



## **#ActuallyAutistic: Using Twitter to Construct Individual and Collective Identity Narratives**

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*ABSTRACT* Employing *Critical Autism Studies and Narrative Analysis*, this project examines how autistic Twitter users engage in narrative meaning-making through social media. By analyzing the hashtags #ActuallyAutistic and #AskingAutistics this project broadly explores how individuals construct identity when lacking access to positive representations and identity communities. Answering the research question, “How do autistic people construct individual and collective identity narratives through Twitter?,” findings indicate that autistic Twitter users use their social media presence to build virtual learning communities. Common knowledge about autism is often oversimplified and highly medicalized. Therefore, autistics use Twitter to make meaning of their experiences that are not represented within cultural notions of what it means to be autistic. Autistic Twitter users reject medicalized narratives by contesting stereotypes, flipping negative narratives into positive stories, re-inscribing “deficiencies” as beneficial, and resisting rehabilitation and “cure.” Users do important social activist work by building strong autistic communities in ways that counter current negative representation, constructing positive self-affirming individual and community identities and resisting eugenic notions that autistic people are “less valuable.”

**KEYWORDS** autism; neurodiversity; critical autism studies; Twitter

### **Introduction**

Employing *Critical Autism Studies (CAS)* and *Narrative Analysis*, this project examines how autistic Twitter users engage in narrative meaning-making through social media. By analyzing the hashtags #ActuallyAutistic and #AskingAutistics this project broadly explores how individuals construct identity when they lack access to positive representations and identity

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communities. Specifically, I examine how autistic people use Twitter to engage in community and identity building.<sup>1</sup>

The idea for this project was born out of my work examining the community building of autistic and neurodivergent queer people in online blogs through the development of the politic neuroqueer. In this (once) small corner of the internet resides a group of self-advocates, activists, and academics engaging in dialogues and dreaming up non-medicalized ways of being neurodivergent. Through this project, I came to the realization that my personal identity as an autistic person was almost entirely shaped by the interactions I have had with medical professionals, therapists, teachers, and the few other grade school students in the special education program I attended in rural Pennsylvania. I had no peers in my identity community when I was a child and I have none now as an adult. Yet, I was sure that I had an understanding of my autistic identity, that I knew many other autistics, and that I was a part of a community. I realized almost every interaction I experienced with other autistic people was in the virtual world. With the development of social media, seemingly overnight, a vibrant and active community of autistic people was gaining ground in virtual spaces, on blogs and LiveJournals, on Tumblr, Facebook, Instagram, Twitter, and now TikTok. From a quick glance at my social media news feeds #ActuallyAutistic people were everywhere.

Yet away from social media it was as if autistics didn't exist. They didn't in other forms of media, outside of one-dimensional, medicalized portrayals and the occasional depiction of an autistic savant, and not visibly in our daily lives. While there are some gathering places for autistic people outside of the virtual world, there aren't many.<sup>2</sup> Like most people with disabilities, we are likely born into families of all able-bodyminded or allistic people.<sup>3</sup> We rarely have a vertical identity group (or what Goffman (1963) described as tribal identity) from which to learn and build connections. Similarly, it is difficult for autistics to build horizontal community or communities made up of peer groups. We can't join an autistic club on a college campus or hop down to the autistic bar to meet up with friends. So, I came to the question: How do autistic people, who lack positive media representation and rarely have cohort communities, construct individual and collective identity narratives? By examining social media data this paper explores one component of this

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<sup>1</sup> Reflexivity statement: As a queer autistic scholar, I believe my work should be emancipatory in focus and I wish to bring academic attention to the way disabled and autistic people resist

<sup>2</sup> While such groups do exist in larger cities and the occasional college town, they are almost entirely non-existent in rural spaces, are a challenge to find, and are often framed in terms of support groups.

<sup>3</sup> Inspired by O'Toole (2015) and Price (2015), I use the term "bodymind" to refer to bodies and minds collectively as a rejection of the Cartesian mind/body split that situates bodies and minds as separate and/or oppositional. Able-bodyminded refers to the experience of not being disabled. Allistic is a common term for people who are not autistic. Allistics can be neurodivergent or neurotypical.

guiding question and attends to the specific research question: How do autistic people construct individual and collective identity narratives through Twitter? To attend to this question, I begin by situating this work within both CAS and Narrative Analysis and highlight the importance of self-narrated accounts.

### **Critical Autism Studies**

Much of what is socially and culturally understood as autism is constructed from the perspective of health professionals, therapists, and parents who frequently unintentionally or explicitly rely on deficit-based models of autism (Barnett, 2014; Woods et al., 2018). Narratives of autistic personhood are often oversimplified, highly medicalized, and view autism as a series of deficits (O'Dell et al., 2016; Woods et al., 2018). It is imperative to provide scholarly examinations of autistic experiences through lenses that challenge stigmatizing and overly medicalized depictions of autistic people. This paper uses Critical Autism Studies (CAS) to examine autistic peoples' self-narrated experiences via the social media site Twitter.

CAS is a rapidly emerging field, developing out of the Neurodiversity movement, and describes a body of work produced mostly by contemporary autistic scholars who are exploring social, historical, and cultural considerations of autistic identity and experience (Waltz, 2014; Woods et al., 2018). Beginning in the late 1990s neurodiversity activists began publicly calling for the de-pathologization of autism, rejecting medical definitions which highlight deficiency (Shapira & Granek, 2019). Neurodiversity is a politic that recognizes the diversity of human neurology, in which neurodivergence is understood as natural human variation not to be devaluated (Silberman, 2017). Neurodivergence refers to deviations from neurotypicality, while neurodivergent references those who identify as non-neurotypical (Strand, 2017). CAS scholars “investigat[e] power dynamics that operate in discourses around autism, questioning deficit-based definitions of autism, and [are] willing to consider the ways in which biology and culture intersect to produce ‘disability’” (Waltz, 2014, p. 1337). This group of interdisciplinary researchers examines medicalization of autism, construction of autistic identity and community, disability rights, and autism as a site of structural inequality (Woods et al., 2018). Over the last decade, critical approaches to autism have resulted in the expansion of autism research led by autistic researchers or partnered with autistic participants, such as work in participatory research (see Fletcher-Watson et al., 2019; Jivraj et al., 2014; MacLeod, 2019; Nicolaidis et al., 2011). Here, I employ CAS to explore autistic community and identity through self-storying.

## **Narratives**

Narratives are culturally recognizable stories embedded with cultural, symbolic, and emotion codes that contribute to the construction of personal, organizational, and institutional meaning and identities (Loseke, 2007, 2009). They can be powerful resources for making sense of the self and others (Loseke, 2011; Melucci, 1995). When narratives are evaluated as believable and important, they can be successful at acquiring societal support. Narratives about marginalized groups that do not conform to cultural expectations that rely on stereotypes frequently receive little public support because they are not culturally recognizable (Egner, 2019). Narratives rely on various systems of meaning based on “local cultures” (Holstein & Gubrium, 2000), and “emotion cultures” (Mesquita & Walker, 2003). Systems of meaning are changeable, locally and historically situated, and there is no absolute universal interpretation (Stearns & Stearns, 1985). Both storytellers and listeners are active participants that can resist, create, and alter cultural meaning systems and narratives (Atkinson, 2006; Loseke, 2018). Identity-based groups seeking to change stereotypical depictions must create new self-stories that challenge dominant depictions and stock stories through the employment of resistance narratives that oppose or reject dominant cultural codes and ideology (Atkinson, 2006). New stories provide the possibility to construct alternative and positive “self-stories” and community