much less willing to engage me in casual group discussions after several weeks of workshopping. I learned from Tobi, one of the handful of women who occasionally attended the group, that more and more participants in the space believed two things: first, that I possessed an abundance of social skills knowledge and would therefore scrutinize others who were interested in acquiring and further developing their social prowess. Second, they believed that my regular interactions and friendship with Steven could compromise their interactions with him if I was to share information that negatively impacted his assessments of them. This shows how important leadership roles were to group members in my offline sites. They actively sought the appreciation and approval of leaders and wanted to avoid circumstances that would reduce their ability to be positively evaluated by the people they took as experts and held in high esteem.

The concern with negative assessment by others who were ruled to be more expert did not only impact group members. As I described above, I learned that group leaders were also concerned with this. Toward the end of my research period, Steven admitted to me that he only asked me to lead the Thursday workshops because he believed that he "still [had] a lot to learn." These things that he needed to learn, he explained, were not easily gleaned from texts, allistic family members, and *YouTube* videos, which he sometimes mined for tips. “Otherwise, I wouldn’t have asked you to help,” he told me. Continuing, he added,

> I probably wouldn’t say anything like this around the group … They really look up to me, and I think it’s important for me to keep up their confidence … Plus, with them expecting me to know so much, I get really motivated to push through my laziness and research to find good answers to their problems.

The above account illustrates the way leaders of the three offline groups I studied understood themselves to be just that, leaders to their followers and teachers to their students. These leaders were present for nearly every group meeting. In two of the three groups, when the leaders were ill or unable to attend, they would typically cancel the scheduled meetings. The Mid County group was exceptional in that the leader, Adam, identified a couple of people to take his place and execute his agenda when he could not attend the get-togethers. Importantly, the couple of gatherings where Adam appointed a substitute only involved time-keeping responsibilities. "Ring the bell when it’s time to switch activities, unless everyone really likes the activity." When I asked my interlocutors at each group how their participation had changed over time, I learned that, by and large, they were uninterested in assuming leadership roles, believing that it was a skill they were incapable of acquiring, or an inborn gift that was not and would never be part of their make-up.

The leaders of these groups, Adam, Steven, and Kyle, being lauded for their work on behalf of the membership, and praised for the ways they propelled themselves forward, tells us what many of the support and activity group members valued. The vast majority of the members, wanting to observe these “experts” in action, showed up at each meeting, participated in planned activities for each meet-up event, upheld the leaders' group management efforts in times of disruption or conflict, and welcomed and helped orient newcomers on their behalf. Those who disrupted the flow of the group by challenging the authority of the leaders, were usually tolerated for a short period of time and then asked to leave the group if they were unrelenting. I was never present when a member was asked to leave a meeting, but I learned from my interlocutors that once such a request was made, the heckler usually never returned to the group.

Mid County Group

The Mid County group held social skills workshops once every month. After their large Saturday afternoon activity group meetings, which were often held at a local independent living center, a handful of group members would hang back to chat and finish eating what was left of the take-out pizza and donuts, while gulping down what was left of the various bottles of soda and fruit punch that Adam bought with money donated by us attendees at previous gatherings. As we neared the two o'clock hour, our usual start time, the chatting would die down and the food and drink would nearly be gone. Like clockwork, on the hour, Adam would call us to order, requesting that we quickly seat ourselves and be silent so that we could get through everything and wrap things up at a "decent hour."

One Saturday in October 2015, I sat with workshop participants awaiting Adam's lesson on resolving conflicts with friends, family members, and colleagues. Waiting for the workshop to start, I asked a few of my interlocutors why they stayed for the workshops each week. They explained that very simply they assumed that Adam's advice would work if they executed his action steps precisely. Even though only two of the five people I asked that day had implemented Adam's ideas, they all seemed to agree emphatically that "he must know *something*" to teach them the way that he had over the years.

The workshop was beginning, and to start, we each practiced introducing ourselves. Since Adam had already described and provided examples of the kinds of interpersonal conflicts he would be discussing, he asked us to include in our introductions that day either a question that we had about the day's coming lesson or one piece of advice that we had for resolving social tension. As we went around the table that was just a bit too large for the handful of us in attendance, Adam stood at the front of the room, dry erase marker in-hand, writing notes on the large whiteboard that took up most of the wall. I noticed that I was the only attendee who offered suggestions for resolving disagreements and started to wonder if I had overstepped some boundary. Everyone else offered questions and seemed eager to learn about Adam's ideas and possibly actionable techniques. For a moment, I wondered if I was I toeing out of my role as student? Adam thanked me for my questions and jotted down something in his note pad. "I'm going to do my best to hit on all these points and help out, but no guarantees, guys. We might need a part two for this one." He said this with an exasperated sigh after Trevor ran through a short laundry list of questions he "needed" answered.

Adam pulled a gray pocket-folder out of his book bag. Inside, he had a small stack of typed up notes in large print. He introduced us to the idea of conflict resolution and proposed that we each "take responsibility for how [our] social interactions go." He offered tips on how to appear more friendly and approachable and speak in a way that could quickly diminish existing tension and could prevent strife from emerging in the first place. His source material, he stated, was a slew of autism-specific texts on how to navigate "tricky social situations," but also Dale Carnegie's (1936) *How to Win Friends and Influence People*. This was his favorite book, and I heard his rave reviews of it many times over the few years that I participated in the group and interacted with him. Importantly, Adam informed me in a couple of interviews before and after this particular workshop, that he did a great deal of reading for his own “personal development” and "for the benefit of the group.” He told me, "I do all this because I just want them to do the best, but a lot of them won’t read this stuff on their own … or wouldn’t know how to make sense of it by themselves, so I make this my ... service to them.” Adam's conception of his work leading and teaching group members as his way of "being of service" encapsulate the ways the leaders of the South and North County groups also viewed themselves in relation to their groups. They saw themselves as the primary builders of momentum for ongoing group activities and membership participation. In their role, they assumed identities as managers and experts and reinforced for others that they were equipped to do so through routine practice and performance. In doing so, they showed themselves to be both the core of their respective groups, involved in every aspect, and beyond them, as overseers of all intra-group happenings.

Shortly after Adam’s 20-minute primer on conflict resolution, Lei began to cry. I quickly dug through my backpack for the small travel pack of tissues that I kept there. Knowing that she did not appreciate unexpected physical contact, I set the pack before her on the table, and quietly reached out to lightly touch the arm of her chair – the most comforting gesture I could come up with in the moment. She surprised me when she hugged my arm tightly, before releasing me and turning away to bury her head in her hands. With Lei visibly upset, we sat quietly, with most everyone looking down into their laps, waiting for Adam to intervene. The group’s silence, which played key roles in group interactions each week, played a pivotal role in the workshops to distinguish teacher and student roles.

While on this occasion, all in attendance maintained their silence, save Lei, every now and then, a group member would fail to be quiet while waiting for direction or response from Adam. In those moments, one or more persons would look fiercely at the disruptor, place their index fingers to their lips, and loudly hush the offending parties within the group, making way for

Adam's training. Most often, Adam would sit or stand quietly before the group, waiting for the raucous to die down, perhaps knowing that his long-time group members would ensure that all others fell in line so that he could manage the day's activities without too much disturbance. I suggest that the ways leaders and some members of the groups used silence, particularly in workshops, helped show that they no longer viewed themselves as newcomers who were figuring out how to become and feel themselves to be a part of the group. Having graduated from the novice position, they demonstrated how they valued their participation within the group by enforcing its guiding principles. The idea that silence could do work for Adam, the group as a whole, and their individual relationships with Adam, "crystallized in the collective expectations of the community" and their means of reinforcing established standards of conduct for group members (Lave and Wenger 1991, p.106).

It was a long couple of minutes before Adam asked Lei to share the problem she was facing. Still sniffling, she looked at him reluctantly. He responded flatly, slowly, and confidently, "Trust me, I know what I'm doing … if you tell me the problem, I can walk us through it all." Lei struggled to remove a tissue from the pack that I left on the table. When she gained her composure, she described in great detail the isolation she felt in her college program. Adam listened intently, while others attending the workshop grew distracted, fussing with their pockets, bending over to tie their shoes, or leaning back in their chairs to stare into the ceiling lights overhead. Adam's attentive, calm, and thoughtful approach reinforced his position as leader and teacher amongst those in attendance, who individually and collectively accepted and performed in the student role (as distracted as some of them were). When Lei finished explaining the crisis she was experiencing, Adam used the whiteboard to plot out the main players and potentially unseen factors in Lei's drama. He used the opportunity to lay out a series of approaches that she might employ to resolve the issues she faced. Adam later explained his approach to me:

> It’s something I picked up in the big personal development workshops I go to. I practice all the techniques to be sort of ... charismatic to calm everyone down and ... be helpful so that they pay attention. I run hypothetical scenes in my head all the time … It’s not natural for me to be like this at all, but I've practiced for years until I got it down and now I can turn it on when I needed to manage the room and help people out.

As we packed to leave at the end of the workshop period, I asked Lei if she now felt equipped to resolve her social dilemmas. Rather than respond to my question, she apologized for derailing the group conversation. She leaned in and whispered to me and Trevor how impressive she found Adam and his knowledge base:

> I’ve been frustrated about this for *forever*, and I just cried. I’m so embarrassed. I didn’t even know it bothered me so much … I think some part of me assumed he would know exactly how to help, so my brain was like, ’Now! Cry and get your answers!’

Trevor chimed in, chuckling and saying, “I would have told you to leave if I was him… but that’s obviously why Adam’s the boss … He’s crazy wise!” Trevor's expression of appreciation for Adam's know-how was not unusual. Other frequently commented on how impressive they found him, usually while minimizing their own social capacities. The ways group members consistently deferred to Adam demonstrates how my offline groups' members perceived their predetermined intellectual or socializing limitations and used that understanding to inform how they would willingly submit to the role of student or follower, conforming to group hierarchical structures.

While the aim of such participation, according to the legitimate peripheral participant framework that Lave and Wegner (1991) laid out, is often to deepen one’s specialized skills and capacity to learn from a designated master so that eventually they might become masterful and possibly occupy a leadership role themselves, all but four of my approximately 120 offline group interlocutors were content to master only the student role and abide in it indefinitely.

In the above account, I examined workshop dynamics in the Mid County group to highlight general trends rather than to claim that all three groups’ members deferred to their leaders in equal measure and in exactly the same ways. There were some exceptions, with the occasional member being disruptive or contradicting information relayed by their group and workshop leaders. On one occasion, for instance, a member's disruptive behavior so agitated Kyle of the South County group, that they were asked to leave the meeting. "I never saw Kyle get mad like that," James told me. He explained that

> It was a while ago ... can't remember dude's name, but he started getting rowdy and wouldn't stop getting up and interrupting [Kyle] ... He did this a few weeks back to back and I guess Kyle had enough. He gave him this choice: 'be quiet and sit down or go.' Dude was so pissed. He turned all read and we thought he was going to fight [Kyle] ... but he just knocked over a fake plant and actually left.

Kyle was very upset by the event, I learned, but everyone in the group kept tabs on each other to ensure that no other members "ticked off Kyle." That "rowdy" member never returned. While this recounted event shows that all group participants did not hold group protocol and hierarchy in high esteem, it still reinforces my observation that the greater majority of the members did. When the unnamed, disruptive person that James told me about left things in group meeting out of balance, others in the group rallied together to facilitate swift recalibration.

In general, I found that members of the groups I studied expected and acted in alignment with three suppositions: one, that their leaders possessed some expert knowledge and authority they did not have; two, that their expertise or guidance could, to some extent, be assimilated by them; and three, that their silence and/or deference were central mediators in that transmission process. Those of my interlocutors who felt sure that leading a group was somehow *always* going to be outside of their capabilities were most content to not only praise their leaders, but also to take instruction and accept rewards and mild reprimands from those they saw as their "higher-ups." Critically, that same level of submission and respect was often absent when members interacted with one another.

I found that within the South County, Mid County, and North County groups that I took part in and studied, members were more apt to levy harsh critiques of fellow group members or ignore them altogether. Unless they had relationships outside of the group, a rather rare occurrence, members seemed to compete for leaders' attention or acknowledgment. And disagreements about the goodness or efficacy of these group organizers tended to result in the silent treatment, the "stink-eye," or eye rolling. Newcomers to the groups, however, received more courteous treatment from members. I suggest that this is due to established members' senses that in relation to these new people were apparently wanting to learn how to belong and be good group members members they occupied a higher rank (knowing the lay of the land and the rules and expectations for proper conduct) and appreciated the opportunity to lead and support integration into the body of the group on a smaller, one-on-one scale. “Oh my God, I *love* when we have new people come,” Jazz told me,

> I always hope its someone different from what we’re used to … maybe someone older or girls or something ... like they could be new friends … I always get their contact information because ... they could need help with something I know about or maybe the missed a group message from Adam.

My interlocutors in these groups attained the kinds of explicit knowledge that they sought out from their designated experts, the leaders of their groups. In general, they valued the ways their events were structured, toeing the line between formal and informal. In this kind of group space, the explicit knowledge that they acquired was accompanied by tacit forms of knowledge about how to be a good member and participate in these spaces of autisticness. This became a way of maintaining the group. Group members invested because they were invited to align with learning agendas that spoke to their desires and interests to have a "safe" social space for autistics and learn how to be more proficient in developing and maintaining social relationships. This supported them in deriving meaning from their participation (whether as leaders or followers) because of how occupying these roles allowed them to "contribute to organisational goals" (Wenger 1998, p. 10). They could make decisions about how to engage with the group by understanding expectations for conduct that were associated with their chosen roles and individual capacities. They were thus enabled to "fully engage their ... knowledgeability" of group protocols and align with them (Wenger 1998, p. 10). Critically, as newcomers grew more and more acclimated with the group members and activities, established members' enchantment with them seemed to diminish. They were far more likely to be disregarded by the majority of the members and engaged by only one or two of them. That is, of course, unless they brought salty, greasy, and sugary snacks to share with everyone.

Participating Remotely in a Non-profit Organization

Autistic self-advocate organizations' webpages and profiles on *Facebook* and other social media platforms often serve as a forum where expert-novice roles are played out. As I will show, however, this hierarchical structure is not the primary one in this non-profit space. The "services" these experts offer, especially in terms of disability news commentaries, links to their perspective or point-of-view essays, encouragement of newly diagnosed and prospective autistics, for-you-information posts and comments to their groups, and informational and community resource guides supported organization members in finding their place and standing affirmed in the particular autistic self-image they project within autistic spaces and in the broader social world. In my research with the Association of Autistic Women (AAW), I found that their activities centered on the idea that becoming knowledgeable about the fundamentals of autism and acquiring understanding of the primary themes undergirding autistic adults' life experiences prepares them to serve autistic women and gender minorities within the community, demand recognition of this underrepresented group, and demonstrate for non-autistics the inherent value of autistic life. With this in mind, the organization regularly updated its blog with original content produced by in-house writers or invited contributors from other autistic run blogs and websites. Careful to include a wide variety of perspectives, AAW's stated aim was to enhance the inclusive capacity of the autistic community for those who are most frequently marginalized. As a non-profit organization, they also created numerous committees and working groups in order focus self-advocate energies toward concrete, measurable outcomes for autistic minorities across the United States. These committees provided entry points for self-identified autistic adults to begin engaging critically with key conversations taking place at institutional, state, and national levels. These conversations tackled issues of diversity within community spaces, lacking representation of autistic women, the violence of anti-autism rhetoric, and the ways functioning labels promote anti-autistic ableism. Through content marketing, they tried to spread the word about their agenda.

For my interlocutors who were involved in AAW, their continued participation in these committees helped develop not only the necessary skill of recognizing one’s autistic voice as a valuable addition to ongoing discussions, but also a desire to assume greater roles within the organization, such as participating as a board member and helping make executive decisions for the non-profit. Maple, a 38-year-old woman had been volunteering with AAW for four months when I started my research with the organization. She told me that on old autistic forums and chat rooms, she would have extraordinary difficulty "speaking [her] mind and defending herself as an autistic woman."

> For a real long time, she told me, I just avoided most autistic community activities because of how much male energy there was everywhere. I'd say I was autistic, and the guys would talk to me like they didn't believe me, and then ... the conversation would turn into a competition of who was more autistic. I left one of the last times, before I got involved [at AAW] and actually felt embarrassed, like I was ... taking up space when I shouldn't be because my autism doesn't look like the boys'. Even though the guys on the

> pages had their own major differences. They were actually targeting and picking on me because of my gender. It was weird.

Here, Maple shows how her previous attempts to get involved in autistic spaces left her feeling as though she was invalidated and unable to participate in digital autistic spaces in meaningful ways. Becoming involved with AAW required some adjustment, she told me, but it opened up opportunities to expand her reach as a member of the autistic community and as a self-advocate wanting a more substantial platform for their activism. Importantly, Maple was not the only one of my interlocutors who were able to leverage their connections with AAW to get involved with other, bigger self-advocacy organizations like the Autistic Self Advocacy Network (ASAN).

Observing the ways my interlocutors at AAW networked with other organizations, I learned that their consistent engagement in any one role at AAW could increase their opportunities to increasing their audience and influence. Maple's blog contributions at AAW, increased traffic to her other social media profiles so that she received invitations to contribute to publications across the web, comment on news events, sign onto petitions, take on paid roles, report on institutional efficacy, and develop new collaborative projects with other autistics.
My own participation in AAW’s smaller projects and activities and then its more significant committees and boards, illustrates the general trajectory many autistic self-advocates follow, from peripheral participant to core participant in the space. In the summer of 2013, as part of my research, I began volunteering with AAW. During this time, I was asked to create a health care provider guide for autistic women. Daniella, the founder and executive director of the organization expressed her concern for autistic women’s health outcomes. When I sought to learn more about her concern, I found out that her experience with psychiatric disability and chronic illness shaped her perspective on medical care for autistic women and compelled her to use the AAW platform to address it. Regarding me as her student and, rightfully so, a novice in

the world of autistic nonprofit work, she explained,

> I refused to go to the doctor for several years, and I couldn’t ever tell my friends and family why. It was clear that I was in pain and suffering due to past psychological trauma and some physical issues that would come and go and get worse and worse over time. But I was always ... panic-stricken when it came time to show up for my doctor appointments. I never wanted to go, so I didn’t. I was terrified ... Once I was diagnosed a few years back, things started to click … It was my sensory dysfunction! Can you even imagine how many autistics can’t take care of their health because the experience is *so* traumatizing? And it's probably even worse for the people who have no idea what's going on with them. This is the kind of thing that gets overlooked a lot in parent orgs, okay? No one talks about this type of thing for autistic adults … and [for] autistic women? No dice ... People aren't getting the care they *need*. This is about rights …It’s what self-advocacy is for … it’s not going to be [Washington]D.C. stuff *all* the time ... Think of *this* project like your first ... move as an [autistic] activist.

To complete my "sensory friendly practitioners" project with AAW that summer, I took instruction (and correction) from Daniella and organization board members, who asked me to pull reviews of doctors from all across the internet, make some phone calls and write emails to medical clinics across the US, solicit recommendations from autistic and other neurodiverse people, and make some independent determinations about who might serve as ideal medical practitioners for AAW readers across the country. I completed that assignment successfully over a six-week period and after having my work reviewed by the board and other committee heads, I took on a few other administrative tasks that were geared toward helping the very young, but quickly growing organization. It was not until approximately one year of entry-level volunteer work had passed that I was asked to co-lead one of the organization’s burgeoning committees on neurodiversity, gender, and sexuality. Later, approximately two years after starting my research and volunteer work with AAW, Daniella asked me to volunteer first for the board of directors and then the executive board.

My experience working my way up through the ranks of the organization as a researcher and volunteer highlights how within this particular space the hierarchal structure of the master-apprentice dynamic served as a way for me (and other volunteers) to learn how to develop the knowledge and practical skills that would provide them a way to practice their activism. While instruction in how to do activism is linked to explicit engagement with the organization's internal projects, services, and public policy commentaries, AAW made instruction in autistic self-advocacy "fundamentals" priority. Simply, find a common "pain point" that autistic people experience and let others know that this problem can be ameliorated if "more and more people understand that autistic pain is everyone's pain." This instruction, I found, was crucial not only because it was a first step in growing a pool of potential volunteer and employee recruits for the organization, thus legitimizing and maintaining its relevance among autistics. It also helped influence the discursive lean of the autistic and autism communities. The organization produced and circulated information about the underdiagnosis of autistic women, the representational struggles this population faces, and the legitimacy of the many, varied ways that autisticness can manifest in gender and racial minorities. In doing this, autistic women and other gender minorities on *Facebook*, *Tumblr*, and *Twitter*, who were uncertain about their diagnostic status, or who were refused autism evaluation out-right, saw given chances to re-evaluate their own stories, push for formal diagnosis or stand firm in their self-diagnosis, feel confirmed in their autistic identity, and participate directly in and on behalf of the autistic community.

Crucially, AAW was firm in its determination that it was and would continue to be in full support of informed self-diagnosis, with or without peer confirmation. Being able to make diagnostic decisions after "doing [their] due diligence … and then being accepted" was a first step in Jem's participation with AAW. And their participation with the organization ultimately sparked their passion for autistic self-advocacy, motivating them to advance in their scope of influence within the broader autistic community through the development and maintenance of queer autistic blogs on *Tumblr* and *WordPress* and an *Etsy* shop that sells "autistic pride gear":

I started this blog and opened up an Etsy shop ... to help spread the word about autistic pride … and I included a lot of information for LGBTQIAA autistics. We can get shit on in the community because everyone questions if, like, being trans is somehow autism’s fault … Daniella and AAW as a whole have been my mentor for maybe four and a half years now … they told me my self-diagnosis was valid, that my gender and sexual identity are valid … It took a while, but eventually ... I got the nerve to do my own thing and they were totally supportive of my blog and shop.

Online: Ask-an-Autistic Blogs

The actuallyautistic hashtag was created in the early 2010s by autistic bloggers on *Tumblr* and *Twitter*, two major short-form and micro-blogging platforms. The tag was also taken up in other digital spaces, like the art sharing site *DeviantArt*, where autistic users use the tag to share their unique ways of perceiving bodily sensations, autistic pride, social exchanges, and environmental stimuli through graphic design, comics, and photography. The pioneers of the hashtag were at the cutting edge of online autistic self-advocacy using social media, leveraging their knowledge of autism fundamentals, personal experience with autism, and capacity to communicate through text and image on various platforms.

In a conversation with two of my long-time friends on *Tumblr*, Detta and Connor, I learned that the tag was created by what was once a “core of autistic bad asses” whose primary aim was to "dethrone" self-proclaimed non-autistic experts on autism, especially parents of autistic children. This group aimed to create content that one of the earliest users of the tag, Detta, said “directly opposed the negative stereotypes about autistics” and the “exploitative and expositional behavior that autism parents displayed when it came to their neurodiverse kids.” In an earlier phone conversation with Detta, she explained the impact “autism parent blogs” could have on the perception of autism and autistic people:

> These [autistic] kids … and even young adults were being humiliated constantly by their parents who were really outspoken about how *terrible* their lives were because of their autistic kids. But then once in a while they would levy all of this swoony love garbage about how precious their children were … There was all of this misinformation about mental age and being locked away in autism ... right next to posts with videos and long-ass blocks of text with horrible stories about how *betrayed* they felt that they ended up with disabled kids, because 'God, they did *everything* right when they were pregnant' … And then every now and then there would be pics of their 'precious' sleeping kids ... Like, can we get an honest story? … Those bloggers were honestly feeding new parents so much junk that they were commenting on the posts that they were depressed and terrified of their kids ... or, like, angry with them for existing and ruining their lives before they even got a chance to be actual parents to them.

The above quote from my conversation with Detta presents a couple of important problems autistic self-advocates aim to address. For autistics, the marketing philosophy that regards all publicity as good publicity does not work in their favor. The US-government-backed war on autism[19] which seems to play on the fears and anxieties of parents struggling to make do with their autistic children has deleterious and even deadly consequences for the autistic children and young adults being cared for by parents who are desperate to normalize their children or find relief from the pressures they feel to match idealized images of parenthood (see McGuire 2016).

Accounts that were on their face inconsistent in their representations of parenting autistic children, grieving the loss of normality in one instance and celebrating the joys of parenthood in another, were perceived as threatening and scrutinized. However, this kind of changeableness is evidenced in all manner of personal accounts, as people sort out the ebbs and flows of daily life, celebrating the high points and mourning the low (Stahl 1977). The imperative to counter messages of autistic people as a burden and reprimand "autism parents" for their anti-autism

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[19] In 2009, President Barack Obama announced a war against autism committed considerable funds to the project of discovering the cause of autism, improving early detection and diagnosis, and developing a cure that would eliminate ASD as a supposed epidemic and national tragedy (McGuire 2016).

rhetoric speaks to the sense of danger that many autistic people experience. For these autistic people, campaigns for an end to autism are understood as calls for the evisceration of the autistic population (Walker 2014, Hayasaki 2015, Kansen 2016).

That said, the actuallyautistic hashtag opened up a portal for not only autistic-to-autistic socializing, but also instruction and advising for people in the broader autism community (which includes autistic people and allistics (or non-autistic people who love, care for, and are interested in autism). Detta explained her involvement in the actuallyautistic space on *Tumblr* and *Twitter*, saying

> That's why I really got into the actuallyautistic tag at first. It was a way to show everyone that there are actual people with lives under the label and fear mongering. Everyone putting in their voices is what makes it work. You have to take it as a whole thing, a huge conversation between people who don't even know they're chatting with each other. It was very important to me as someone ... who grew up knowing I was on the spectrum and then … *decided* that I was an autistic … as in owning it completely ... I had the parent who *hated* having an autistic kid and embarrassed me pretty much every chance they got … They didn't know about my hurt feelings for a long time since I went through long bouts of selective mutism ... maybe they thought I didn't know what was going on or ... what they were saying. Actuallyautistic is supposed to be that outlet for me now that I can communicate better ... I say the tag ended up going from *a lot* of ask-an-autistic type blogs to what we have going right now … more of a community of people chatting each other up and being fabulous … I liked the old way a lot, but a bunch of us got really burned out … what we have going now is pretty great and slightly less stressful.

As Detta explained, using the tag, autistic users collectively engage in generative, joint imaginings of autisticness, so that their work of imagining and expressing autisticness was a social and embodied activity (Murphy 2004). By contributing to the tag with their own stories and questions, they were engaged in a process negotiating the meaning of autisticness in that particular digital group space[20]. In doing this, they were adding nuance to existing conceptualizations of what it means to be autistic by talking about their direct experiences and

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[20] See Bernal (2006) for discussion of the ways social media interactions facilitate joint meaning-making and narrative-formulating processes among members of the Eritrean diaspora.

challenging routinely regurgitated, limiting notions of what autism is and can be.

Some blogs mobilizing the tag used their platforms to instruct and advise others, playing out the student-teacher, master-novice dynamic that was similar to what I encountered in the offline group and non-profit spaces that I have discussed above. I propose that the primary, overarching spirit of engagement in the offline and non-profit spaces was service-based. Leaders supplied pertinent information and took on the duty of organizing and managing group and organization activities and agendas. I suggest that while on Tumblr and Twitter, in the actuallyautistic spaces, I could not characterize the primary participation structure as hierarchical, the ask-an-autistic genre of actuallyautictic blogging constituted a sub-arena in which the autistic master-teacher realized their expert status and was affirmed by others who actively sought out what they willingly provided – answers and advice for autistics and curious allistics.

Zippy

Zippy, a 26-year-old autistic man and sketch artist frequently posted on his *Tumblr* advice blog about so-called “exceptional autistics,” those who are labeled “autistic savants.” For him, his ask-an-autistic blog was a platform dedicated to serving his followers' needs for advice. He had an almost 7,000-person audience made up of both autistic and non-autistic people that he won over because of his ability to simultaneously legitimize experiences of autism (for caregivers) and autisticness (for autistic people). Importantly, because of his many posts on the subject of exceptional autistics, the kinds of questions that he would field generally came from adults on the autism spectrum and related to living up to “savant-like or aspie standards as people who just didn't have those abilities.” To address their concerns, he emphasized the importance of understanding the inherent value in diversity and the problematic obsession with "providing value to others" by apologizing for autistic difference and striving to maintaining the status quo in social situations of all kinds. In an interview with Zippy, I learned that in providing advice to his readers, he learned of the damage autistic people are vulnerable to when they are embedded "in an anti-autistic culture that gives certain privileges" only to people who live autistic lives that are exceptional or that have certain special capabilities. He explained,

> I have nothing at all against people who have amazing gifts of perception or memory and scholastic aptitude, right? I'm gifted in my own right ... I have many autie friends who can do *incredible* things, and I'm always shocked at how good they are at their craft ... But … it's something we talk about a lot on my blog … how they end up with all of these allistics drooling over their work and commenting on how 'special' autistics are, but only when they have these almost super human skills ... And it's not their 'fault,' if I can use that word at all … It's terrible, but it seems natural when we think about how we're all requiring that people have to be normal across the board. Or ... they have to be out of this world in one area and compensate so they're now okay in everyone's eyes ... This hurts people who are just who they are and how they are ... no matter what they won't be anything else or that science genius or Beethoven like other people want them to be.

Though Zippy occasionally received critical messages from self-described savants and people on the spectrum who called themselves "aspies," the majority of his readership consisted of newly diagnosed autistics, diagnosis-exploring individuals, and parents who were trying to reconcile their "below-average realities" with their desire to be either generally accepted because of their normality or recognized and praised for their children's exceptional talents. Zippy told me that because of his blog, he had been able to "teach" his followers or subscribers to recognize that the problem of anti-autism is a systemic cultural ill rather than one for which they must hold themselves accountable and apologize:

> It's that conditional acceptance of autistic people that just really breaks my heart. Or ... it's that really superior mindset that allistics can have when they see an autistic person doing something really great. Like, 'oh, good, you're not totally useless then, I guess you can stay … won't treat you any better, but I won't actively hate you for breathing.' It's scary, because autistic people are most of the time just one step away from losing any footing they have with people in this society. We're useless and dangerous unless we can love and express things so people feel warm and fuzzy inside, and we're useless if we can't sit still in class, but we're *maybe* okay if we can remember everything we see and sketch all of it in crazy detail. It's not right. We have so much depression and anxiety about it like it's our own fault. So, I … do this answering questions thing and include non-autistics, to

> show them ... how shitty it is when they're being ableist, and for autistics … so they can see that they are allowed to hold the *right* people accountable for how they're being mistreated.

Kassya

Like Zippy and Detta, Kassya, an autistic woman who frequently posts to the actuallyautistic hashtag on *Twitter,* focuses primarily on answering fellow autistics' questions about autism and autistic life. She had been self-identifying as autistic and a member of the autistic community since 2008 and enjoyed participating in different kinds of autistic spaces online, starting to use the actuallyautistic hashtag in the summer of 2013, shortly after it entered the scene on *Tumblr*. In an interview, I learned from Kassya that she aimed to make her "work" productive. Wanting to provide information that was "autism-positive" and that would "help autistics think about how they can serve the community" through small-scale (one-on-one) and large-scale (organization-based) self-advocacy, she focused on making sure that she "always addressed ableism and anti-autism bias," so that those who reached out to her with questions, and others who were simply reading, could clearly recognize how the specific situations that her readers experienced were connected to overt and subtle manifestations of ableism. She told me:

> I was on all of those [autism] forums back in the day. In 2007 or 2008, I think, I got really hooked on the forums. That's ... where a lot of my questions got answered … About socializing, dealing with ableism, coping with family, finding work … My fairy autistic godmother told me that when I could put the pieces together for myself so I wasn't seeing everything in separate parts of my life it would bring me a lot of peace ... she was almost 60 and retired when she was diagnosed, so I actually believed her. Now, I think of her as my fairy godmother ... because she gave me a ... sense of responsibility for what I do with my time on social media now. I don't mess around … I am there to help autistic people see how they fit in the big picture, where ableism is *everywhere*, and how ... it can be even worse if we don't fit expectations for how autistics *should* be. I think we usually get how obvious fights with ableists are when they talk about how bad we are making American society. But ... most of the people asking me questions over and over and over don't actually get that a lot of the time the small person-to-person problems also have society's ableism at the root of it.

Kassya's "responsibility" and "work" fit the idea that ask-an-autistic blogs in the actuallyautistic space have service and instruction as its bases for engagement and make the legitimate peripheral participant concept a useful tool for analyzing how interactions of this kind play out. This framework helps show how my interlocutors' intentions and beliefs in their own expertise with regard to autism and autistic life allowed them to receive continued, external validation of their self-perceptions. Prospective and newly diagnosed autistics would ask other autistics like Kassya, Detta, and Zippy, who conceived of themselves as experts on autism and autisticness for help with their specific concerns, prompting their chosen experts to share with them their conceptions of autism and autisticness as well as their readings of various kinds of psycho-social dramas and proposed remedies.

While all of the people who sought support from these established autistics did not keep in touch with them, especially on *Tumblr,* where users often make use of the ability to submit questions anonymously, substantial connections have been made. Kassya, for instance, recalled that she connected with and supported a troubled, young autistic user on *Twitter*. She traced her mentee's personal development and recently-assumed role as autistic expert on the site back to how she mentored them. She told me about the ways that her "service" not only drew prospective and previously unengaged actuallyautistic participants into a deeper "sense of autisticness." It also helped produce a new, expert participant:

> It really pays off … One of the kids [age 19] that I answered questions for when they were going through a really tough time transformed. They ... asked some questions here and there and then things started to seem really bleak for them. So, I offered to chat with them one-on-one instead of on the timeline. And it was ... way worse than I thought. So, we set up some phone calls on *WhatsApp*[21] here and there, just to check in because I was so worried they were going to do something to hurt themselves ... It started to get better for them over time ... We lost touch for a few months last year, but then they ... popped

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[21] WhatsApp is an application that enables users to communicate with people across the world using only an internet connection.

> back in January of this year and they completely did a 180 re-brand. Changed their pic[22], their URL[23], their description ... They're answering their own questions and giving pretty good advice, repeating some of the stuff I told them ... not that I'm taking credit for any of that, but I know I ... made a difference there, and we have one more strong advocate for our cause … So, I'd say this is *my* form of self-advocacy or activism ... I read this thing about 'lazy activism' online and it's bull. There's nothing lazy about it. This is hard work. It's emotional because there are actual people involved, and being autistic is hard.

Cordelia

Fielding questions from anonymous inquirers about what autistic life is like, how to manage social and emotional challenges as autistics, and how to better understand the experiences of children and young adults on the autism spectrum, ask-an-autistic blogs on *Tumblr* provide a digital database of "expert" takes on autistic experience given that the information produced and circulated originates from people who are actually autistic.

Scrolling through the actuallyautistic hashtag on the site one February afternoon in 2016, an "ask" post on the blog Autie-Inquire, one of the longest running ask-an-autistic blogs on *Tumblr* (started in 2012), caught my eye. This blog was moderated by five US-based autistic adults between the ages of 19 and 26. As the moderators tell their story, the team was assembled primarily because they were of diverse gender, disability, parent, racial, sexuality, and socio-economic statuses. They believed this diversity would support them in answering questions from the diverse autistic readership they wanted to attract. That February afternoon, the question that caught my eye as I scrolled through the hypertext space was submitted by an anonymous parent of a non-speaking autistic child. It read,

> How should I handle it when my child stims violently? On the one hand [the stimming] is doing *something* for them, but on the other, it's hurting them. Bruises, cuts, scrapes … it's horrible. As a parent, I just want to see my kid happy and give them what they need *and* keep them safe at the same time, but I can't figure out what they want. It's

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[22] Their profile picture on *Twitter*.

[23] The username that the user gave to their account

breaking my heart.

Cordelia, a 23-year-old autistic person, and the founder of the Autie-Inquire collective, responded to the question, suggesting that the parent “exercise discretion" because "Sometimes the stimming experience is really intense and the sensations get too deep and it becomes loop-like ... your kid could feel the pain and not be able to pull out of the stim … or maybe they’re not aware of their injuries because they don't feel it." She added to this general advice with her own personal experience, writing

> I have high tolerance for pain. I used to surprise myself with new injuries after I would get really deep in stimming. I would get caught in that loop … So if you notice that your child is stimming violently and is going to hurt themselves do what you can to clean up the area they’re in before you touch them so you don’t cause them to meltdown from the shock of being pulled out suddenly. If you can’t do anything with the area or they’re still at risk, take action ... but always make sure you're safe. I don’t know how old or large your child is relative to you so keep that in the back of your mind. I know it’s hard, but it’s great that you care enough to ask. That’s partly what this blog is here for!!!

Bookmarking that post in my web browser, I kept track of its activity for nearly four days before I noticed that it was “liked” and “reblogged” by a user who, shedding their anonymity, declared that they were the parent asking the question. They wrote: “I’m the one who sent in this question. This is incredibly helpful … and thoughtful information. I’ve heard similar suggestions before, but having it come from ‘actually autistic’ people makes it seem more … sound? Your blog has turned my view of my son around.”

What this parent-user's interaction with Autie-Inquire demonstrates is how the blog established a digital domain in which autistic experts connected with people who were effectively autism novices. Autie-Inquire facilitated new forms of autism literacy that centered autism as a way of being rather than a biomedical puzzle to be solved. In this way, autism did not require engagement with designated biomedical experts on autism as a pathological condition. Futhermore, the interaction was not merely between Autie-Inquire and the parent who submitted a question about their autistic child. It was actually between Autie-Inquire, the parent, all of their respective followers, and potentially everyone who hung out in the actuallyautistic space on *Tumblr* at that time.

It is important to note that, by and large, manifestations of autistic community and self-advocacy on the three major social media sites that I studied, *Tumblr*, *Twitter*, and *Facebook*, generally focused on autistic-autistic interactions and sometimes seemingly unilateral expressions of autistic identity. The ask-an-autistic genre of autistic blogging on *Tumblr* and *Twitter*, however highlighted the interrelatedness of different kinds and levels of activity on the platform and the way that interrelation constituted different peripheral to core participant trajectories within actuallyautistic hyptertext spaces. It entailed shifting roles within a digital space of inquiry, so that new ways of relating to others could be mediated through a recognized claim to expertise on these topics. The genre took answering follower questions as an important part of its purpose to demonstrate how to be an effective self-advocate through commitment to pro-autism education and displays of autistic people's inherent expertise on matters related to autism and autistic life. The "owners" of these ask-an-autistic blogs were individual autistic people and autistic collectives who fielded "loads" of questions each day, from earnest inquirers (and trolls) from different walks of life. Cordelia explained to me,

> these blogs are *a lot* of work. I wish there were more of them because of how much work they end up being. I mean, you can't forget to log in for *one* day or else you're sinking … that's exactly why having other moderators is such a good idea. It gets new autistic people involved, who usually don't even think they have answers to anything. Honestly, I just scrolled through actuallyautistic one afternoon and, plus the call for moderators I posted on the blog, I sent messages to different Tumblr users who were really consistently posting stuff self-advocates usually really like … news, commentaries, personal stories… eventually some people agreed to join, and they really fast became superheroes on the blog.

Cordelia's explanation shows how they were able to identify autistic *Tumblr* users who could *become* expert through their participation in their co-moderated blog. Looking for several alignments, or points of conjuncture, between bloggers' self-identification as autistic, their proficiency with the *Tumblr* platform – demonstrated by their consistent activity on the site – and their ability to perform autisticness textually – demonstrated by their ability to produce text posts about personal experiences and current events related to autistic experience constituted an abstract form of testing for others' capacities to learn how to consistently perform in the role of expert autistic.

Yet passing the test did not guarantee that expertise would actually be performed in an effective manner. Effectiveness, or the successful management of participant roles in interactions with blog readers and inquirers, was key to being regarded by the readership as having expert status. "Our blog has cycled through a few collaborators because it can get overwhelming, especially if someone disagrees with advice you're giving or the opinion you have about a topic and you lash out, which happened a few times," Cordelia told me laughingly. "We had to ask this one guy to step down after the second outburst like one week after they started, and they actually ended up cutting off all ties, which was surprising … like, they deleted their own blog so no one could find them or reach out. They weren't really ready for our blog."

Not regarding their co-moderators as novices, Cordelia expected their chosen *Tumblr* users to quickly acclimate to their new role and assimilate the unspoken rules of respectful conduct on such a platform. Yet their need to eliminate one of their co-moderators for misconduct shows that there is a learning-by-doing process in play that is captured particularly well by ask-an-autistic blogs like Cordelia's Autie-Inquire. The selection event, being identified as potential expert, and the co-moderator role itself did not create a legitimate expert. Rather than instructing them outright in the most effective ways to navigate potentially challenging interactions with inquirers, Cordelia quickly inducted them into the expert role without further questioning, a choice they have since learned from:

> I compiled this resource guide for new mods and made, like, two rules for everyone to follow … one is, if you're having a really rough day, don't log on and ask someone else to cover your shift. And two is this ... just don't yell at anyone on our blog. Just give your advice and be done with it. Everyone won't appreciate what we have to say.

LATERAL ENGAGEMENTS

In the offline and non-profit autistic spaces that I studied and participated in, the legitimate peripheral participant model encapsulates effectively the hierarchical relational structures that I observed. This model also sheds light on how interactions in some online social media spaces worked, as with the ask-an-autistic blogs that I discussed above. Still, I observed another interactional mode in actuallyautistic spaces on *Tumblr* and *Twitter* and in a large group for autistic adults on *Facebook*. In terms of structure, this mode seems to be situated somewhere between the Lave and Wenger's (1991) hierarchical master-novice framework, Wegner's (1998) conceptualization of negotiated meaning in communities of practice, and Gee's (2005) peer-to-peer, membership-less affinity space, as if the three were all on a sliding scale of possibilities. Wenger (1998) and Gee's (2005) frameworks lack the clear hierarchical structure for interactions but learning continues to happen. I propose that in my online field sites, alongside more hierarchical ways of relating, my interlocutors also engaged with one another laterally through identity-anchoring or affirming practices. These practices supported social connections (however short-lived) and reinforced participants' sense of legitimate autistic identity and community belonging.

Many of the posts and interactions that I observed and participated in on *Tumblr*, *Twitter*, and *Facebook* involved touch-and-go exchanges. They were brief, involving "likes" (which served as indications of approval, acknowledgement, or personal resonance) and extensions of social reach as participants in the space circulated each other's content through retweeting, reblogging, and reposting. I learned from my interlocutors' accounts, observations, and direct experience interacting with others on these sites that unless users had some relationship established offline or through some other shared activity (like participation in AAW or ASAN, for instance) very often, interactions with posts in the actuallyautistic hypertext space seldom resulted in deep or sustained interpersonal connections. I also learned that interactions that went beyond liking and recirculating, entailing consistent exchanges of comments, direct messages, and mutual following (or subscribing to one another's updates) tended to take place between peers who saw themselves as essentially evenly matched, operating within a horizontal rather than vertical interactional structure.

I found that the anchoring and affirming practices that my interlocutors engaged in took three primary forms: posts that involved participants' (1) *self-expressing* by sharing art, general daily updates, and selfies; (2) *ranting, provoking, and commiserating* about personal life events, observations, and opinion posts; and (3) *priding* through the circulation of encouraging quotes, links to buyable products, images, and videos. Often, even when my interlocutors shared personal details, long text-based rants, and statements describing their need for genuine social connection the content producer received little in the way of direct contact from others. Instead, the content of their posts (rather than the content producer *and* their appeal) were spotlighted.

For instance, I routinely saw posts from users on *Tumblr* and *Twitter* in the actuallyautistic space expressing how saddened they were by their lack of friendships and social connections. One *Tumblr* post from duck_nukem read: "I'm bummed out ... I think about how easy it is for other people to make friends. I find it so hard to do. Even on [Tumblr] I see some people tagging to each other and I feel a bit of jealousy." Of the 248 notes on the post, 246 were likes and reblogs that did not involve any indications of interest in establishing connection with duck-nukem. Two notes were reblogs with comments that simply indicated that the users could relate to the content producer's dilemma. Following up with duck_nukem on their post, I learned that, in spite of attaining almost 250 notes and being seen by hundreds of users in the actuallyautistic space, they received no direct communications from fellow autistic *Tumblr* users. "I should have known better lol," they wrote to me, "I was just having a rough day but people just reblogged it and used my words without saying anything to me about how I was feeling. It was nice knowing other people could relate [though]."

This example shows how socializing between my interlocutors often worked on *Tumblr* and *Twitter*. In other instances, users reblogged original posts and added copious amounts of personal commentary, and this usually did not involve direct acknowledgement of the content producer. It was not necessarily that my interlocutors were neglecting one another in the digital space that they shared. Instead, they seemed to use the actuallyautistic space on *Tumblr* and *Twitter* to refine their own self-images, which they put on display on their personal blogs. The abundance of likes and reblogs of the post, and the absence of direct communication stemming from it, points to what I believe users found most valuable about the space. The space was teeming with opportunities to see some of the ways in which other autistics experienced life as they did.

On *Tumblr*, *Twitter*, and *Facebook*, many of my interlocutors were content to “lurk,” in the words of Morgan, an interlocutor from the *Facebook* group in which I studied.

> I don’t really feel like I need to add these people to my personal Facebook friend list. I’m never going to meet them IRL[24] … they’d have to be pretty amazing for me to even accept a friend request from someone in the group, and I would never send one myself. I spend most of my FB time in the group anyway so they could just catch me on there if they REALLY wanted to. But I don’t look for autistic friends on Facebook, I just like

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[24] Shorthand for "in real life."

being connected to the community.

Importantly, Morgan, and many of my interlocutors from *Facebook* irregularly published original content in the group and only occasionally left comments on others' posts. Martin, an autistic man who was recently added as co-moderator of the *Facebook* group told me, "I basically feel connected everyone in the group off the bat, I don't need to do a lot of talking to anyone unless I need help with something specific and ... then they're all usually pretty nice about giving feedback …

> We all have the diagnosis or are getting one or feel like we should have the diagnosis even if we can't be diagnosed officially … so I'd say the vast, vast majority of people are like me ... just clicking in and checking the group to see what new shit other Aspies and autistics are up to and nothing more. I'd guess that most of the [more than 16,000] members in the group come to scroll through don't leave comments or talk to anyone … half of the people who actually say something are asking for help with issues and the other 50% are telling us what they ate for breakfast or showing pics or talking fandom. Most of us just like looking and reacting with likes and whatnot.

Martin's observations, which he later told me were based on a group analytics tool supplied by *Facebook*, supported my own. The number of group members was far greater than the number of people who participated in the group by posting content and comments. That said, it was revealing to sift through and examine the conversations that were shared between group members. This examination helped me better understand how my interlocutors related to one another laterally. In what follows, I present several examples of the practices (self-expressing; ranting, provoking, and commiserating; and priding) to show how this lateral relating played out in spaces that also supported vertical interactions that centered on a teacher-student, master-novice dynamic.

Self-Expressing

Kelly-Ann was one of the most engaged members of the *Facebook* group for adults with autism. The 22-year-old autistic woman posted updates and links to her *WordPress* art blog nearly every day. One day in September of 2015, she posted a series of photos of herself while she was "in the zone." Collectively, the photos captured her multiple artistic talents. She was not only a skilled painter, she was also a photographer, graphics designer, sketch artist, and ever-improving jewelry maker. "Here I am!" she captioned one image. "The mad aspie genius at work," she captioned another, pointing out how "blissed out" she looked in each image.

> It's almost like stimming the whole time when I'm making my art. I get tingles all over. I feel the patterns before I can paint them like vibrations in my body, which I learned is quite an unusual gift! Sometimes, I have to stop what I'm doing and jump up and like run and stomp and flap my hands because I get that pattern … and can't get it down fast enough.

Here, we see that Kelly-Ann is not requesting advice or expressly calling for a particular kind of feedback from members of the group. Instead, she is sharing who she perceives herself to be for a group of others whose autistic or aspie identities allow them to experience a sense of mutuality. She refers to herself as an "aspie," demonstrating her affinity for the Aspergian rhetorical character, in spite of the fact that the classification is now outmoded.

Furthermore, Kelly-Ann describes her experience of art-making as it is mediated by both stimming and synesthetic experience. The former is an extremely common aspect of autism spectrum disorder with which the many group members could identify. Her synesthetic experiences, though much less common, are a hallmark of supposed autistic savants, many of whom channel their unique sensory-perceptual experiences of the world through various art forms (see Ward et al. 2017 and Baron-Cohen 2013). To her post, Karly, a 53-year-old autistic woman in the group responded: "I'm glad there's at least one other synesthete in the group. I see music in color and patterns … so it's kind of the inverse of you. I can't make the art, just the music. Who knows … maybe we can collab one day LOL." It is important to note that Kelly-

Ann never responded to Karly's comment under her published post. She might have, however, contacted her privately through direct messaging on the *Facebook* platform.

In addition, early in my research period, Kelly-Ann's posts in the group received some positive feedback, usually with fewer than twenty comments and fifty likes each. This is a relatively low volume of interaction considering the more than 16,000 members in the group. I suggest that this low volume of interaction was primarily rooted in the fact that her posts, though consistent, consisted of just a link to her blog and the title of her latest blog post. The people who liked or commented were willing to follow the link to her blog and engage with her content there. The comments she would receive from members who clicked through to view her blog applauded her creativity (and sometimes, her good looks) and expressed pride in autistic and aspie "brilliance." This post, however, having a series of photos of Kelly-Ann engaging in her art, was very well liked by members of the group, amassing more than 6,000 likes in approximately three weeks. Moderators of the group eventually "pinned" it to the top of the group page, helping advertise her post and increasing engagement with it.

I even saw the post on my private *Facebook* timeline, evidence that several of the group members, who added me as friends on the platform, had re-posted Kelly-Ann's photos to their own profiles in order share them with friends and acquaintances outside of the group. They praised her and expressed how their "friend's" artwork left them feeling a sense of "autistic pride." I suggest that Kelly-Ann's post helped anchor her identity as an autistic person whose synesthesia enabled her to create remarkable works of art. It also helped indirectly anchor other group members' autistic and aspie identities, as they saw her display of "brilliance" as a reminder of their senses of pride. Through their interactions with the post and their circulations of it, they anchored or reaffirmed their autistic/aspie identities.

Ranting, Provoking, Commiserating

Clint

One night in late December of 2016, I sat at my desk checking out the most recent posts in the Facebook group. I was in the middle of a brief, impromptu chat with Fabby, a co-moderator of the group, I learned that while the group's name indicated that it was specifically geared toward people with "high functioning" autism and Asperger's syndrome, by her count, the vast majority of the roughly 16,000 members were "probably diagnosed with autistic disorder and labeled as moderate to high functioning autistics." One of the first posts that appeared on the group's timeline that night in February was from Clint, a brand-new member of the group. This was his second post to the group. He had just joined two days earlier and left a message for everyone introducing himself. That post received many likes and only a couple of welcome-to-the-group comments. On this night, however, Clint had just broken up with his long-time girlfriend, a "non-autistic younger woman." "Angry" and "frustrated," he posted details of their conversation from earlier that day. He wrote that he "never saw it coming" and blamed himself for trusting a neurotypical woman. He also noted that he "despised the idea of being single again after so many years of partnership," and he feared that he would be unable to "woo another NT[25] woman," his preferred "type."

In less than one hour, Clint amassed almost 50 comments and many more likes on his post. While some of the comments expressed "sincere" apologies and words of encouragement, others used the opportunity to lambast non-autistic women for their supposed "heartlessness in breakup scenarios" with autistic men, suggest that an "aspie girl" might be a better match for

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[25] NT is an abbreviation for neurotypical, a term usually used to describe people who are non-autistic or who have no known psychiatric, cognitive, or developmental disability.

him, or issue warnings about the “dangers” of romantic relationships in general. “Clint my man,” commented Anthony, another new member of the group, "this is just what women are about and probably created for … to hurt us … aspie guys who are more sensitive than NT guys. No problem getting you hooked, leading you on and then dropping you just like that.” Scrolling through, I could see that Clint had interacted with almost every comment left on his post, liking each one of the sympathetic offerings from group members. While several members were expressed their outrage about Anthony's misogynistic note, Clint replied favorably, writing, “Truer words have never been spoken, I didn’t know this about NT women before now, I’m absolutely devastated.”

Clint’s post, with its assertion that his autisticness (or aspieness) was at odds with his former partner’s neurotypicalness, resonated with many of the men in the group, who identified with his feelings of shock and devastation. In fact, posts like this were not uncommon within the group, which had a mostly-male membership. By and large, posts about dating women were shared by men on the spectrum who explicitly requested help from more capable others in navigating dating relationships, particularly with neurotypical women. Their calls for assistance centered on the fact that they faced difficulty picking up on cues that their dates or partners were sending through body language, facial expressions, and tone of voice. Women in the group, though smaller in number, also sought support for the challenges they faced while dating. Their posts, however, took on a different tone, communicating uncertainty about how to trust and be safe with dates and partners, autistic or neurotypical, who might harm them. When posts about love relationships were not about dealings with a date or partner, they were often about the sadness or loneliness the group member felt about being “forever alone.”

Clint’s post differed from those that explicitly called for help from others who were potentially more knowledgeable. I suggest that his post not only expressed his particular romantic dilemma but also re-affirmed for him his identity as an aspie man whose struggles with reading complex social situations involving his partner. A struggle that resulted in his surprise and heartbreak. For others in the group, Clint's post provided them the chance to express their displeasure with dating and romantic love. In only two days, his post had more than 200 comments and twice as many likes. Clint's difficulty reminds me of the difficulties many autistic men across my field sites expressed: dating is especially hard on autistics. And the story went that it was double the challenge for autistic men whose expressions of masculinity are supposedly misaligned with that of neurotypical's, which constitute the dominant mode. KyloPhen-Phen, my interlocutor from *Tumblr*, explained autistic men's "plight" in this way:

> Romance is built on the premise that we're all talking the same romantic language, we share the same codes because we all picked up on them as we became interested in being in sexual and romantic relationships with others. Straight women of all kinds receive the women's code to being attractive to a man. The dudes get the code for how to be attractive to women … it's way less strict than the women's but there's still the basic thing about seeming masculine enough to be datable. And you can't be creepy. We [autistic men] can't read a lot of these codes bc [because] our OS [operating system] is different. I don't know any autistic guys of any orientation who have mastered dating and NOT worked with a dating expert of some kind.

Clint's example shows not only how ranting about his relationship troubles was a catalyst for increased group engagement, but how the rant itself encapsulated assumptions about autisticness or aspieness and how those ways of being might undercut potential for success in romantic and sexual relationships. Clint's rant was also polarizing because of the assumptions he made about romantic relationships, women, and neurotypicalness. Anthony's comment on his post frustrated women in the group who called for moderators to delete or block the post because of its "misogyny." The post and all comments went untouched by moderators, who allowed the tense conversation to continue for days.

Lanny

Tagging his posts actuallyautistic on *Twitter*, Lanny, an aspiring autistic comedian routinely published observation-based posts that were "not for educational or advocacy purposes." Rather, with his posts, he wanted to share all of the "strange things that he noticed about people and the world in general," from his autistic perspective. Commenting on all manner of things, from the "god-awful, horrifying taste and texture of mega-minty toothpastes" to the way patrons "walk out of grocery stores, pushing their carts like animatronics or zombies." In October 2015, when I first encountered Lanny's tweets, I noticed that he had just 23 followers (I was one of them) and almost 200 posts. In spite of all of his activity on the site, he had only the occasional like or re-tweet. I believe that, in large part, this was due to his reluctance to tag approximately 93% of his tweets, which were posted over the course of almost six months. All of the five or six tagged posts were published within his first two weeks on the site. Using tags on major social networking sites like *Twitter* and *Tumblr* (and now *Facebook*) allows users who intend to interact with specific kinds of people and information to create and enter into hypertext spaces. The tag is, therefore, both space and role defining. In practice, tagging opens the digital pathway *and* identifies those who participate in the digital space, the target audience. Actuallyautistic was simultaneously defining the digital space and its occupants. That said, by virtue of the fact that there was an extraordinary volume of information being circulated each minute on the site, Lanny's tag-less tweets easily fell by the wayside and remained unseen by autistic people, those he told me were his target audience.

Though Lanny had a robust *Twitter* timeline and had followed more than 500 other *Twitter* users, most of whom had not reciprocated by following his profile, he had limited interactions with other actually autistic people on the site. Examining his profile, I also noticed a link to his *YouTube* channel, which had just one six-month-old video posted, introducing himself as a comedian and his channel as a platform to share his unique perspective on the world.

Curious about his motivations on *Twitter* and *YouTube*, I asked Lanny for an interview. We exchanged a series of direct messages on *Twitter*, before he suggested a more "conversation-friendly" application like *Google Chat*. To learn about his social media strategy, if he had one at all, I asked if he was actively trying to attract more followers on *Twitter* and boost his subscriber count on *YouTube*. "Yes and no," he typed to me. I found this surprising. Surely this aspiring comedian wanted more followers. He wrote:

> Yeah I want more followers in the sense that I want to share my autistic POV to make people smile. I think other autistics would really like it … but they don't follow me and I'm not sure why. Maybe it's [because] most of what I'm saying seems really simple and boring to most people so they ignore it [and] follow other people or like other posts … And … no I don't [want more followers] in the sense that if I get too many I'm going to try to figure out how to get more and more and then I won't be myself anymore and I'll be trying to be funny which is not funny at all … that's what happened at the beginning when only a few people followed me and then no one else did.

Asking Lanny to share his stand-up comedy aspirations with me, he explained that he will definitely be a comedian and that he loves to

> perform with a small group of friends with different disabilities at a coffee shop in my neighborhood… it's fun and people are generally supportive. I thought I could do that same kind of thing on Twitter … For me it's about sharing who I am as an autistic because most people think that autistic people can't or wouldn't, and I can and will. It's like any kind of abstract art … so like some people are gonna get it, but most people are just gonna be like, 'you just drew a banana on a brick wall, wtf[26]?' My whole Twitter persona is like that, except it's not a persona, it's just how I am. My siblings just got tired of me yapping at them all day, so I took it to the web.

Lanny's example highlights a couple of things: first, how his attempted interactions with other autistic adults on *Twitter* (and on *YouTube*) spoke primarily to his desire or intention to express himself as an autistic person with a unique perspective on everyday life experiences. Second, this example shows how availing oneself to engage with other autistics on sites like

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[26] WTF if an abbreviation for the exclamation, "what the fuck."

Tumblr and *Twitter* might be dependent on how one plays by the rules of space. Tagging posts is essential to identifying both content producer and audience, a first pivotal step in launching interactions and relationships with preferred peers. Lanny's aims to be expressive, heard and seen among people he related to, was common among my other interlocutors. While others were happy to lurk on social media without engaging in conversation or establishing one-on-one social relationships with others in the space, those of my interlocutors who regularly made posts to share with others wanted to express their experiences of being different, misunderstood, feared, or abused because of their autism diagnoses, atypical behavioral patterns, and unique sensory realities. For many of my interlocutors, and especially for those who conceived of themselves as self-advocates and activists, choosing to simply express their everyday autistic realities, without requesting responses from anyone, was vital to making headway in combating culturally sanctioned rhetorical and symbolic violence against autistic people of all ages. Daniella, for instance, explained to me one afternoon over a *Skype* coffee interview,

> I don't necessarily approve of everything your John Robison or Temple Grandins have done, and what [Steve] Silberman has done … they're practically in bed with Autism Speaks … but they had a huge freakin' impact on autistic visibility … Autistic people were these victims of circumstance. So many stereotypes and myths out there, but with their books and Grandin's movie ... people have a different benchmark of knowledge about autism.

Self-advocacy in this case does not necessarily entail educating or advising autistic and non-autistic people. Rather, through lateral engagements with autistic others, self-advocates can influence positive perceptions of autisticness by relaying their authentic expressions of autistic life. "I think it's important for everyone concerned to be very comfortable with expressing autism in lots of different ways," Daniella said. "This whole thing in some way is about creating a new normal because the old normal hasn't been working ... because autistics usually don't know it's okay for them to be another way."

Priding

In June of 2015, after *Tumblr* added a feature to its platform that enabled users to create and share GIFs of themselves, my interlocutors started using it to circulate original content that expressed how proud they were of their autisticness. They did this by capturing short clips of themselves while they were stimming. Several weeks after the launch of the feature, I noticed that dozens of blogs that focused exclusively on celebrating autistic stimming had emerged. These blogs featured actuallyautistic users' stimming GIFs as well as autistic pride themed toys, gadgets, pins, and patches. Actuallyautistic bloggers on the site enthusiastically submitted their videos and GIFs to these new blogs and circulated images of their friends and other participants in the actuallyautistic tag. Some of my interlocutors published posts with captions that expressed gratitude for being "born autistic," notes on how others' stimming GIFs reminded them of their own ways of stimming, or comments about how just seeing others stim inspired them to "start stimming immediately," after consuming the images.

Interestingly, I found that a few autistic bloggers on *Tumblr*, who had maintained a high level of anonymity on their blogs and released minimal amounts of information about their personal and social lives, except for admission of their autistic identity in the headers of their blog pages, began recording themselves with smiling faces and flapping hands captured in the shot. FoilStarzzz27, a young autistic woman, told me

> I really don't like selfies, plus I'm generally private and introverted. But I'm fucking *obsessed* with the gifs, man. I normally ... just come on to see what other autistics are talking about and don't interact much. But I actually like the stim gifs a lot ... it's a level I actually want to connect on … So one day, I was like, 'what the fuck I'll just post a gif. So I did it and then deleted it right away lol. Weird thing is one of my followers tried to like it and reblog it but I deleted it already, so they messaged me about it and I put it back up … That post got like 50 likes! And now that user and I talk all the time. I never talked to my followers before then ... It was just a basic way to express how happy I am to be able to stim and *really* enjoy stuff like ... water from the faucet or how the blinds move when there's wind lol.

As FoilStarzzz27's example shows, the GIFs feature expanded my interlocutors' available options for expressing autistic pride. Very quickly after the feature launched, they created new blogs that focused on "the magic of stimming" and even advertised "products for stimmy autistics." Autistic self-advocates on *Tumblr*, used the sudden spike in displays of autistic and stimming pride on the site to launch weekly and monthly movements on the platform. “It’s a great opportunity to show how much fun we have as autistics," Bennie explained to me in late 2015,

> I think right now, it’s really scary for people, and especially brown and black autistics who stim a lot … our ‘weird’ behavior can get us attacked or even killed ... especially if law enforcement is involved … What’s cool is this is a fun way for us to share between autistics and with the world what stimming is like for a lot of us. Like, it's NOT scary or that weird … or we show that most NT people do it too already … just in more discreet ways like with leg bobbing or tapping.

The way Tumblr's GIF feature influenced displays of autistic pride in the actuallyautistic tag had few offline equivalents. Over the course of my research, I observed and participated in workshops that were geared toward helping autistic people normalize their body movements in public space. This was a form of education and intervention that aimed to increase autistic people’s abilities to “blend in” with others and minimize risks of being targeted for atypical body movements. The idea that unusual ways of moving the body and interacting with various forms of sensory input would make autistic people vulnerable to attack or hurtful scrutiny was connected to the ways in which many of my interlocutors received primary and secondary school training. My own experience working in a behavioral modification clinic for autistic children in a southern California school district resonates with my interlocutors’ accounts of having experienced extreme pressure from caregivers and educators to move through space and among peers in ways that were preferable to those who were assigned to “manage” them. “I can’t show my face on the GIFs,” said Fabby,

> It’s a carry-over from special ed. The ABA instructors were so brutal. I remember I use to

> stim with my hands a lot and I loved it, but my mom thought it made me look really strange, especially when we went to church. So, she made my teachers "fix" my stimming. One of them even held my hands on the table while I cried one day at lunch. I can't forget that, I screamed and screamed because they wouldn't let me eat until I promised not to stim. But I couldn't help it. I was just a kid … I was so upset that *that* made me want to stim in a panicky way. Totally traumatized … I make the GIFs but I feel like if my mom saw them, she would judge me even though she's changed her mind about my autism a lot and probably wouldn't [judge me].

Priding through the intentional display of autistic stimming was one way for my interlocutors to learn and express autistic identity through lateral relating. Furthermore, this mode of anchoring and reinforcing autistic identity constituted a form of resistance against pathologizing and anti-autistic rhetoric. For some, this resistance was incidental rather than deliberate, while for others, it was a display of intentional rhetorical pivoting. In April 2015, just a couple of months before the GIF feature launched on *Tumblr* and before the boon in stimming pride posts in the actuallyautistic space, I was invited to and participated in an offline autistic pride stimming event in southern California. All the people in attendance had been instructed to "gather their favorite stim toys and gadgets to use and/or share with old and new friends."

Explaining the central aim in organizing and administering the one-time event, Carl told me that rather than inviting autistic adults, children, and their caregivers to convene to "lovingly teach autistic people how bad their autism *just is*, we wanted to lovingly teach ourselves how cool autism *just is*." Carl and several others from the North County and Mid County groups attended the event. Local autistic children and their parents also attended with bags of toys. A long table was set up with snacks so that attendees could refuel after their intense stimming sessions. Many of the autistic children and adults laughed, spun around, hummed, and squealed. Non-autistic parents joined in, spinning their bodies, making sounds with their mouths, examining soft fabrics and textured items, and pausing to witness their kids' enjoyment.

CONCLUSION: AUTISTIC PROOF SPACES

As the above examples show, the ways my interlocutors participated in the different offline and online autistic spaces differed. In general, my offline sites were hierarchical in structure and this influenced the ways in which North, Mid, and South County group leaders interacted with members. By and large, in their groups they assumed the role of teacher and manager, while members tended to defer to them. Online, this dynamic also appeared, particularly with the ask-an-autistic themed profiles and blogs on *Tumblr* and *Twitter*, and in advice solicitations on *Facebook*. In my online sites, however, I also observed lateral ways of relating and learning, showing that there was not always a need for autistic teacher and autistic student roles, or for the apprentices and masters of the LPP model.

James Gee (2005) distinguished his notion of "affinity spaces" from the legitimate peripheral participation model by emphasizing that, increasingly, contemporary forms of sociality do not always require that individuals taking part in a group activity feel that they belong amongst their co-participants. Affinity spaces, he asserted, enable people from very diverse personal backgrounds to come together to acquire and deploy skills and information in the interest of some shared goal. Using strategy gaming as a primary example, Gee developed a set of defining characteristics for affinity spaces. Among these characteristics, three help us distinguish the affinity space from legitimate peripheral participation model: one is a diminution of concern with socio-political identity categories in favor of the shared aim. The second indicates that in spite of lacking the hierarchical structure encountered in a master-apprentice or teacher-student context, learning, teaching, and exercising acquired knowledge and skills still take place. Third, participants in the space do not *need* to feel any sense of connection to other group members. It is the shared object of interest that matters instead.

While none of the autistic groups that I studied fit neatly with Gee's (2005) conceptualization, the affinity space framework of learning and social interaction still seems to offer an important tool of thought for exploring what assumptions are made about the meaning of belonging or what looks like in spaces of joint attention and collaboration. In my field sites, there were undoubtedly some temporary, data-extraction-emphasis participants who prioritized direct fulfillment of a specific need (i.e., answers to a question or a referral to a service) and the left, returning as needed. Others were decidedly more interested in personal investment and exchange in the communal spaces they entered and the activities they took part in, even if those investments were "touch-and-go." Simple digital gestures of acknowledgment and confirmation of other ways of seeing and understanding autism and autisticness made a difference. When a person repeatedly saw the same users liking or reblogging their content, a connection (however subtle) was made. The simplicity of these forms acknowledgment, therefore, does not necessarily indicate less investment in the space or its activities.

It is also important to note that some of my interlocutors emphasized that it is important for autistics to relate to one another laterally. This kind of relating was essential to shedding the assumption that "autistic people need other people ... mostly non-autistics or normal-ish people to think for them or tell them what to do and how to do it," said Foilstarzzz. The emphasis that Foilstarzzz and some other placed on laterality, along with the examples I have provided in this chapter, show that digital autistic spaces, especially those that are tag-driven, have the capacity to support various kinds of relating. Among my interlocutors who were concerned with laterality and belonging, I saw their interactions taking place in digital "proof spaces," where autistic self-expression and acceptance were exalted. As Boellstorff (2004) notes, "In postcolonial societies ... discussions of authenticity typically carry implications concerning belonging." Even though my study focused on autistic identity and community online and offline, not gay language in

Indonesia, there were connections between the ideas of presenting oneself and interacting with others authentically and achieving group belonging. Among my interlocutors who rejected perseverations on other autistics' expertise and prioritized lateral engagements, "being confident in your autistic identity" and "your place in the community" depended on the ability to just be autistic without responding to the internal drive or external prompt to explain why autisticness was an acceptable way of taking up space in the world. In my field sites, especially when engaging laterally, my interlocutors shared, assessed, refined, and consolidated in a domain of autistic play and dialoguing their knowledge about autism and their direct experiences as autistic people. As sites of confirmation and deliberation, propositions about autistic life were formulated and disseminated through key portals (like actuallyautistic on *Tumblr* and *Twitter*). Connected in these spaces, they consumed others' accounts and could then choose to accept or reject their co-participants' interpretations of what it meant to be autistic and how to situate personal experiences of autisticness in the broader autistic community.

4

DISIDENTIFICATION

In this chapter, I explore autism disidentification–the rejection of an autism diagnosis and autistic identity by people who formerly understood themselves to be autistic. I do this by thinking through forms of instability in diagnostic process, modes of self-identification, and personal narrative revision. My aim is to explore how misdiagnosis, reclassification, and diagnosis rejection interplay with or shape how autistic adults self-identify self, align with the concept of the autistic community, and participate in autistic groups.

Autism is presumed to be a fixed condition among both biomedical professionals and laypeople. However, some have claimed to have been "cured of autism" (Fr33man 2017; Dawson 2015), and others say that they (or their children) have "grown out of it" (Sarris 2016; Goodman 2012). Others still believe that they were misdiagnosed, having been ascribed the incorrect label (Almendrala 2015; Harris 2016). While this chapter deals with disidentification with autism, it is less concerned with whether or not it is possible for someone to "recover" from autism or to be cured. The rhetoric of healing or recovering from autism is significant, though, because it reinforces the assumption that autism is pathological (an idea that has persisted for approximately 30 years) and the consequent aims to identify its causes and formulate a remedy that would free us of the autism problem.

Furthermore, this rhetoric seems runs counter to the increasingly accepted idea that autism has an inborn, rather than acquired, neurobiological developmental disorder with significant psychosocial ramifications. This is an idea that is widely accepted and that validates psychiatry's rights to claim expert authority and the right to govern over and manage both the specifics of the classification and correct diagnostic procedure. Moreover, the assumption that autism is an inborn way of being rooted in neurobiology is foundational to assumptions underlying the neurodiversity movement and the self-concepts of many individuals who have self-diagnosed with autism spectrum disorder and discovered themselves through that category. For the movement and many autistic people, the difference is brain-based.

LABELLING AND THE REALITY OF A "DISORDER"

Social science scholars have shown that psychiatric diagnostic labels and forms of institutional (mis)management of supposed “deviants” influence the kinds of things that people can do in the world, “altering their social fates” (Goffman 1961, p.128). Sociologist Howard Becker (1963), for example, suggested that deviance is produced by the "application ... of rules and sanctions to an 'offender,'" rather than it being a state or condition of being that inheres within the offending individual (Becker 1963, p. 9; also see Goffman 1963). The transformative power of deviance as a concept is owed to a shared perceptual framework that reads dysfunction into existence and can encourage those labeled dysfunctional to submit to and inhabit the sociopolitical space carved out for them by their assigned label. This does not mean that these labels are necessarily meaningless or always deleterious. It does, however, offer opportunities to explore the power of shared perceptual frameworks in US mediculture and pay particular attention to how ascribed psychiatric labels, like autism spectrum disorder or Asperger's syndrome might influence people’s ways of knowing themselves and understandings their lived experiences. The data I share in this chapter highlights the ways in which autism diagnoses can be transformative, not simply because they can be used to overwrite or invalidate self-concepts that preceded diagnosis, but because diagnoses help formulate a new context for making sense of and giving voice to those experiences.

Because the autism diagnostic label is used to highlight particular features of a person's comportment, which are made to speak meaningfully to the utility and functioning levels of their bodies and brains, rather than the quality of the intrapersonal and interpersonal experiences they have, the inclination to identify with the ascribed label can be strong. I suggest that this is an important consequence of medicalization, which focuses on the dissection of the body and brain in a manner that serves the specialization model of practice that dominates United States biomedical culture and has been exported to other medicultures across the globe. The preoccupation with utility and functioning levels of the body and brain over the quality of experience also speaks to the nature of the central question psychiatry poses in diagnosis – what is *wrong*?[27]A question rooted in presumptions about the rightness or wrongness of ways of comporting oneself while alone or in the presence of others. My interlocutors' disidentification narratives suggest that the diagnostic label they were ascribed served the purpose of delivering an answer as to why they were failing to meet expectations and to alleviate the discomfort that they and (potentially) their charges experienced. For many, the aims to amplify the quality of their experiences through expanded self-understanding was brought into the equation only after diagnosis was made, when they were made to ask *what now?*

Santa, a 34-year-old woman I met on *Tumblr* and had kept in contact with for a couple of years, asked me in a Skype chat,

> Why do you think anyone gets a diagnosis voluntarily? Like, why do you think I walked myself into the doctor's office and told them to check out everything about me and ... have them GRADE me on how well I was doing the normal thing?

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[27] See Sholl (2017), Brinkmann (2016), and Szasz (2007) for critical discussion about biomedicine's concern with wrongness.

Thinking about her question I replied, "I dunno, I think maybe people who go voluntarily do so because they think dx[28] info can help them make a next move to fix a problem their facing." She replied:

> Maybe ... I think about it sometimes, and I go, what the fuck was I thinking? why did I do that? ... I literally felt compelled to do that because I felt like I was *so* weird and ... like nothing was working in my life and I wanted answers. It couldn't have been that other people have a very small amount of social discomfort they're open to experiencing at any point in time. So ... me being twitchy or stimmy or whatever one day was a good enough reason for people to look at me like I was clownish or talk down to me ... I literally took all that shit onto myself and came to the conclusion that they all must be right and I must be wrong. So, I went on my diagnosis trip, searching for answers for why people weren't vibing with me ... I got my AS dx and the MD was SO sure. I assumed they had to be right, ya know? ... It seriously never occurred to me that I wasn't the broken one and that maybe it was ... the way they were looking at me that was fucked.

This conversation with Santa, helps illustrates how my disidentifying interlocutors, who accounted for 24 people out of the nearly 400 people I interacted over the course of my study, attempted to come to terms with their past efforts to make sense of themselves through medical evaluation and then make do in the aftermath of diagnosis. For Santa, it had not occurred to her until nine years after her diagnosis of Asperger's syndrome that her experience as an autistic woman was built on a fundamental misunderstanding of why she struggled to form and create social relationships. "I really didn't have such a tough time making friends at all," she recalled. "I got my diagnosis and then all these friends popped up because I could just be myself around them and a lot of them didn't see me as weird." Though she admitted that she is "probably stuck with the dx in [her] medical records" and would "probably" still meet the criteria for autism spectrum disorder or Asperger's syndrome, "if AS was still an option," she rejected the label because it's acquisition was due to a critical "misunderstanding." For her, the determination to disidentify with autisticness boiled down to this: "We should be diagnosing our communities instead."

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[28] My interlocutors often used "dx" as short-hand for "diagnosis."

Medicalized identity formation speaks to the ways identity can become attached, through diagnostic procedures and medical therapies, to an idea or concept that, because of its apparent scientific truthfulness, is assumed to be grounded in reality. At the level of the individual who is diagnosed with a psychiatric disability like autism, and who accepts that diagnosis as valid, there may be efforts to match the self to, or find major points of alignment with, the constitutive aspects of the category. Like Santa, others of my disidentifying interlocutors' narratives show how they recast their diagnostic processes and identified new explanatory possibilities for past experiences as autistic people.

In the online and offline groups in which I researched, I noticed that my interlocutors and others group members who were dissatisfied with the existing diagnostic criteria made efforts to modify standards for diagnosing autism. These modifications, which maintained much of criteria included in the DSM classification, were circulated and agreed upon by many group participants. Those who required a more flexible conception of autism to make their self-diagnoses and peer confirmations work for them were especially apt to affirm or "co-sign" the modifications. Importantly, these adjustments, thought they used the existing diagnostic criteria as their foundation, were framed as being more legitimate than the criteria implemented by most medical professionals today, because they were developed by autistic people who are more "intimately aware of what it means to be on the spectrum," as franticpanda, one of my *Tumblr* interlocutors, told me.

For example, *Tumblr* user franticpanda added to their revision of the criteria the qualification that the "difficulties" the autistic person faces should be considered legitimate signposts even if they are intermittently occurring rather than persistent across various social contexts. In conversations that I observed between franticpanda and others, I saw that there was agreement amongst hundreds of actuallyautistic participants that the composers of the official classification and the diagnosticians alike should factor in cultural biases against certain manners of comporting the body and communicating through speech. Taking this into consideration, they claimed, is essential because "behaviors like stimming and being non-speaking are not inherently problematic ... even though most people see them as things we should have to fix."

Group members frequently encouraged one another to continue sharing their accounts because of the possibility that doing so would normalize autisticness. To this end, many also reinforced members' narrative that seemed to buck the accepted biomedical definitions of autism by highlighting how the rigidity of the criteria had impeded marginalized genders, racialized people, and adults (in general) from receiving the autism label. Most of my interlocutors agreed that the official autism spectrum disorder criteria were improved in 2013, with the *DSM-5*'s statement that indications of autism should be present from early childhood though they might have gone unnoticed until social conditions and pressures exceeded capacities of the patient. Still, there remained a general air of dissatisfaction with the focus on determining what is wrong with autistic people. This is in part why group members would sometimes come to the determination that their own explanations for autistic difference were more compelling than those of biomedical experts.

Disidentifiers seemed to go further with their analysis, determining that in the absence of inquiry into the supposed social failing that produced the psychiatric label in the first place, autism effectively loses its meaning. Yet, in spite of their feelings of disillusionment with psychiatry, in their personal accounts of disidentification, there were still traces of the co-opted paternalistic rhetoric of medical practitioners and scientists. I suggest that this is in large part due to the reality that psychiatric notions of debility and deviance are so pervasive and widely accepted as the starting point for formulating a logical assessment of abnormality. For instance, Myles, who we met in Chapter 2, expressed her distrust of psychiatry's sturdiness or capacity to capture an accurate portrait of someone's psychobiological reality. Still, she was willing to concede that the diagnosis she received from another medical professional, who she regarded as having greater authority, appeared valid enough to overwrite her previous diagnosis of autism and autistic identity.

Pressures on autistic individuals to conform to culturally accepted representations of autism persist. The examples of Santa and Myles both show how autistic individuals (and many others who are seen as atypical) are expected to subject themselves to biomedical evaluation, surveillance, and treatment (see McGuire 2016 and Yergeau 2018). An autistic person may feel the burden of representing autism inaccurately if they do not fit the prescribed mold, or if they experience significant transformations in their behavior or comportment that would place them outside of the category of autism should they be re-evaluated. Santa's realization might invert this case. She saw that "society got a pass" for its unyielding commitment to conforming to cultural notions of normality, leaving her to feel that the diagnostic label was unsuitable for occupancy, at least by her. For Myles, the limitations of the diagnostic classification which described particular dysfunctional engagements with others and the surrounding environment, forced her to see that she no longer fit within the boundaries of classification. For both, the imperative to be "authentic" mandated that they extricate themselves from the label and cease their claims to membership in an autistic community. This demonstrates that autism disidentification narratives offer insight into the multiple ways that former autistics draw from various information sources to make sense of contrasts between self, an undefined normal, and categories of disorder. In sharing their accounts, they draw out alternative ways of making sense of autistic difference.

DOUBTING AUTISTICNESS

Because the *DSM* classification system is used to construct a crucial aspect of personal identity for many autistic adults, narratives of disidentification have useful implications for thinking through issues of expertise and knowledge production within disability anthropology and cultural anthropology writ large. My interlocutors showed that this can be the case whether they were diagnosed in childhood or adulthood, and whether they were diagnosed by certified medical experts or through personal research and self-evaluation,

The biomedical construction of the autistic subject as dysfunctional and generally requiring rehabilitation or cure, and the circulating stereotyped characters of autisticness in autism discourse, show up in both autistic identification and disidentification narratives. They describe biomedically-informed conceptions of neurologically and developmentally different selves. That only some ways of being autistic are more widely accepted seems to pressure those assuming autistic identity to conform to those accepted modes, particularly when interacting with allistic (or non-autistic) others. Furthermore, because of the ways in which medical personnel and laypeople are entrained to conceive of autism, through various public and private organization campaigns for awareness and cure, autistic people face intense scrutiny, whereby notions of being insufficiently autistic arise and get levied at members of the autistic community. "It happened all the time," Myles told me. "When I thought I was autistic, it might have been the hardest thing to have someone who is anti-autistic call you out for talking out of turn ... I heard that a lot ... that we," referring to autistic activists who could communicate through speech and typing, "were talking over autistic people, and I would get so pissed off, like 'who do you think you even are?' because I assumed they were calling me a fraud. It really broke my heart, I think, because I had those doubts that I even fit in as autistic. There were things that didn't quite match up."

When I asked Myles whether being "called out" like this had any bearing on her decision to look for other diagnostic possibilities to explain why she felt challenged in her mental health and social relationships, she responded: "More than I would have admitted when I first realized I wasn't autistic ... Remember how I first rejected the doctor's new [diagnosis] of PTSD? I really felt like it was a slap in the face because I felt like it proved all of those people right who said I was disrespecting severely autistic people by spreading information about accepting autism." Myles's reference to "severely autistic people" in the above quote is important to note given that she was staunchly opposed to using such labels when she was identifying as an autistic woman. To explain her shifting perspective on functioning labels in the wake of her disidentification, she told me,

> That's correct, I didn't believe in functioning labels before, but that's mostly because I was *taught* about how bad it was by all the other activists online. I'm totally all for SJW stuff ... but when I got some distance from autism, I started feeling like it's not that simple to just say these things are arbitrary and make no difference at all. Like ... it's a lot of responsibility for a speaking person to say 'this is what your non-speaking kid wants from you ... how the heck would I know that for sure? What if I *was* wrong and some of the kids really did want cures or *were* suffering?

In the above conversation, Myles shows how critiques coming from "anti-autistics," who were pro-cure people with autism and caregivers of children on the spectrum who sought out cures, could compromise one's sense of certainty in their claimed identity. As someone who was recognized as “mildly” autistic," an aspie, or a “high-functioning” autistic, she was made to explain how she related to those who were labeled "severe" or "low-functioning." Given the doubts she had been managing even before she decided disidentification was appropriate for her, these challenges pushed her to give greater attention to the possibility that she was not really autistic after all.

The diagnostic classification for autism spectrum disorder and the rhetorical characters of autisticness that are in circulation serve as rubrics for assessing autisticness and can stir up senses of doubt about the veracity of one's status as an actual autistic person who has the right to claim membership in autistic community. This is not to say that encountering these challenges stood as outright invalidations of diagnostic status and autistic identity. However, it appeared to be scrutiny from others and/or an internal shift in patterns of belief around diagnosis and the potential for inaccuracy in psychiatric diagnoses that spurred either rejection of the diagnosis and investigation into alternative psychiatric explanations or rejection of the diagnosis and of psychiatry writ large. For the most part, my interlocutors responded to detractors by mobilizing their frequently well-rehearsed narratives and even the narratives of their autistic peers to demonstrate that their identities are legitimate. These narratives would draw on childhood experiences, borrowed stories from parents about awkwardness in childhood or aloofness in infancy and toddlerhood. Others responded with a focus on the letter of the diagnostic criteria or their varied interpretations of it.

Though the vast majority of my interlocutors faced feelings of uncertainty and inauthenticity when they were speaking or writing to a general public audience about their diagnostic status and self-identification as autistic persons, few actually allowed that doubt to inspire them to seek out other diagnoses. In fact, within online autistic groups on *Tumblr* and *Twitter*, disidentification with the diagnostic classification and autisticness sparked tensions, where formerly autistic people who expressed their new non-autistic identities went head-to-head with autistic self-advocates who believed that such expressions countered community assertions that autism is a “natural,” lifelong neurobiological reality. In addition, conflicts between former autistics and self-advocates that I observed centered on the problem of autisticness as a legitimate way of being in the world. To reject autisticness was read as a way to deny the legitimacy of autism and autistic experience. "Why bother to even come on here if you don't think you're autistic anymore? *Tumblr* user herewegoagain82 wrote in a comment to one of my disidentifying interlocutors, Len, who had just announced that he was no longer autistic after being evaluated for PTSD (like Myles). Herewegoagain82 continued, writing

> You can act like you've grown out of it or that it no longer applies to you but it's not that simple. Have you thought about what you're doing to autistic people by denying your identity? And all of you saying that now you're not autistic anymore are just falling into the trap allistics set for everyone. We can't have anything real to say about anything because we're autistic and we don't have the right to speak for *all* autistics across the spectrum because we're "HF," and that we should want to get rid of autism no matter what. You guys should just leave actuallyautistic alone now that you're supposedly not autistic anymore.

In herewegoagain82's comment, we see worries that denying autistic identity and talking about that denial post a threat to autistic people who were struggling to encourage acceptance of autism. It also highlights the doubt that the reclassification to another diagnostic label or to no label at all held water. This shines through in the proposition that Len was "*supposedly* not autistic anymore." In response to herewegoagain82, Len wrote,

> I appreciate that you're worried that my story makes your diagnosis worthless, but it doesn't. If you're autistic, then you're autistic. Don't mind me. But there are people who were diagnosed with one thing and ... still haven't actually gotten to help themselves because they're working with the wrong information. So, I'm going to keep posting my stuff [to the actuallyautistic hypertext space] because ... everyone deserves to know that maybe they shouldn't stop looking for answers yet.

RISKY FORMERLY-AUTISTIC SUBJECTS

Today, much of the public discourse about autistic people, and people with developmental disabilities in general, reinforces conceptions of autism that have been developed and circulated by medical professionals since the 1980s. Significantly, parent advocates and parent-led autism organizations' conceptions of autism have reinforced autism-pathologizing sensibilities of biomedicine. This is not only because of the presumption of biomedical expertise.

It is also because of the ways neoliberalism mandates that individuals be responsible, serving as targets of blame for ills experienced, administrators of treatments, and primary financial sponsors for their health and wellbeing as well as their families' (McGuire 2016). Given the financial, psychological, physical, and time constraints of caregivers of autistic people, resolution of the challenge of raising a disabled child and caring for a disabled adult seems vital, and the idea that a solution in the form of a "magic-bullet" cure or treatment exists is non-negotiable. "You beat yourself up trying to find [the cure]" said Pamela, a 67-year-old mother of 2 autistic adults. I met Pamela and her son, Kav, at a during the lunch break during the Autism Society of America annual conference[29] in New Orleans, Louisiana in July 2016. Pamela explained the sense of being driven to "resolve things for her children" in part because she felt limited in her ability to provide adequate care for them. She explained:

> Something I learned over the years is that that sense of urgency I felt was related to the feeling of being alone in the whole thing. Even though I had my husband, he worked non-stop and I worked full time but had a more flexible schedule. But my work was exhausting and ... not very fun, so I would get home, pick up my kids and find out all of the things they did to get in trouble and then have to go home and deal with meltdowns and [the kids'] trouble sleeping.

It was not just the physical and emotional strain of caring for her children, Pamela explained. Her adult kids, now in their mid and late twenties "were supposed to be healthy." She told me:

> I didn't realize that they actually were healthy, because all I heard about when I took them to the doctors was this treatment or therapy or that one. I went hunting for a cure because I assumed the answer was there even though the doctors I knew weren't sure what that was. I was obsessed with the statistics that told me about how fast autism was spreading. I knew it wasn't contagious, but I did think it was a disease. But my kids have always been healthy for the most part. I couldn't see that at the time because I was so depressed and anxious about their futures, which the doctors made sure I knew was non-existent ...When they diagnosed my boys, they apologized so much that I had no choice

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[29] Though it has expanded its scope in its 53 years to include and celebrate autistic self-advocate perspectives, ASA has continued to be a parent-driven autism advocacy organization.

> but to breakdown. I didn't even know what autism was at that time, but I could see in the doctors' faces that autism was like a death sentence.

Importantly, many of my autistic interlocutors received similar messages from the medical practitioners (typically psychologists and psychiatrists) who diagnosed them. "They were like, 'I'm so sorry to tell you this, you have something called Asperger's syndrome,'" recalled Steven, head of the North County offline group. He continued, saying

> I thought, 'wow, this must be really serious.' So, I definitely went through that time of thinking my brain was absolute trash before I could focus in a more positive direction ... Now I tell myself that it's like this ... who could do this [group] work exactly like how I do it? I don't think anyone else could ... And I did it with this 'messed up' autistic brain.

Because biomedical perspectives on disability focus primarily on the intractable and degraded quality of autistic life, public conceptions of autism as necessarily undesirable, unnatural, and dangerous persist (McGuire 2016). My disidentifying interlocutors who rejected the validity of psychiatry saw this as sufficient reason to remove effectively remove themselves from psychiatric surveillance. For others, it was the sense that their symptomology was not "as bad" as autism was framed to be that shifted their views of the diagnoses they had acquired. Ostensibly, they understood that their challenges were not on par with what the US government and several large viewed as a problem with which to go to war. Their condition, whatever it was, was not as *severe* as autism, which was scary enough to spur organizations to endeavor to eliminate the supposed autism problem by identifying, in concrete terms, its physiological causes or environmental triggers, and by developing a cure or effective therapeutic modalities have increased pressures to chase ceaselessly for resolution.

These ways of constructing autism have contributed to the normalization of physical and rhetorical violence against autistic people. This normalization has provided justification for violence against autistic people, children in particular, so that in the wake of the murder of an autistic child, we are permitted to think that it is impossible to know precisely why such violence is taking place (McGuire 2016, Yergeau 2018). Certainly, this has had implications for the marginal social, political, and economic status of autistic people in the United States and their encounters with anti-autistics. I suggest that in part, US cultural narratives of autistic faultiness and the justification of violence against this group of people influences disidentifiers' decisions to distance themselves from the identity category. In Santa's example, we see an outright disavowal of psychiatry and thus all of its seeming authority to associate them with intractability. Meanwhile, Len's receptivity to being diagnosed with PTSD, a condition that suggests they were at the effect of deleterious circumstances, rather than having one's nature be the cause of challenging circumstances, might provide some insight into the perceived perils of association with autism. Even as Len aimed to alert other autistics that they might have been misdiagnosed, they were also "relieved" to no longer be autistic:

> It was hard to go online, listen to parents talk about how hard it was to take care of their kids and then tell them that the stuff they were dealing with was all conceptual and not really real ... and think that in theory their kids are how I probably was as a kid, putting my parents through hell. I know it might sound sketchy, but I still really think that PTSD is the real thing I need to deal with and that I've never been autistic.

For disidentifiers to be associated with autisticness, it makes them risky subjects. I suggest that this works in two ways: one, because of the framing of autism itself as a risk and problem that requires massive troubleshooting, people who identify with autism and autisticness are vulnerable to internalizing ableist rhetoric.[30] Two, disidentifiers who continue to interact with other autistics through groups that were meant to be exclusive, pose risks to autistic members who may start to

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[30] Internalized ableism refers to the assumption of anti-disability ideologies by disabled persons. This may result in experiences of depression and anxiety about being labeled with a diagnostic label as well as inspire disabled people to align their interests with non-disabled rather than disabled people. See Campbell (2009) and David and Derthick (2014) for more on internalized ableism.

doubt the validity of their own (and their peers') autisticness. Since many of the autistics in these spaces struggled for years to come to terms with their diagnoses and learn to celebrate their autistic differences, disidentifiers, as individuals who inspire doubt, pose a threat to group coherence and stability. We see this concern for the group manifest in herewegoagain82's response to Len:

> Have you thought about what you're doing to autistic people by denying your identity? And all of you saying that now you're not autistic anymore are just falling into the trap allistics set for everyone ... You guys should just leave actuallyautistic alone now that you're supposedly not autistic anymore.

Len's quote shows how autistic self-advocates, whose aims are essentially oriented toward countering ableist ideas, resist disidentification claims, not only on the basis that they appear to threaten to delegitimize autism diagnoses in general but also because they are seemingly inflected with a sense of shame about being associated with the autism label and autistic people.

COUNTERING CERTIFIED AUTISM EXPERTS

My informants' autism disidentification experiences and narratives highlight the ways disidentifiers might attempt to demobilize psychiatric labeling in their life histories or redirect it in seemingly more innocuous directions. This contrasts with the ways autistic self-advocates attempted to reclaim and repackage autism, stripping it of the depreciatory rhetoric of pathology in American psychiatry. Doing this, these advocates aim to create a space where autistics themselves can give a more holistic account of what it means to be "on the spectrum."

In sharing their experiences disidentifiers may directly or indirectly counter notions of psychiatric expertise, which has been widely accepted as having its basis in sound scientific research. Contemporary scientism encourages concession to the white coat[31] and sponsors assumptions that psychiatry is able to accurately represent our collective neurophysiological reality and issue forth effective treatments for problems that might arise in it. Disidentifiers who reject psychiatry's capacity to do this work deny the that the field's diagnostic categories reflect reality. Other disidentifiers who seek out alternative explanations or reclassification in the wake of suspected misdiagnosis deny the accuracy of diagnosis, and they speak and write in opposition to the existing psychiatric professionals' rulings. They offer their experiences as examples of psychiatry's limits and thereby situate themselves, wittingly or unwittingly, as icons of its failures.

In fact, several of my interlocutors recounted moments of feeling triumphant in catching an experts' error, after doing in-depth research on diagnostic possibilities before seeking out re-evaluation, or rejecting medical diagnosis altogether. A common theme in these accounts is the spark doubt and growth of dissatisfaction with medical professionals' protocol and delineated autism interventions. For both reclassification disidentifiers (who sought out reevaluation and new diagnosis) and anti-psychiatry disidentifiers (who rejected psychiatric classifications altogether) there was a perceived mismatch in everyday experiences and all that was set out in the autism spectrum classification in the diagnostic manual. In this way, their narrative approaches remained entangled with psychiatry's own efforts to textually reify autism, as an actual psychiatric disease (or disorder) in the world.

As my interlocutors have shown in the above examples, those disidentifiers who perceived that medical and cultural narratives of autism and disability constituted false realities were faced with the extraordinary problem of coming to terms with their own self-concepts, which required reconstruction, and the self-concepts of others who believed in the label they were ascribed and

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[31] For more on the persuasive power of the white coat, a symbol of expertise and good will, in and outside of the clinic see Salhi (2016).

believed in. Camall, a disidentifying man in his late 20s, talked with me in a South County coffee shop after I had wrapped up an afternoon at the autistic adults' activity group meeting that he used to frequent. He was explaining to me that among autistics diagnosed in adulthood, it was the suggestion of autism that actually preceded the clear, embodied expressions of autisticness. He explained his perspective, saying:

> I was always a little strange ... But once I heard autism from my doctor, all these ideas floated up for me … and my strangeness became a particular kind of strangeness. Before I was diagnosed, no one would have said, 'That Camall, yes, he is very autistic.' But then I started thinking, 'I'm autistic' ... I must have changed because other people started recognizing me as autistic.

In Camall's retrospective account, diagnosis was the beginning of his autisticness. Before that moment, he was simply "a little strange." When he began to recognize signs that he was deviating in his comportment and manner of interacting with others from the specifics of the diagnostic classification, he felt this served as evidence that his diagnosis was invalid and he was misdiagnosed with autism. Camall's experience underscores the ways in which psychiatric diagnoses can become performative displays of otherness. In such cases, the label becomes like a garment the diagnosed person unwittingly slips into. The challenge arises when the integrity of that garment collapses leaving its occupant primed to challenge the integrity of all diagnostic classification. Camall, for instance, found in his particular diagnostic experience evidence that justified his denial psychiatry's legitimacy and, ultimately, his accusations of its duplicity:

> I don't think it's fair that I was allowed to believe that I had this condition that I just did not have. How many years of my life did I spend thinking that I couldn't do this thing or that because of the way I was wired [neurologically]? ... I think they know exactly what they're doing. They took advantage of the fact that I was somewhat odd. That doctor was *so* certain. They prescribed me medications for the anxiety and depression and sleeping trouble that autistic people 'always' are supposed to suffer from. I took them and got other problems. They wasted my time and then I went and wasted my friends and family's time.

Disidentifier's accounts, as we see in the above example with Camall reflected the complex of emotions that might arise when trust in wisdom and capacities of biomedical experts is gutted. Like Camall, my other disidentifying interlocutors, expressed their confusion, disappointment, and frustration linked to a sense of loss of community, autistic identity, and possibly life story coherence. In writing and speaking to people within the autistic community about their experiences, it might have been that they sought to establish and grow a community or group of autistic disidentifiers.

Despite their disillusionment, these formerly self-identified autistic adults continued working to make sense of why they were “strange” or "odd," without autism and autisticness as mediators. For all of my disidentifying interlocutors, whether they received diagnostic reclassification or not, this meant continuing to identify as neurodivergent and interacting with others who identified similarly (including autistics). In effect, they continued to abide in the same sort of “neurotribe”[32] (Silberman 2016) as autistic people.

ANTIPSYCHIATRY IN DISIDENTIFIERS' NARRATIVE REVISIONING

It is important to note that the ability to reject one's autism diagnosis and psychiatry in general was the privilege of those whose dependence on psychiatric care was limited. That they were able to refuse continued surveillance by their diagnosing professionals indicates that they occupied the conceptual space near enough to normality that their absence in the doctors' office raised no red flags. Furthermore, it indicated that they retained, even after diagnosis, the authority to make decisions for themselves and their families, a right that several of my interlocutors who were diagnosed in childhood had removed and had not been able to retrieve.

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[32] *Neurotribe*, a term coined and popularized by Steve Silberman (2016), a science writer, speaks to an expanded, progressive notion of neurodiversity that accounts for humanity's many neurosocial ways of being rather than setting in opposition neurodivergent and neurotypical groups.

Furthermore, the choice to deny their autisticness, as people who would be labeled "high functioning," reinforced the belief that the only legitimate autistic person, is the one who has greater needs for caregivers or public supports. I observed bound-for-greatness posting to the actuallyautistic tag on *Tumblr,* writing on this issue:

> We [self-advocates] do all this work to make the case for us having the right to speak for the best interests of all autistics, while parents are feeding their children bleach and taking them to sketchball clinics in South America to get dangerous treatments and ... in swoops these "I'm not autistic anymore" assholes to make us look like we're all pretending to be autistics or like we are all goddamn fickle. It's trash and all of you former-autistics are garbage.

This criticism demonstrates how many autistic self-advocates felt about outspoken disidentifiers. Bound-for-greatness is one of several self-advocates who expressed in the actuallyautistic spaces on *Tumblr* and *Twitter* how detrimental their accounts were to the autistic community. in the actuallyautistic spaces on Tumblr and Twitter.

Tomas, an interlocutor from *Twitter* and *Tumblr*, took issue with the "attacks" that he and other disidentifiers experienced at the hands of actuallyautistic participants. Believing that he was doing a service to the autistic communities, he saw himself and others like him working to help increase the legitimacy of the classification by "cleaning up" the community's mistaken autistics. In my online conversations with him, he likened his discovery of being misdiagnosed to having a covering removed from the eyes. He told me:

> It's like I see what psychiatry really is ... It's clear that I'm not autistic now, for sure. But it was clear back then, when I think about it. And I'm not the only one this has happened to ... How many others are buying into this bullshit? It's a really elaborate guessing game, and because they have the credentials they congratulate themselves and each other for giving a good enough guess. There's so much at stake for people, I wanna say. Being autistic is great in lots of ways, but it's not great in a lot of other ways. Plus, there's no way to prove, like actually prove, that these diagnoses are right. It's not like you go in for a scan or blood draw and the docs are like, 'there it is - autism!' It's not like that ... And now I'm like a pariah in my old autism groups. No one wants to hear anything, like *anything*, about my diagnosis being wrong, because then it might mean that *their* diagnoses are wrong, too. And I'm not even trying to say that their autism diagnoses are false–that's not

> my place, right? But it should be acknowledged that this is a real possibility ... Lives get totally built around this idea, and when the idea unravels, like, a big part of your life unravels too ... It just sucks.

Tomas' reflection reveals an important reality about many of the psychiatric classifications that widely accepted and diagnosed, with varying degrees of success. The nature of psychiatry holds that there are, as yet, definitive markers for autism spectrum disorder. This corresponds to the distinction Tomas made about how verifiable autism diagnoses can possibly when they aren't truly locatable in the body or the brain. That lives can be "unraveled" by the misdiagnosis of a psychiatric condition that has scant objective data and lines of probable causality drawn is a key issue that has been explored in philosophical treatments of biomedicine but must also be considered in autism studies scholarship. This is not merely an issue of scientific literacy and integrity in biomedical cultures. It has potentially significant consequences for psychiatric patients who may be receiving ineffectual or risky therapies.

Ultimately, for many people diagnosed with autism in adulthood, the belief in the category and reality of classifications can lead to the assumption of a label that they might eventually feel is a poor fit. Certainly, identifying the most fitting psychiatric diagnosis is not a simple process for adults who are seeking to better understand, through biomedical channels, why they are, or feel themselves to be, so different from their peers, family, and local community members. Before questioning her autism diagnosis, Myles searched for years to define her behavioral differences *as* PDD-NOS or pervasive developmental disorder not otherwise specified[33] Between the ages of 34 and 37, Tomas sought out six different psychiatrists, psychologists, and marriage and family therapists to discover that he had Asperger's Syndrome.

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[33] PDD-NOS is a diagnostic classification that was used in clinical practice prior to the 2013 revisions to the *Diagnostic and Statistical Manual of Mental Disorders.*

Yet even after diagnosis, the clarity that purportedly comes from medicalization eluded them as they eventually struggled with a self-concept that never quite aligned with the psychiatric labeling and explanations that they received. In a series of short conversations, Tomas revealed that the sense of strained association with autism might have been due to cultural and family barriers – for several years his immediate family refused to accept the diagnosis and posited that it must have been an error. He explained: "A lot of Latinos really don't vibe with psychiatry. Too much distrust there … and with good reason, you know?" Compounding the sense of inauthenticity that grew from his family's refusal to acknowledge his autisticness, he continually felt that the autism discovery narratives that he encountered online, and in the few local autistic adults social group meetings that he attended, were foreign.

> Honestly, I felt like a fraud, but just a little … it's kind of like I was that guy who got the part of the autistic man in the school play, but I wasn't qualified to play the part and couldn't even get into character all the time. I didn't know when it was going to finally click and I'd finally get my head around it ... It just didn't feel true for long enough that I decided I need to go get some answers. And I was open about it, you know. I wasn't trying to say I was misdiagnosed at that time. I just wanted someone else to tell me that the diagnosis was still right ... I couldn't get any confirmation. I can't say why; I really don't know. But the word "autism" was never, not once, uttered when I sat there in those shrinks' offices when I went back for new opinions. I tried to go in with a blank slate, and all of the sudden, a whole new set of possibilities came up. Each shrink had a new answer ... It's totally fucking ridiculous, in my opinion. The system is broken but it's got a lot of buy-in.

Central to my interlocutors' processes of disidentification was their quest for answers about who they are, their real nature, and why. As I've described, for some, the answer came in the form of a different diagnostic label. For others, it came from asserting the absolute naturalness of their ways of being in the world so that any psychiatric classification would be meaningless. The latter perspective is grounded in the understanding that psychiatric classification systems are based on identifying what is wrong or deviant in human mental faculties. Because of this, any psychiatric labeling would serve as an admission of living life as an objectionable person. This contrasts with perspectives of many newly diagnosed individuals who view their diagnoses as supportive of their attempts to bring a sense of resolution to the seeming incoherence of their life experiences, even as they are given the opportunity to connect with others who are oriented to the social and material world in similar ways. Coming to resist or deny autism diagnoses, whether formally or informally attained, means embarking again on a journey to acquire answers to questions that may have been left unanswered – or only partially answered – in the diagnostic process, psychiatric treatment, and participation in online and offline autistic groups of self-identifying autistic people.

The notion of autism, as a psychiatric and neurodevelopmental disability, is presented as being in disagreement with the intrapersonal and interpersonal realities of anti-psychiatry disidentifiers who share their stories online and offline. My disidentifying interlocutors portrayed not only parent-driven autism non-profit organizations but also autistic led organizations as antagonistic to autistic people's attempts to secure better lives for themselves because they "want to protect autistic people from seeing stories like ours without having *their* chance to say something about whether we are telling the truth or not," as Tomas explained. This perspective, he related, is due to the view that even at the risk of missing a misdiagnosis there must be some focus is on preserving the concept of autism and the experience of autisticness.

In my interlocutors' accounts, they felt as though they were left to take on the role of amateur psychiatrist and diagnostician, if they were seeking reclassification. To them, resisting the claims of their old psychiatrists to seek out other explanations seemed to constitute a mode of combatting the structure of psychiatry professionalization to attain the answers and supports that best fit their lived experiences. By seeking re-evaluation and/or alternative, non-autism, explanations for the differences they experienced, reclassification disidentifiers seemed to uncover newly realized courage in resisting, to some extent, long-established psychiatry expertise. It was not an easy to manage confusion, disappointment, and feelings of being totally unqualified to even suggest that their autism diagnoses were doubtful. Similar to those who opt to self-diagnose with autism, many others doubted their capacities to self-evaluate and make sense of diagnostic criteria. Meanwhile, for them, there is a downgrading of medical professionals' primacy in the diagnostic process. As in self-diagnosis, there's the assertion that one's own self-labeling and self-inquiry are valid in disidentification: "Yeah, I know that this is unconventional," Myles explained,

> and it's *possible* that I'm wrong and this new doctor is incorrect, but it's a risk. And, like, I've learned that that's not different from buying into *any* diagnosis from a professional. They're wrong *so* much of the time. So now I'm less concerned with accuracy, I mean, that's kind of a lie, but, like, accuracy has to mean resonance for me now. It's not enough that it I have this diagnosis in my hand … or in my head or whatever. It's got to make sense or be reasonable or something.

Myles's boldness in rejecting autism as a reality in their lives ultimately separated her interlocutors from even their closest confidants within the autistic community. They expressed that a distance between themselves and their autistic friends formed very quickly after disclosure of their disidentification and the reasoning provided as justification. Interestingly, this sense of isolation led them to find unique understandings of their life stories. Tomas explained to me that these understandings came with the

> white noise of a hundred people seriously committed to the idea of autism and being autistic yelling in my ear about how I was just secretly, or I guess not so secretly now, anti-autistic. I was like, guys, seriously? I'm not trying to undiagnose *everyone*, but I think everyone should think twice. Is this label doing me a service or not? For some people, it is, whatever, I have *no* fight with that ... For others, it's something else and it's not what it seems to be. They get the label or give it to themselves and it becomes *everything*. I was that guy. I made it so that I was Autistic Tomas, you know? It was like I could never just be Tomas.

For my disidentifying interlocutors, the beginnings of transformation followed an initial sense of awareness that they were simply unsatisfied with the answers that their "gifted" diagnoses were believed to offer. The presumption was that autism as a label constituted its own sort of answer, the gift of coherence they were seeking. On its own, the label filled in blanks in their life stories. Before diagnosis they just had yet to make sense of all of the specific things autism would allow them to explain. The sense that they could perceive a seemingly endless source of autisticness within themselves initially gave way over months and years to a sense of autisticness exhausted. They could not seem to milk any more sincerity out of their claims to being actually autistic.

RECLASSIFIED NEURODIVERGENCE

As my interlocutors demonstrated in the examples that I have presented thus far, while some of my interlocutors withdrew themselves from the care of psychiatric medicine (certainly a privilege that many autistic individuals do not possess), others retained their belief in the truth or validity and accuracy of psychiatric science. Those in the latter category transformed their expressed modes of self-identifying by creating new diagnostic possibilities for themselves by nullifying previous ascriptions. Examining my research participants' disidentification narratives shows how formerly autistic adults seeking reclassification may need to wrest ascribing power away from psychiatric professionals while they reframe the positions they occupy in relation to autistic community. They inspire questions about how we might think constructively about how age factors into psychiatric evaluation and post-diagnosis identity management, especially in cases of late-diagnosed and self-diagnosed autism. In these cases, there is a complex matrix of direct life experiences, habituated modes of interpreting what is perceived, and diagnostic agendas. What my interlocutors' accounts show is that these issues interplay with one another and may not easily distinguished from legitimate neurodevelopmental disability distinctions.

Furthermore, these accounts challenge cultural assumptions about psychiatric evaluation and care, autistic people, and allistic (i.e., non-autistic) neurodiverse people. In a few of the narratives, there is a stated intention to seek out new possibilities and practices that allow people to critically examine the utility and truthfulness of their diagnoses in conversations about diagnosing autism. These kinds of conversations are less common when it comes to disidentification, but are very common for self-diagnosis. In forums, blogs, chatrooms, and social networks where conversations like these take place there is an abundance of anecdotal information shared. Social media is a primary resource of this approved kind of self-inquiry and autistic participants on these platforms encourage prospective autistics' increased senses of personal autonomy and boldness in declaring oneself an expert on their own selves. These arenas for supportive discussion in cases of disidentification were either not present in the digital and offline spaces in which I studied or they were very well hidden.

Critically, in articulating their processes of disidentification, my interlocutors drew on claims of self-knowledge just as those who came to diagnose themselves as autistic had. Now, however, their claims were mobilized, much to autistic group members' chagrin, to establish distance between who they conceived themselves to be and the autism label and autistic identity. In doing this, they gave themselves, and others who were able to locate their accounts, evidence that they were not alone in their determinations that it was time to "rebrand" themselves after discovering that for them autisticness failed to constitute a narrative truth. However limited their influence appeared to be in autistic communities online and offline, I believe that records of these disidentification narratives may increase as more and more self-diagnosed autistic people find their assumed labels mismatching their self-images. These personal narratives stand to establish for others a new set of possibilities (and possibly cautions) for seeking out evaluations for neurodevelopmental disabilities and self-diagnosing autism.

In these accounts, autism is something that can be rendered unreal through the experience of life as an autistic person. Having worn autisticness and been made to discard it, autism becomes a tool rather than identity that, through in light of its lacking utility still contributes to projects of assembling of a coherent life narrative. That old labels may be found to be inappropriate or out of resonance with disidentifiers' self-concepts show how, within autistic community, disidentifiers perceptual shifts get measured up against accepted forms of medical expertise and authority as well as autistic people's claims to expertise. Some members of autistic groups who understand disidentification to be detrimental to autistic community, which already faces a great deal of skepticism about legitimacy of so-called "high functioning" autistic individuals, assert that disidentifiers "get off on stirring up confusion and conflict needlessly." On *Tumblr*, ittybittyautiebon, an autistic person who was diagnosed in early adulthood, countered an anti-psychiatry disidentifier, saying:

> Why are you doing this?!! Ok, you got your answer, psychiatry is a joke. FOR YOU. More of us actually rely on it to get through the day. I'm not about to say psychiatry is amazing and perfect ... I won't because it mostly sucks and hurts a lot of people by condemning ... It's shitty, but that doesn't mean it's totally useless or always wrong. It's really not fair for you to tag your bullshit post with actually autistic when you don't even identify that way anymore. There are people who just found out they were diagnosed and they're so happy to have some sense of closure or an answer … ummm, and services (hello!). And here you come blasting through the tag with your complete anti-autism and ableist bullshit.

Ittybittyautiebon wrote the above post in response to funnyjellyring's condemnation of psychiatry's inconsistent diagnostic practices and lacking capacity to "consistently confirm diagnoses on a 'blind' trial across multiple practitioners." Ittybittautiebon highlights an important narrative link between newly diagnosed autistic adults and autism diagnosis seeking adults. For both prospective autistics and disidentifying persons, there's the common exclamation that they have a sense of "waking up" to a new diagnostic possibility. They employ whatever resources are available to them to attain the clearest answers to their questions, "what is wrong with me" or "why am I like this, really?" This kind of self-inquiry takes place amidst social barriers to diagnosis seekers' efforts and may take the form of families and peer groups who refuse to accept their autism diagnosis. Disidentifiers, on the other hand, may also pressures to maintain an autistic identity in spite of the persistent sense of narrative incoherence. Encountering these barriers and responding to them from place of determination enabled my interlocutors to make sense of how and why they became convinced that they were autistic or were not autistic after all. In both modes, there is emphasis on the rhetorical play of expertise claims (e.g., "I know myself and I've done my research") and efforts to defend or strike against the integrity of the autism classification.

As metaphors, diagnostic labels are powerful devices that carry meaning and social value.[34] These labels are assumed to capture through rigorous scientific investigation the disparate everyday experiences of people whose ways of being in the world have been stigmatized through predominate notions of normalcy by integrating them into a consequential entity (Berger and Luckmann 1966). The concept reinvents and repackages day-to-day sensations, thought processes, communication styles, and bodily comportments into a literal and symbolic vector for identification. Often, diagnosis narratives involve a recounting of how the diagnostic label first came into their sights, sparking a need for my interlocutors to explore whether or not they could feel or make a case for likeness between themselves, the diagnostic label, and its established criteria. For some of my interlocutors, their diagnoses involved this careful measuring of similitude between self and classification and led to them encouraging their physicians to

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[34] Social science scholars have proposed that it is vital that we acknowledge that diagnostic classifications and labels are metaphors. These things are "an idea about illness that evolve and spread and endure in the community and ... serve to organize distress into a meaningful narrative tolerated by the biomedical model" (Huibers and Wessely 2006, p. 897).

consider other diagnostic possibilities when the proposed label seemed either unsuitable or even undesirable.

If you will recall, Myles and Tomas's disidentification with autism and autistic community was framed as controversial by members of the autistic communities with which they engage, and although their narratives counter the ideals of the autistic community, which assumes "once autistic always autistic." Kayla, a 37-year-old woman and formerly prominent voice in autistic self-advocacy, faced similar controversy about her decision to speak out in the actuallyautistic tag about her disidentification. She came to disidentify with autism as she began recovery from more than 20 years of disordered eating. She had been diagnosed with Asperger's syndrome at the age of 19, approximately two years after she began binging and purging after each of her meals.

> It took a major toll on my physical health, obviously. Tore up my esophagus and my digestive system. And mentally, psychologically, it was painful to face myself. I really felt out of place as a 'thicker' girl and I just wanted to slim down at first. But then it became an obsession. And rather than seeing the weight drop off … it piled on, so the obsession intensified. But then the obsession sort of expanded, ok? And I'd already been a bit obsessive and excitable and introverted, sure, but like, everything became a thing to obsess over ... I was always in a sort of fog, and all of my relationships, which were always pretty awkward got more and more strained.

Unlike several of my disidentifying interlocutors, Kayla didn't have any interest in attaining psychiatric care and a diagnosis. "I was forced to go to satisfy my parents who paid for everything." Importantly, she was terrified of her eating disorder coming to light. Therefore, she refrained from disclosing her binging and purging from her physicians:

> I did what I needed to do to survive my own self and choices. Like, I was pretty sure I wouldn't have made it through eating disorder treatment ... too much shame. So, I hid this one thing and landed an autism diagnosis. And I didn't know anything about psychiatry or diagnosis. How was I supposed to know at 18 or 19, that not telling my doctor about my eating disorder would change what was possible for my diagnosis? That's not something I would know at 18 or 19.

After more than a year post-diagnosis, Kayla, who had been uninterested in socializing with her peers, began participating on and off in online forums and chatrooms for adults with Asperger's syndrome looking for social connection. It was only after she had her second child in 2011 that she started taking part in offline social groups. She explained to me that after joining offline groups near her home in South County she started to question the idea that she was on the autism spectrum:

> I became one of those Aspies … I started to think that maybe Asperger's Syndrome was different from regular autism. I wasn't like that before … I got really involved in the activism activities and online communities ... I was publishing things on my blog and getting a lot of readership ... Even though I loved everyone there [at the group] and they seemed to love me back, there were *some* things that I had in common with the people who were actually labeled with autism, but I thought there were some important differences too. I could relate them as friends but not really as a fellow autistic person.

For Kayla, these perceived differences centered on ideas about early childhood socialization. Before her teen years, I learned, she had been very socially outgoing and made many friends easily. She also grew concerned about conversations about autism severity or the intensity of disability. Eventually, she told me, she experienced confusion about how she *and* her group peers might all be sharing the same autism diagnostic label.

Kayla's decision to disidentify with autism came after receiving a diagnosis of complex post-traumatic stress disorder (C-PTSD), which seemed to be a recurring trend among my disidentifying interlocutors, resulting from sustained childhood trauma and eating disorder. Seeking confirmation of suspicions that she was not autistic, her new psychiatrist explained that it was improbable that her experiences and challenges required such a high level of "diagnostic complexity." EDNOS and C-PTSD covered all of the bases. With the start of her new treatment protocol, she noticed significant improvements in her obsessiveness, anxiety, sensory dysfunction, and selective mutism, some of the very traits that contributed to her autism diagnosis in her late teens. She soon saw even less resemblance between herself and her friends at the South County group, which she continued to attend in the early stages of her C-PTSD and EDNOS treatment. Kayla explained that when she brought her concerns to the group's manager, she was informed that she was displaying "aspie elitism,"[35] a thing that she had "railed against" when she was an active self-advocate movement. "When I told the leader that I was questioning my autism diagnosis and felt more and more distant from it," she said, "I was accused of being ableist."

Among autistic adults, concerns about ableism in conversations about disidentification speak to frustrations about the seeming impossibility of autism. Autistic individuals are expected to fit a particular mold (i.e., being unmistakably autistic when measured against the stereotypical image of a young white, male child who is socially disengaged and preoccupied with mechanical objects) and then keep quiet (McGuire 2016; Yergeau 2018). To violate this expectation frequently results in challenges to the legitimacy of the autistic person's diagnostic status, pressuring the autistic person to dredge up narrative proof that they are really autistic.

For example, farahumakemelol, explained in a brief chat on *Tumblr* that they feel much of the "hoopla" around disidentifiers boils down to autistics taking the classification too seriously. "We forget that the classification was written by a bunch of allistics," she told me as she began explaining that she believes there needs to be balance in representing what really counts as autistic:

> I know there aren't that many people saying they were misdiagnosed with autism. But more people are coming out with this story. That wouldn't be a problem if the world wasn't already against us and telling us that because we can do this and that we can't

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[35] Aspie elitism refers to a consequence of buying into the linear spectrum model of autistic disability. Prior to 2013, when Asperger's syndrome was included in the DSM and diagnosed, the condition was commonly understood to be "milder" than autistic disorder, a separate but related classification. Because mildness was more near to normality or "allism," many Aspergians believed that they should not be placed in the same category as those with more "severe" pervasive developmental disabilities like autistic disorder.

> possibly be autistic. That’s exactly what actually autistic is about! ... A ton of us are not the kind of people that get read as autistic. But we are. And have to make the distinction. Just because we act a certain way in public or with others, it doesn’t mean that we are that way all the time. Even online! Sometimes we act a certain way just because we learned to and it’s the easiest way to get on without trouble. The issue is … is it natural for us to be that way [responding as we were conditioned to]? Maybe it is, maybe not. We’re diverse … hence *neuro*diversity. We need more representations of autistic people being themselves than of non-autistic people denying autism.

Farahumakemelol's explanation of the problem as they see it was seldom articulated in such a way. Where the majority of retorts to disidentification narratives were about defending the validity of autism diagnoses and autistic identity in general, Farahumakemelol brought to the fore a particular concern in relation to diagnosis and identity validity: the dangers of having had a limited range of rhetorical characters of autisticness in circulation. Although images of autisticness are diversifying, the stereotypes of autism as a condition that impacts white male children who are either non-speaking or savant-like persist. This observation poses an important problem for psychiatric patients, diagnostic professionals, researchers who may want to glean somehow a notion of authentic autisticness. Particularly in cases of adult diagnosis, the waters muddy where cultural conditioning, traumas, and acquired perceptual modes may mistakenly mimic psychiatric conditions that are presumed to be congenital.

CONCLUSION

A common theme in the accounts of my formerly autistic interlocutors, whether they disidentified because they rejected psychiatry or because of their diagnostic reclassification, is the emphasis on diagnostic imprecision and the malleability of the autism classification. Through self-inquiry and sharing of personal accounts, my interlocutors attempted to explain the importance of acknowledging the possible consequences of misalignment between personal and institutional narratives of autism. In the presence of misalignment, my interlocutors continued to press for narrative coherence and the sense of diagnostic integrity. When they did not hinge their claims and perceptual shifts on anti-psychiatry beliefs, they often incorporated medical terminology or reasoning to defend their choices and augment the apparent sincerity of their accounts. Arguably, the use of medical terminology in their interpretations of the diagnostic classification was assumed to lend to their credibility. This use, however, was frequently accompanied by some hedging. Take for instance the first of Kayla's six *Tumblr* posts on her diagnostic reclassification:

> I just wanted to come on here and let you all (my friends) know what's going on with me ... It's been a whirlwind because I'm *finally* getting treatment for what's *really* been going on with me for so long, since before my boys were born. Ok, here it goes ... I'm not #actuallyautistic after all. Don't hate me, PLEASE ... I'm not a doctor, but I did my own research for many months before reevaluation ... when I look at the DSM entry for autism spectrum disorder or the past revision for [Asperger's syndrome], I never actually met the requirements. Like, never ever. The doctor saw a few traits and diagnosed me even though most of them did NOT apply. The lesson is that we should stay curious, even ... or probably especially about the diagnoses we get and don't be afraid to say so when you catch a humongous mistake.

The above quote from Kayla's post demonstrates not only the sense of apprehension she (and nearly all of my other interlocutors) experienced in telling their friends that they no longer identified in the way they did, as autistic. There was not only the sense of unease about losing social connections or gaining enemies, there was also concern about having her new findings challenged by others. She does not rest her choice argument on her new psychiatrist's expertise. Rather, she roots it in her own knowledge about the DSM criteria for autism spectrum disorder and Asperger's syndrome as well as who she knew herself to be then (at the time of her autism diagnosis) and now (having been undiagnosed with autism). Yet, she is not speaking in a definitive tone. She acknowledges that she's "not a doctor" and therefore not really an expert on how to read the diagnostic criteria for autism. Putting in "many months" of study, however, are intended to be redemptive and assure her friends in the actuallyautistic tag that she put in as good an effort as anyone serious about finding out their diagnostic truth.

On the other hand, disidentification narratives that resisted formal diagnostic labels altogether drew on rejections psychiatry's medical and scientific authority. In these narratives, the notions of neurodiversity, neurodivergence, and neuroqueerness stood in for overtly psychiatric conceptions of mental disorder. Because images of brain scans circulate widely in popular media and neuroscientific conceptions about what those scans mean about human behavior, sociality, and lived experiences, they are often readily accepted and sometimes read as relating biological facts rather than medical ones (see Dumit 2004). Disidentifiers who explicitly resisted identifying with psychiatry's concepts would frequently and unquestioningly mobilize notions like neurodiversity and neurodivergence. Importantly these concepts, which rely heavily on how contemporary medical science conceives of brain structures, wiring, and chemicals, are grounded on biologization of autistic people and others with acquired and congenital cognitive, psychological, and developmental differences. They are seen, however, as separate from classifications that are framed as inherently pathological or requiring cure.

"I would say that I am neurotypical or neurodivergent still … not autistic anymore, " wrote *Tumblr* user fresher_than_ur_mom in response the post by funnyjellyring. This claim is significant because it simultaneously places rhetorical distance between disidentifiers and autisticness, without severing completely ties to the autistic community. “I am not autistic anymore” is a clear disavowal of former ways of conceiving of oneself and the foundation of relationships with others who participated in the actuallyautistic tag on *Tumblr*. “But I am still neurodivergent” allows fresher_than_ur_mom to maintain some connection to the autistic groups she participated in through the notion of a "community" of neurodiverse persons, in which the autistic community is nestled.

That disidentifiers often butt heads with members of the autistic groups of which they were once members is not surprising. Within those groups most appear to be either content with their diagnostic statuses, relieved to have an answer to their questions about their neurosocial differences, and proud to claim autistic identity and membership in an autistic community. Therefore, the antipsychiatry framework and reclassification mode have not (yet) been embraced by self-advocates who believe that rejection of autism diagnoses might speak to disidentifiers' internalized ableism. In the examples that I have shared in this chapter, we see that assertions that one has been misdiagnosed can be resisted and attempts to seek alternative explanations for life experiences, behaviors, and baseline comportments might chocked up to widespread misperceptions about autism. Ultimately, whether they were railing against the institution of psychiatry or falling back to psychiatry for reclassification, my interlocutors' accounts are laced with a keen sense of instability and in the diagnostic process and resolve to attain narrative redress.

CONCLUSION: DIAGNOSIS & BEYOND

Sitting on the leftmost cushion of a too-soft loveseat, I am in my psychiatrist's chilly office. I run a hand back and forth across plush black fabric, feeling its softness pass quickly under the palm of my hand and under my finger nails. I press my left elbow into the arm of the loveseat and feel steadied. I am facing Dr. B who is seated behind her large wooden desk. The smell of cinnamon is strong in the office, but I cannot determine where the scent is coming from. The doctor is not saying a word, just moving papers around and scribbling in what I assume is my file. Her desk must be six feet away from me, so I am unable see what she is writing. I can only see the top of her pen cutting smooth circles and lines into the air. I hear her ball-point scratching out something mysterious onto the lined sheet of paper that is clipped to the manila file folder she sometimes waves around when she talks. I scan the room and notice that her small wall calendar is still set to February. It's the second week of May. I wonder if she even looks at the thing.

"You're very anxious," Dr. B says as she looks up. She speaks softly and slowly, and I wonder if this is how she speaks out in the "real" world. Maybe she speaks this way only in her practice, when working with restless patients. I have no clue what to say about being anxious, so I keep quiet and nod. When the crying starts, it catches me by surprise and I quickly sink into a pit of self-loathing. I cry harder. Dr. B walks over to sit a box of tissues beside me and then returns to her desk. Embarrassed, I hide my face with my left hand, and jut my right hand out feeling for the tissue box. I pull out a few sheets and fold myself in half, forehead to knees.

Dr. B asks if I want to know why I have been struggling. Why I have been so sad and anxious; why I rock myself and pace; why I have had trouble socializing. I don't respond, but I quickly gather that her question is rhetorical, because she shares her ruling anyway. "Your brain is broken." There's a long pause. I don't look up. "Don't worry," she says, "broken's not *bad*. I believe you’re dealing with a condition called Asperger’s Syndrome.”

That day, I walked out of the doctor’s office, feeling like I was carrying an odd balloon – a strange token. It was as if I held the words “Asperger’s Syndrome” by a long, thin string and it floated high overhead. At 22, it felt like I was holding someone else’s balloon – someone else’s Asperger's Syndrome (AS) – an idea about a broken-but-not-necessarily-bad brain. In the first few months following that doctor’s visit, I looked for answers obsessively. I sought a second and third opinion that confirmed the initial verdict.

It was not until I embarked on this study that I learned that my AS "evaluations," which centered on only information collected from interviews with doctors, were essentially incomplete. Critically, most childhood diagnoses involve the use of developmental screening tools and comprehensive evaluation protocols (CDC 2016). These kinds of diagnostic tools, it seems, are not employed on a broad scale for adults, however. Most of my interlocutors who were diagnosed in adulthood experienced similar diagnostic processes. Physician inquiry seemingly stopped short. A series of interviews, with no rigorous testing, could lead to the determination that autism was the "problem." In general, psychiatrists aim to be thorough in their patient interviews. Diagnostic precision is the goal even though accuracy in diagnosing autism in adults is difficult to achieve and can be hard to verify across practitioners. Psychiatric diagnoses like autism are sometimes easily and quickly overturned when practitioners see something that was missed or ignored by previous doctors (Densmore 2015 and Prizant 2012).

As it sometimes went with my interlocutors, I ended up with a rickety AS diagnosis, a label and explanatory tool that would later be seen as unfitting. Back then, I saw that "AS probable," "Asperger likely," and "dx: adult AS" were scrawled out in my files, and this scrawling was almost magical. It enabled me to access services and accommodations that I needed on campus and on the job. The accommodations that I required were minimal, and I was fortunate to have a couple of teachers and an employer that were willing to assist. I learned that a great many of my interlocutors were not so privileged, however. Rather than having diagnoses that afforded them access to needed supports, they were sometimes penalized for asking for more accommodation than their employers and educators were willing to provide.

Over the years, in both my personal and research involvements with groups of autistic adults, I have found that many of my autistic friends and interlocutors have been saddled with peculiar, incomplete and semi-formal diagnoses because they, or their doctors, were either unable or unwilling to push for more intensive diagnostic procedures and disability services. Still, like many other newly diagnosed adults, in my post-diagnosis life, I spent months in search of cures and therapies that might eliminate the impulse to flap my hands and rock my body, dull my overactive senses, and develop social intuition and grace. These searches turned up loads of information about alternative therapies, which included heavy metal cleanses, leech treatments, major diet revamping, and prayers and supplications, among other things. It was a mixture of strange, impractical, and sometimes dangerous "solutions," that tended to be geared toward desperate parents of young autistic children.

In searching for a way to undo AS, I stumbled upon a now-defunct message board for adults with Asperger's Syndrome. In that space, I learned that there were "aspies" who weren't hunting down cures. They had not only accepted their diagnoses, they took pride in them, felt solidarity with other so-called "neurodiverse" people, and had no qualms about openly identifying as autistic. I stalked the message board daily for three years, before it was dissolved by the website's host. My time on the site provided opportunities for me to learn about the various ways that some autistic people endeavored to not only fashion good autistic lives for themselves, but also take part in crafting a broader community of autisticness and celebrated neurodivergence.

In developing this research project, I tapped into my own curiosity about how diagnoses of autism and other ASD classifications figure into the formation and maintenance of a more or less shared autistic identity and sense of community belonging. What drove people to seek out and connect with others on the so-called autism "spectrum?" How did they become involved in a so-called autistic “community” that stretches across digital and physical world spaces? And how could one become transformed, from a person *with* an autism spectrum disorder into an *autistic* person, who accepted and celebrated their way of being in the world?

In an interview for this study, my friend Mitch, a self-identified autistic man in his thirties, offered an explanation that resonated with me and my experience. He told me that in fumbling around and growing depressed after his diagnosis of PDD-NOS nine years ago, he stumbled upon support and activity groups online and offline. Through his regular participation in these groups he "discovered the beauty of the autistic community” and realized how powerful it was for him to engage in it. “There’s an element of surprise,” Mitch told me. “I went from hating autism to finding a bunch of other socially awkward weirdos who feel free to just be weird together ... I was accepted …We all wanted to know more about each other and then ... we naturally got to know ourselves better, too.”

The above personal account is a reflection on my own diagnosis process. It highlights the intrapersonal struggle that ensued following my diagnosis, which was initially a jarring and troubling event. Like my interlocutors, who were diligent in their studies of autism symptomology and classification criteria, I also dug into as many medical and lay descriptions of life with Asperger's Syndrome as possible. After months of attempting to fix my "broken brain," I began considering what made AS real and maybe even good for me. That feeling that my sense of aspie-ness was almost always a *becoming* rather than an established fact persisted for years after that appointment with Dr. B. I began to understand the Asperger's label I was assigned and later, just prior to the 2013 changes to the *DSM*, I began making nice with the notion that I was autistic. Throughout the process of reconciling with my new autistic identity, my parents' accounts of my withdrawn nature and "unusual" behavior as a child (and even as an infant) made sense. Bit by bit, I found new ways to see myself, past, present, and future, as actually autistic.

In this research, I saw my interlocutors do similar things. As I have proposed in the preceding chapters, my interlocutors' work of reframing their life stories highlighted the ways that narrative coherence became a vitally important achievement that was not especially easy to come by. In the presence of external and internal forces that compelled them to rethink their accounts and resituate themselves in relation to new conditions or redefined categories of disorder and belonging, my interlocutors expressed sincere desires to be able to share an authentic and sensible life story. Their autism diagnoses, however they were acquired, were often the things that helped them do that.

In the preceding chapters, I laid out some ideas about the achievement of authentic autisticness and belonging in autistic community through interactions with rhetorical characters of autisticness and participation in autistic spaces, online and offline. For my interlocutors (and for me), authenticity and belonging in autistic community were accomplishments produced not only by giving routine accounts of autisticness but by purchasing and embodying a rhetorical character of autisticness that was accepted and regularly legitimated by chosen groups of autistic others. Rejections of autisticness or disidentification were not common, but the various ways that my interlocutors responded to others' claims of no longer identifying as autistic clued me in to how stories of *un*becoming autistic could shine a light on the tenuousness of their self-concepts and ways they attempted to *really* get to know themselves through narrative formulation and reformulation processes.

Most of my interlocutors were uninterested in debating about or questioning the validity of their autism diagnoses. For me, undiagnosis was neither sought after nor avoided. But it happened, throwing a wrench into a process of becoming. Since that appointment with Dr. B in my early twenties, and perhaps even before then, I was on course to becoming autistic, each day learning more and more, from direct experience and connections with other autistics, what autisticness might mean and look like for me. And then, suddenly, a set of new diagnostic possibilities came to the fore and I was no longer sure what kind of self was unfolding. The tension that kind of uncertainty generated for me was potent. Reflecting on my observations and interlocutors' accounts, I see that this pressure also played out in the stories of prospective and self-diagnosing autistic adults, whose desires for a life story that made sense propelled them forward toward their goal of an autism diagnosis.

In my study, I found that autistic identity and community constituted intertwined conceptual bridges that allowed my interlocutors to formulate, individually and collectively, self-images that supported their abilities to connect with one another and advocate for greater acceptance of neurosocial diversity. Disidentification accounts were important in my field sites because they constituted threats of discontinuity and neurosocial displacement for people who had often endured significant challenges to attain answers for why they had experienced social rejection, misunderstanding, medicalization, and pathologization. If knowing oneself to be autistic and identifying in that way was a vital part of their processes of personal narrative refinement and solidification, disidentification threatened the integrity of their habituated acts of self-persuasion and seemed to indicate the potential for narrative degeneration and chaos.

In this dissertation, I have attempted to explore rhetorical characters of autisticness, autistic narrative, participation in online and offline autistic spaces, and autistic identification and disidentification as central, interrelated processes that buttress the very notions of autistic community and identity. By studying the identity and community formation and maintenance practices of autistic adults, taking them on their own terms, I have aimed to show that rather than living as embodiments of a biomedical and social problem needing to be remedied, autistic adults are truly powerful social actors who are shaping knowledge practices and challenging cultural stereotypes of autistic absence and inadequacy. I have also aimed to show that the goal of narrative coherence and the work of narrative revision are tricky because of they seem to rely on our will and sense of being impelled to sift through disorienting relations between our experiences of what is ostensibly solidly real and the labels that we might be ascribed and may assume for ourselves. In the case of autism and other psychiatric classifications, these are labels that are changeable and are rooted in metaphors that spawn from the belief that atypicalness is the death knell of much-revered normalcy.

Becoming autistic and unbecoming autistic are relational and the ways these two ideas played out for my interlocutors in their group spaces underscores the ways the rutted terrain of the autism discursive field interrelate with the complex of dynamic forces that help produce autistic identity and form and maintain autistic community. "The autistic are in continuous motion" in relation to one another, autistic scholar Melanie Yergeau wrote (2018, p. 213). The diagnostic classification of autism spectrum disorder, its prior forms, our willingness to assume the label and our rejections of it, and the practices autistic adults engage in to maintain a sense of self and group and community belonging interplay and do things in the social world. They are indexes that shape the ways people who self-identify as autistic relate to not just the field of psychiatry and its concepts, but also to one another and cultural conceptions of acceptability and normality.

REFERENCES

Agar, M. (1994). *Language Shock: Understanding the Culture of Conversation*. New York: Morrow.

Alley, C.S. et al. (2017). Violence is Rare in Autism: When It Does Occur Is It Sometimes Extreme? *The Journal of Psychology* 151(2017), pp. 49-68. https://doi.org/10.1080/00223980.2016.1175998

Almendrala, A. (2015, October 27). Some Children Do Outgrow Autism: But It's Not What You Think. *Huffington Post*. https://www.huffingtonpost.com/entry/children-outgrow-autism-why_us_562a931de4b0aac0b8fcf369

American Psychiatric Association (2013). *Diagnostic and Statistical Manual of Mental Disorders. Fifth Edition, DSM-5*. Washington D.C.: American Psychiatric Association Publishing.

American Psychiatric Association (2000). *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (Text Revision).* Washington, DC: American Psychiatric Association.

American Psychiatric Association (1994). *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition.* Washington, DC: American Psychiatric Association.

American Psychiatric Association (1987). *Diagnostic and Statistical Manual of Mental Disorders, Third Edition (Revised).* Washington, DC: American Psychiatric Association.

American Psychiatric Association (1980). *Diagnostic and Statistical Manual of Mental Disorders, Third Edition.* Washington, DC: American Psychiatric Association.

American Speech-Language-Hearing Association (n.d.) Autism (Autism Spectrum Disorder). *American Speech-Language-Hearing Association*. Retrieved from https://www.asha.org/public/speech/disorders/autism/

Autism Speaks (n.d.). DSM-5 Diagnostic Criteria. *Autism Speaks*. http://www.autismspeaks.org/what-autism/diagnosis/dsm-5-diagnostic-criteria.

Autism Speaks (n.d.). What Causes Autism? *Autism Speaks*. Retrieved from https://www.autismspeaks.org/what-autism/learn-more-autism/what-causes-autism

Ayometzi, C.C. (2007). Story as Becoming: Identity through the Telling of Conversion. In Bamberg, M., A. De Fina, and D. Schiffrin (eds.) *Selves and Identities in Narrative and Discourse* (pp. 41-70). Philadelphia, PA: John Benjamins Publishing Company.

Bamberg, M., A. De Fina, and D. Schiffrin (2007). Introduction. In Bamberg, M., A. De Fina, and D. Schiffrin (eds.) *Selves and Identities in Narrative and Discourse* (pp. 1-8). Philadelphia, PA: John Benjamins Publishing Company.

Baron-Cohen, S. (2008). Theories of the Autistic Mind. *The British Psychological Society* 21(1), pp. 112-116.

Baron-Cohen, S. et al. (2013). Is Synaesthesia More Common in Autism? *Molecular Autism* 4(2013):40. http://doi.org/10.1186/2040-2392-4-40

Becker, C.L. (2012, October 25). The Tony Attwood Apologist. *No Stereotypes Here*. Retrieved from http://nostereotypeshere.blogspot.com/2012/10/the-tony-attwood-apologist.html

Becker, H. (2008). *Outsiders: Studies in the Sociology of Deviance*. New York, NY: Simon & Schuster, Inc.

Benjamin, K. (2012, September 11). 11 Historical Geniuses and Their Possible Mental Disorders. *Mental Floss*. Retrieved from http://mentalfloss.com/article/12500/11-` historical-geniuses-and-their-possible-mental-disorders

Berger, P. L. and T. Luckmann (1966). *The Social Construction of Reality: A Treatise in the Sociology of Knowledge*. New York, NY: Open Road Media.

Bernal, V. (2006). Diaspora, Cyberspace, and Political Imagination: The Eritrean Diaspora Online. *Global Networks* 6(2), p. 161-179. https://doi.org/10.1111/j.1471-0374.2006.00139.x

Boellstorff, T. (2004). "Authentic, Of Course": Gay Language in Indonesia and Cultures of Belonging. In W. Leap and T. Boellstorff (Eds.) *Speaking in Queer Tongues: Globalization and Gay Language*, pp. 181-201. Chicago, IL: University of Illinois Press.

Bowker, G. and S. Star (1999). *Sorting Things Out: Classification and Its Consequences*. Cambridge, MA: MIT Press.

Brinkmann, S. (2016). *Diagnostic Cultures: A Cultural Approach to the Pathologization of Modern Life*. London: Routledge.

Broderick, A.A. and A. Ne'eman (2008). Autism as Metaphor: Narrative and Counter-narrative. *International Journal of Inclusive Education* 12(2008), 459-76. https://doi.org/10.1080/13603110802377490

Brown, L.X.Z. (2013, May 8). What is a Shiny Aspie. *Autistic Hoya*. Retrieved from https://www.autistichoya.com/2013/05/what-is-a-shiny-aspie.html

Burleigh, J. (2004, June 1). Was Michelangelo's Artistic Genius a Symptom of Autism? *Independent*. Retrived from https://www.independent.co.uk/news/uk/this-britain/was-michelangelos-artistic-genius-a-symptom-of-autism-756718.html

Campbell, F. K. (2009). Disability Harms: Exploring Internalized Ableism. In C. A. Marshall, et al. (eds.) *Disabilities: Insights from Across Fields and Around the World, Vol. 1* (pp. 19-34). Westport, CT: Praeger Publishers.

Capps, L. and E. Ochs (1995). *Constructing Panic: The Discourse of Agoraphobia*. Cambridge, MA: Harvard University Press.

Capps, L. and M. Sigman (1996). Autistic Aloneness. In R.D. Kavanaugh, B. Zimmerberg, and S. Fein (eds.) *Emotion: Interdisciplinary Perspectives*, pp. 273-295. Mahwah, NJ: Lawrence Erlbaum Associates.

Carnegie, D. (1936). *How to Win Friends and Influence People*. New York, NY: Simon & Schuster.

Carpenter, L. (2013). DSM-5 Autism Spectrum Disorder: Guidelines & Criteria Exemplars. [Electronic document]. *University of Washington.* http://depts.washington.edu/dbpeds/screening%20tools/dsm-5(ASD.Guidelines) Feb2013.pdf

Cascio, M.A. (2012). Neurodiversity: Autism Pride Among Mothers of Children with Autism Spectrum Disorders. *Intellectual and Developmental Disability*. 50(3), pp. 273-283. DOI: 10.1352/1934-9556-50.3.273

Casson, R.W. (1983). Schemata in Cognitive Anthropology. *Annual Review of Anthropology* 12(1)), pp. 429-462. https://www.annualreviews.org/doi/pdf/10.1146/annurev.an.12.100183.002241

Chan, M. and M. Katz (2015, December 2). 2 Suspects Dead in San Bernardino Disability Center Shooting. *Time*. Retrieved from http://time.com/4133250/shooter-san-bernardino-california/

Cialdini, R.B. et al. (1976). Basking in Reflected Glory: Three (Football) Field Studies. *Journal of Personality and Social Psychology*. 34(3), pp. 366-375. http://psycnet.apa.org/doi/10.1037/0022- 3514.34.3.366

Couser, G.T. (2013). Disability, Life Narrative, and Representation. In L.J. Davis (ed), *The Disability Studies Reader* (pp. 456-459). New York, NY: Routledge.

David, E. J. R. and A. Derthick (2014). What is Internalized Oppression, and So What? In EJR David (ed.) *Internalized Oppression: The Psychology of Marginalized Groups* (pp. 1-30). New York, NY: Springer Publishing Company, LLC.

Dawson, M. (2015, June 17). The Miracle that Cured My Son's Autism Was in Our Kitchen. *New York Post*. https://nypost.com/2015/06/17/is-diet-the-key-to-curing-autism/

Dempsey, I. and P. Foreman (2001). A Review of Educational Approaches for Individuals with Autism. *International Journal of Disability, Development, and Education* 48(1), pp. 103-116. https://doi.org/10.1080/10349120120036332

Denmore, A. (2015). What if the Diagnosis of Autism is Wrong? *Psychology Today*. https://www.psychologytoday.com/us/blog/listen-the-kids/201508/what-if-the-diagnosis-autism-is-wrong

DeWeerdt, S. (2011, July 4). Reclassification of Rett Syndrome Diagnosis Stirs Concerns. *Simons Foundation Autism Research Initiative*. Retrieved from https://www.spectrumnews.org/news/reclassification-of-rett-syndrome-diagnosis-stirs-concerns/

Dumit, J. (2004). *Picturing Personhood: Brain Scans and Biomedical Identity*. Princeton, New Jersey: Princeton University Press.

Dutton, J.E., Dukerich, J.M., and C.V. Harquail (1994). Organizational Images and Member Identification. *Administrative Science Quarterly* 39(2), pp. 239-263. doi:10.2307/2393235

Elliot et al. 2015. Creating an Online Community of Practice: The Deaf and Hard of Hearing Virtual Academic Community. Presentation for the Effective Access Technology Conference, Rochester Institute of Technology, Rochester, NY, November 10, 2015. http://scholarworks.rit.edu/cgi/viewcontent.cgi?article=1023&context=eatc

Eyal, G. et al. (2010). *The Autism Matrix*. Cambridge, UK: Polity.

Fajans, J. (2006). Autonomy and Relatedness: Emotions and the Tension between Individuality and Sociality. *Critique of Anthropology* 26(1), pp.103-119. https://doi.org/10.1177%2F0308275X06061486

Fleming, N. (2008, February 21). Albert Einstein 'Found Genius Through Autism'. *The Telegraph*. Retrieved, https://www.telegraph.co.uk/news/science/science-news/3326317/Albert-Einstein-found-genius-through-autism.html

fr33man (2017, June 27). How I Reversed My Autism Naturally (Backstory and Causes) [video]. *YouTube.* https://www.youtube.com/watch?v=QJQILluS1Tc

Foucault, M. (1989). *Birth of the Clinic*. London: Routledge.

Foucault, M. (1977). *Discipline and Punish: The Birth of the Prison*. New York: Random House.

Garro, L. and C. Mattingly (2000). *Narrative and the Cultural Construction of Illness and Healing*. Berkeley, CA: University of California Press.

Gee, James. 2005. Semiotic Social Spaces and Affinity Spaces: From the Age of Mythology to Today's schools. In David Barton and Karin Tusting (Eds.) *Beyond Communities of Practice: Language Power and Social Context* (pp. 214-232). New York, NY: Cambridge University Press.

Gensic, J. (2018, April 2). Viewpoint: Reflections from a Parent on Autism Awareness, Acceptance. *South Bend Tribune*. Retrieved from https://www.southbendtribune.com/news/opinion/viewpoint/viewpoint-reflections-from-a-parent-on-autism-awareness-acceptance/article_532a8bdc-b66d-5924-b068-bb6c9fbcde2e.html

Goffman, E. (1963). *Stigma: Notes on the Management of Spoiled Identity*. New York, NY: Simon & Schuster, Inc.

Goffman, E. (1961). *Asylums: Essays on the Social Situation of Mental Patients and Other Inmates*. New York, NY: Anchor Books.

Goffman, E. (1959). *The Presentation of Self in Everyday Life*. New York, NY: Anchor Books.

Goodley et al. 2017. Critical Disability Studies. In Brendon Gough (Ed.) *The Palgrave Handbook of Critical Social Psychology* (491-505). London, Palgrave MacMillan. https://link.springer.com/chapter/10.1057/978-1-137-51018-1_24

Goodman, B. (2012, January 23). Why Some Children May 'Grow Out' of Autism. *WebMD.* https://www.webmd.com/brain/autism/news/20120123/why-some-children-may-grow-out-of-autism#1

Gordon, C. (2007). Repetition and Identity Experimentation: One Child's Use of Repetition as a Resource for "Trying on" Maternal Identities. In Bamberg, M., A. De Fina, and D. Schiffrin (eds.) *Selves and Identities in Narrative and Discourse* (pp. 1-8). Philadelphia, PA: John Benjamins Publishing Company.

Grandin, T. and M.M. Scariano (1986). *Emergence: Labeled Autistic*. New York, NY: Grand Central Publishing.

Harmon, A. (2004). Neurodiversity Forever; The Disability Movement Turns to Brains. *New York Times*. Retrieved from https://www.nytimes.com/2004/05/09/weekinreview/neurodiversity-forever-the-disability-movement-turns-to-brains.html

Harris, A. (2016, April 18). Misdiagnosis of Kids with Autism Spectrum Disorder Could be a Real Threat. *Irish Examiner*. https://www.irishexaminer.com/lifestyle/features/misdiagnosis-of-kids-with-autism-spectrum-disorder-could-be-a-real-threat-393464.html

Hayasaki, E. (2015). The Debate Over an Autism Cure Turns Hostile. *Newsweek Magazine*. Retrieved from https://www.newsweek.com/2015/02/27/one-activists-search-cure-his-autism-drawing-violent-backlash-306998.html

Heilker, P. (2012). Autism, Rhetoric, and Whiteness. Disability Studies Quarterly 30(4). http://dx.doi.org/10.18061/dsq.v32i4

Hughes, J.M.F. (2016). Increasing Neurodiversity in Disability and Social Justice Advocacy

Groups. *Autistic Self-Advocacy Network*. Retrieved from https://autisticadvocacy.org/ wp-content/uploads/2016/06/whitepaper-Increasing-Neurodiversity-in-Disability-and-Social- Justice-Advocacy-Groups.pdf

Huibers, M.J.H. and S. Wessely (2006). The Act of Diagnosis: Pros and Cons of Labelling Chronic Fatigue Syndrome. *Psychological Medicine* 36(7), 895-900. https://doi.org/ 10.1017/S0033291705006926

Hyman, S.L. (2013, June 4). New DSM-5 includes changes to autism criteria. *AAP News*. Retrieved from http://www.aappublications.org/content/aapnews/early/2013/06/04/ aapnews.20130604-1.full.pdf/

Jack, J. (2014). *Autism and Gender: From Refrigerator Mothers to Computer Geeks.* Urbana, Chicago: University of Illinois Press.

Jasanoff, S. (2004). *States of Knowledge: The Co-Production of Science and the Social Orde*r. London: Routledge.

Johnstone, B. (2000). The Individual Voice in Language. *Annual Review of Anthropology* 29(1), pp. 405-424. https://doi.org/10.1146/annurev.anthro.29.1.405

Kansen, G. (2016). What the Neurodiversity Movement Gets Wrong About Autism. *Pacific Standard Magazine*. Retrieved from https://psmag.com/news/what-the-neurodiversity-movement-gets-wrong-about-autism

Krueger, R.F. and Serena Bezdjian (2009). Enhancing Research and Treatment of Mental Disorders with Dimensional Concepts: Toward DSM-V and ICD-11. *World Psychiatry* 8(2009), 3-6. https://doi.org/10.1002/j.2051-5545.2009.tb00197.x

Lave, J. and E. Wegner. (1991). *Situated Learning: Legitimate Peripheral Participation*. New York, NY: Cambridge University Press.

Levi-Strauss, C. (2016) The Sorcerer and His Magic. In P.J. Brown and S. Closser (eds.) *Understanding and Applying Medical Anthropology* (pp. 197-203). New York, NY: Routledge.

Liang, A.C. (1999). Conversationally Implicating Lesbian and Gay Identity. In M. Bucholtz, A.C. Liang, and L.A. Sutton (eds.) *Reinventing Identities: The Gendered Self in Discourse* (pp. 293-311). New York, NY: Oxford University Press.

Lutz, A. (2013) You Do Not Have Asperger's. *Slate*. Retrieved from http://www.slate.com/ articles/health_and_science/medical_examiner/2013/05/autism_spectrum _diagnoses_the_dsm_5_eliminates_asperger_s_and_pdd_nos.html

Marshall, T. (2015*). I Am AspienWoman: The Unique Characteristics, Traits and Gifts of Adult Females on the Autism Spectrum*. Sunshine Coast QLD: AspienGirl.

McCoy, T. (2014, May 21). Study: 'Significant' Statistical Link Between Mass Murder, Autism, Brain Injury. *The Washington Post*. Retrieved from https://www.washingtonpost.com/news/morning-mix/wp/2014/05/21/study-finds-significant-portion-of-mass-murderers-and-serial-killers-had-neurological-disorders-includingautism/?utm_term=.15339e294cae

McGuire, A. (2016). *War on Autism: On the Cultural Logic of Normative Violence*. Ann Arbor Michigan: University of Michigan Press.

Mead, K. (2017, May 1). Against Eugenics, and for a Future that includes Autistic and Disabled People. *Paginated Thoughts*. Retrieved from https://kpagination.wordpress.com/2017/05/01/ blogging-against-disablism-day-2017/

Milton, Damian and Rebecca Wood. 2017. Beyond Tokenism: Autistic Participation in a Transnational Community of Practice. In *The Globalization of Autism: Historical, Sociological, and Anthropological Reflections.* April 20-21, 2017. London, UK.

Moench, B. (2014). Autism Nation: America's Chemical Brain Drain. *Truth Out*. Retrieved from http://truth-out.org/news/item/23267-autism-nation-americas-chemical-brain-drain

Molloy, H. and L. Vasil (2002). The Social Construction of Asperger Syndrome: The Pathologising of Difference? *Disability & Society* 17(6), pp. 659-669. https://doi.org/10.1080/0968759022000010434

Mortier, Kathleen. 2018. Communities of Practice: A Conceptual Framework for Inclusion of Students with Significant Disabilities. *International Journal of Inclusive Education,* https://doi.org/10.1080/13603116.2018.1461261

Murphy, K.M. (2004). Imagination as Joint Activity: The Case of Architectural Interaction. *Mind, Culture, and Activity* 11(4), pp. 267-278. https://doi.org/10.1207/s15327884mca1104_3

National Institute of Health (2017). What Causes Autism. *Eunice Kennedy Shriver National Institute of Child Health and Human Development*. Retrieved from https://www.nichd.nih.gov/health/topics/ autism/conditioninfo/causes

Ne'eman, Ari (2009). Disability Community Condemns Autism Speaks. *Autistic Self Advocacy Network*. http://autisticadvocacy.org/2009/10/disability-community- condemns-autism-speaks

Ochs, E. et al. (2004). Autism and the Social World: An Anthropological Perspective. *Discourse Studies* 6(2), pp. 147-183.

Ochs, E. and L. Capps (2001). *Living Narrative: Creating Lives in Everyday Storytelling*. Cambridge, MA: Harvard University Press.

Organization for Autism Research. (2017, September 7). But She's Too Social to Be Autistic. Research Autism. Retrieved from https://researchautism.org/but-shes-too-social-to-be-autistic-wrong/

Pentland, B.T. (1995). Organizational Learning: The Social Epistemology of Organizational Knowledge Systems. *Accounting, Managment and Information Technologies* 5(1), pp. 1-21.

Prizant, B. (2012). On the Diagnosis and Misdiagnosis of Autism Spectrum Disorder [PDF]. *Dr. Barry Prizant*. Retrieved from http://barryprizant.com/wp-content/uploads/2015/07/asq_misdiagnosis_of_asd_summer_2012.pdf

Randerson, J. (2009, January 7). A Prenatal Test for Autism Would Deprive the World of Future Geniuses. *The Guardian*. Retrieved from https://www.theguardian.com/science/blog/2009/jan/07/autism-test-genius-dirac

Rappaport, J. (1993). Narrative Studies, Personal Stories, and Identity Transformation in the Mutual Help Context. *The Journal of Applied Behavioral Science* 29(2), pp. 239-256. https://doi.org/10.1177/0021886393292007

Rapoport, J. et al. (2009). Autism-Spectrum Disorders and Childhood Onset Schizophrenia: Clinical and Biological Contributions to a Relationship Revisited. *Journal of the American Academy of Child and Adolescent Psychiatry* 48(1), pp. 10-18. https://doi.org/10.1097/CHI.0b013e31818b1c63

Reddington, S. and D. Price (2018). Pedagogy of New Materialism: Advancing the Educational Inclusion Agenda for Children and Youth with Disabilities. *Disability Studies Quarterly* 30(1). http://dx.doi.org/10.18061/dsq.v38i1

Rett Syndrome Research Trust. (n.d.). Huda Zoghbi, M.D. *Rett Syndrome Research Trust*. https://reverserett.org/about-us/people/huda-zoghbi/

Robison, J.E. (2009, February 28). The Myth of the Black Aspergian. *Look Me in The Eye*. Retrived from http://jerobison.blogspot.com/2009/02/myth-of-black-aspergian.html

Rozsa, M. (2016, October 12). ASD in Girls: Gender Stereotypes Have Made Us Horrible at Recognizing Autism in Women and Girls. *Quartz*. Retrieved from https://qz.com/804204/asd-in-girls-gender-stereotypes-have-made-us-horrible-at-recognizing-autism-in-women-and-girls/

Salhi, B. (2016). Beyond the Doctor's White Coat: Science, Ritual, and Healing in American Biomedicine. In P.J. Brown and S. Closser (eds.) *Understanding and Applying Medical Anthropology* (pp. 204-212). New York, NY: Routledge.

Sarris, M. (2016, January 27). "Recovery" by the Numbers: How Often do Children Lose an Autism Diagnosis? *Interactive Autism Network at Kennedy Krieger Institute.* https://iancommunity.org/ssc/recovery-numbers-how-often-do-children-lose-autism-diagnosis

Sholl, J. (2017). The Muddle of Medicalization: Pathologizing or Medicalizing? *Theoretical Medicine and Bioethics* 38(4), p. 265-278. https://doi.org/10.1007/s11017-017-9414-z

Silberman, S. (2016). *NeuroTribes: The Legacy of Autism and the Future of Neurodiversity*. New York, NY: Avery.

Silverman, C. (2012). *Understanding Autism: Parents, Doctors, and the History of a Disorder*. Princeton University Press

Simone, R. (2012). *22 Things a Woman with Asperger's Syndrome Wants Her Partner to Know*. London: Jessica Kingsley Publishers.

Simone, R. (2010) *Aspergirls: Empowering Females with Asperger Syndrome*. London: Jessica Kingsley Publishers.

Sinclair, J. (1993) Don't Mourn for Us. *Autreat*. Retrieved from https://www.autreat.com/dont_mourn.html

Sinclair, J. (2010). Cultural Commentary: Being Autistic Together. *Disability Studies Quarterly* 30(1). http://dx.doi.org/10.18061/dsq.v30i1

Singh, J.S. (2011). The Vanishing Diagnosis of Asperger's Disorder. In P. J. McGann and D. J. Hutson (eds.) *Sociology of Diagnosis. Advances in Medical Sociology, vol. 12* (pp. 235-257). Bingly, U.K.: Emerald Group Publishing. https://doi.org/10.1108/s1057-6290(2011)0000012015

Singh, J.S. (2015). *Multiple Autisms: Spectrums of Advocacy and Genomic Science*. Minneapolis, MN: University of Minnesota Press.

Solomon, O. and N. Bagatell (2010). Introduction: Autism: Rethinking the Possibilities. *Ethos* 38(1), pp. 1-7.

Stahl, S.K.D. (1977). The Personal Narrative as Folklore. *Journal of the Folklore Institute* 14(1/2), pp. 9-30. https://www.jstor.org/stable/3814039

Strauss, JN. (2013). Autism as Culture. In L. J. Davis (ed.), *The Disability Studies Reader* (pp. 460-484). New York, NY: Routledge.

Szasz, T. (2007). *The Medicalization of Everyday Life: Selected Essays*. Syracuse, NY: Syracuse University Press.

Szasz, T (1987). *Insanity: The Idea and Its Consequences*. New York, NY: John Wiley & Sons.

The Caffeinated Autistic (2013, March 6). I am a person, not a function. *The Caffeinated Autistic: Neurodivergence, Queer Things, and Fandom*. Retrieved from https://thecaffeinatedautistic.wordpress.com/2013/03/06/i-am-a-person-not-a- function/

Thomas, H. and T. Boellstorff (2017). Beyond the Spectrum: Rethinking Autism. *Disability Studies Quarterly* 37 (2017). http://dx.doi.org/10.18061/dsq.v37i1

University of California, Davis (2018, January 29). What Makes Kids with Autism Less Social than Their Typically Developing Peers? Science Daily. Retrived from https://www.sciencedaily.com/releases/2018/01/180129223841.htm

U.S. Centers for Disease Control and Prevention (2018). Basics About ASD. *Centers for Disease Control and Prevention*. Retrived from https://www.hhs.gov/programs/topic-sites/autism/index.html#causes

U.S. Centers for Disease Control and Prevention (2018). Screening and Diagnosis. *Centers for Disease Control and Prevention*. Retrived from https://www.cdc.gov/ncbddd/autism/screening.html

Vicker, B. (n.d.). Social Communication and Language Characteristics Associated with High Functioning, Verbal Children and Adults with ASD. *Indiana Resource Center for Autism*. Retrieved from https://www.iidc.indiana.edu/pages/Social-Communication-and-Language-Characteristics-Associated-with-High-Functioning-Verbal-Children-and-Adults-with-ASD/

Walker, N. (2014). Five Steps Toward Autism Acceptance. *Neurocosmopolitanism: Nick Walker's Notes on Neurodiversity, Autism, and Cognitive Liberty*. Retrieved from http://neurocosmopolitanism.com/five-steps-toward-autism-acceptance/

Waltz, M. (2013). *Autism: A Social and Medical History*. London: Palgrave.

Ward, J. et al. (2017). Atypical Sensory Sensitivity as a Shared Feature Between Synaesthesia and Autism. *Nature*. Retrieved from https://www.nature.com/articles/srep41155

Watters, E. (2013, June 3). The Problem with Psychiatry, the 'DSM,' and the Way We Study Mental Illness. *Pacific Standard*. Retrieved From https://psmag.com/social-justice/real-problem-with-dsm-study-mental-illness-58843

Wenger, E. (1998). *Communities of Practice: Learning, Meaning, and Identity.* Cambridge: Cambridge University Press

Whitehouse, A. (2016, February 18). What Causes Autism? What We Know, Don't Know and Suspect. *The Conversation*. Retrieved from http://theconversation.com/what-causes-autism-what-we-know-dont-know-and-suspect-53977

Willemsen-Swinkels, S. and J.K. Buitelaar (2002). The Autistic Spectrum: Subgroups, Boundaries, and Treatment. *Psychiatric Clinics of North America* 25(2002), 811-36. https://doi.org/10.1016/S0193-953X(02)00020-5

Williams, D. (1992). *Nobody Nowhere: The Extraordinary Autobiography of an Autistic*. London: Times Books.

Wind (2008) Negotiated Interactive Observation: Doing Fieldwork in Hospital Settings. *Anthropology & Medicine* 15(2), 79-89. https://doi.org/10.1080/13648470802127098

Wing, L. (1993). The Definition and Prevalence of autism: A Review. *European Child and Adolescent Psychiatry* 2(1), pp. 61-74.

Wing, L. and J. Gould (1979). Severe Impairments of Social Interaction and Associated Abnormalities in Children. Epidemiology and Classification. *Journal of autism and Developmental Disorders* 9(1), pp. 11-29.

Wood, K. (1999). Coherent Identities amid Heterosexist Ideologies: Deaf and Hearing Lesbian Coming-Out Stories. In M. Bucholtz, A.C. Liang, and L.A. Sutton (eds.) *Reinventing Identities: The Gendered Self in Discourse* (pp. 46- 63). New York, NY: Oxford University Press.

World Health Organization. (1993). *The ICD-10 Classification of Mental and Behavioral Disorders: Diagnostic Criteria for Research (Vol. 2).* World Health Organization.

Wright, J. (2017, March 14). Questions for Huda Zoghbi: Studying Rett in the Rodent Brain. *Spectrum News*. Retrieved from https://www.spectrumnews.org/opinion/viewpoint/questions-huda-zoghbi-studying-rett-rodent-brain/

Yergeau, M. (2018). *Authoring Autism: On Rhetoric and Neurological Queerness*. Durham, North Carolina: Duke University Press.

APPENDIX A: KEY INTERLOCUTORS & THEIR GROUPS

Adam – Mid County group
Akitababy91 – Actuallyautistic on *Tumblr*
Anna – Mid County group
Bound-for-greatness - Actuallyautistic on *Tumblr*
Cal – North County group
Camall - South County group
Clint – Group for adults on the autism spectrum on *Facebook*
Connor – Actuallyautistic on *Tumblr*
Cordelia – Actuallyautistic on *Tumblr*
Corey – Actuallyautistic on *Twitter*
Dani – Group for adults on the autism spectrum on *Facebook* and AAW
Daniella – AAW
Detta – Actuallyautistic on *Tumblr*
Duck_nukem – Actuallyautistic on *Tumblr*
Dustin – North, Mid, and South County groups
Fabby – Actuallyautistic on *Tumblr*
Farahumakemelol – Actuallyautistic on *Tumblr*
Fatimah – Actuallyautistic on *Tumblr*
Foilstartzzz27 – Actuallyautistic on *Tumblr*
franticpanda – Actuallyautistic on T*umblr*
Fresher-than-ur-mom – Actuallyautistic on *Tumblr*
Herewegoagain82 – Actuallyautistic on *Tumblr*
Ittybittyautiebon – Actuallyautistic on *Tumblr*
Jazz – Mid County group and its women's branch
Jem – AAW, Actuallyautistic on *Tumblr*
Kassya – Actuallyautistic on *Twitter*
Kayla – Group for adults on the autism spectrum on *Facebook* and actuallyautistic on *Tumblr*
Kelly-Ann – Group for adults on the autism spectrum on *Facebook*
Kyla – Mid County group and its women's branch
Kyle – South County group
Lanny – Actuallyautistic on *Twitter*
Lei – Mid County group and its women's group
Len – Actuallyautistic on *Tumblr*
Lindsay – Group for adults on the autism spectrum on *Facebook*
Maple – AAW
Matt – North County group
Morgan – Group for adults on the autism spectrum on *Facebook*
Myles – North County group
Ned – Mid County group
Pamela – Autism Society Conference (2016)
Roland – Southern CA Autistic Activists (SCAA) (now non-operational)
Sam – Mid County group
Santa – Actuallyautistic on *Tumblr*

Saul – Actuallyautistic on *Tumblr*
Seva – Actuallyautistic on *Tumblr*
Stephen – Group for adults on the autism spectrum on *Facebook*
Steven – North County group
Tomas – Actuallyautistic on both *Twitter* and *Tumblr*
Trevor – Mid County group
Vic - Group for adults on the autism spectrum on *Facebook* and AAW
Zippy – Actuallyautistic on *Tumblr*

APPENDIX B: GLOSSARY

AAW – The Association of Autistic Women, a non-profit status self-advocacy organization for women and gender minorities on the autism spectrum.

Actuallyautistic – A hashtag that my interlocutors on Tumblr and Twitter used to identify themselves as autistic people and engage together in a hypertext space where they could share text-based content and other kinds of media.

Allistic – A person who is non-autistic. Note that an allistic person is not necessarily a neurotypical person.

ASAN – The Autistic Self-Advocacy Network, arguably the most popular and successful non-profit status self-advocacy organization for people on the autism spectrum.

Asperger's Syndrome – A now-obsolete diagnostic classification for a neurodevelopmental disability that was included, alongside autistic disorder, Rett syndrome, pervasive developmental disorder not otherwise specified, and childhood disintegrative disorder, under the umbrella category of pervasive developmental disorders.

Aspergian – A self-identification term that people who were professionally and self-diagnosed with Asperger's syndrome sometimes use.

Aspie – A self-identification term that people who were professionally and self-diagnosed with Asperger's syndrome sometimes use.

Autie – A self-identification term that people who were professionally and self-diagnosed with autism spectrum disorder (or any of the now-obsolete classifications under the pervasive developmental disorders umbrella) sometimes use.

Autism community – The collection of groups, networks, and organizations, both offline and online that includes people on the autism spectrum and their families, caregivers, medical professionals, teachers, researchers, and others who have vested interests in matters related to autism and autistic people.

Autism Spectrum Disorder – The singular diagnostic classification that, as of 2013, replaces the pervasive developmental disorder umbrella category of disorders, which included autistic disorder, Asperger's Syndrome, childhood disintegrative disorder, Rett syndrome, and Pervasive developmental disorder not otherwise specified.

Autistic – A self-identification term that people who were professionally and self-diagnosed with autism spectrum disorder (or any of the now-obsolete classifications under the pervasive developmental disorders umbrella) sometimes use. Many people who use this term to describe themselves refuse to call themselves people *with* autism, believing that this separates autism from the person rather than viewing it as an integral part of their being.

Autistic activism – My interlocutors generally used this interchangeably with autistic self-advocacy. It described activities that autistic people engaged in to bring positive attention to autistic people, while directly or indirectly counterbalancing negative, stereotypical representations. This could be done in everyday life or through social and political action. By and large, my interlocutors, took steps in their everyday lives to try to shift negative perceptions of autism and autistic people.

Autistic community – The collection of groups, networks, and organizations, both offline and online, that includes professionally and self-diagnosed autistic people.

Autistic Disorder – A now-obsolete diagnostic classification for a neurodevelopmental disability that was included, alongside Rett syndrome, Asperger's Syndrome, pervasive developmental disorder not otherwise specified, and childhood disintegrative disorder, under the umbrella category of pervasive developmental disorders.

Autistic self-advocacy – My interlocutors generally used this interchangeably with autistic activism. It described activities that autistic people engaged in to bring positive attention to autistic people, while directly or indirectly counterbalancing negative, stereotypical representations. This could be done in everyday life or through social and political action. By and large, my interlocutors, took steps in their everyday lives to try to shift negative perceptions of autism and autistic people.

Diagnostic and Statistical Manual of Mental Disorders – The well-known classification system for mental disorders that is published by the American Psychiatric Association. It is used by psychologists, therapists, and physicians to diagnose a wide range of psychological and neurochemical "mental disorders." The manual is regularly reviewed and revised by the APA. These revisions may involve the revision of outmoded diagnostic criteria as well as the dissolution of classifications and categories of disorder.

Facebook – A major social networking site

Followers – People who have subscribed to content published and circulated by a social networking or social media platform user. On Tumblr and Twitter, platform users can see and interact with followers of their content. A person who chooses to follow a user on either of these sites would see that user's new content appear on their dashboard, which collects these real-time updates.

Google Chat – A piece of software that I used to connect with my interlocutors. Usually, this was a preferred way of communicating because it allowed for text-based chatting. This was often preferred over voice and video chatting options.

GIF – Graphics Interchange Format. Can be used for very short animations and clips from larger video files.

Hypertext space – a space entered through a hypertext or hypermedia portal. The hypertext is a code that users of a social media or social networking platform might use to mark their content for a target audience. When many people mark their targeted content in the same way, people might become familiar with the content producers and consumers who use the code regularly.

Like – This is an important way that my interlocutors on *Tumblr*, *Twitter*, and *Facebook* expressed their approval and/or acknowledgement of other users' content.

Neurodiverse – a central assumption of the neurodiversity movement is that there is enormous diversity in neurological and social capacities, preferences, and developmental trajectories. People who have been diagnosed with labels that presume dysfunctional neurology and sociality may identify as being "neurodiverse" or "neurodivergent." This is set in opposition to being neurotypical.

Neurotypical – A person who has no known psychological, nervous system, or developmental abnormalities or challenges.

Official diagnosis – Also referred to ask professional diagnosis. Receiving an official diagnosis meant that the autism label was given by a licensed medical practitioner. This was most often set opposite self-diagnosis, which involved the unlicensed individual studying and coming to the determination that they were autistic. Peer confirmation of this determination was often part of the self-diagnosis process.

Pervasive Developmental Disorder (PDD) – The now-obsolete umbrella category that included five distinct psychiatric classifications: autistic disorder, Asperger's Syndrome, Rett syndrome, childhood disintegrative disorder, and pervasive developmental disability not otherwise specified. This category of disorders was used to justify the notion of a spectrum of autism disorders. In the 2013 revisions to the *DSM*, the category and its five classifications were effectively decommissioned and replaced with the singular autism spectrum disorder classification.

Reblog – A way in which my interlocutors on the *Tumblr* platform circulated content from other users.

Retweet – A way in which my interlocutors on the *Twitter* platform circulated content from other users on the site.

Self-dx – Self-diagnosis. This involved the unlicensed individual studying and coming to the determination that they were autistic. Peer confirmation of this determination was often part of the self-diagnosis process. This was most often seen as the opposite of an official diagnosis, which meant that the autism label was given by a licensed medical practitioner.

Skype – a piece of software and an application that allows people to communicate over the internet using voice, text, and/or video.

Stim/stimming – self-stimulatory or self-soothing behavior. A hallmark trait of autism spectrum disorder and other conditions. Though there are many ways that stimming might manifest, some expressions include hand flapping, tapping, spinning, humming, body rocking, pacing, and swaying.

Tumblr – A short-form blogging platform that emphasizes visual content and short text posts. Though it is geared toward short-form blogging, the social media platform does accommodate long form blogging. The site is largely hypertext or hashtag driven. Users regularly use tags to reach their target audiences.

Twitter – A micro-blogging platform that emphasizes very short text posts (now under 280 characters) and visual content and short text posts. The site is largely hypertext or hashtag driven. Users regularly use tags to reach their target audiences.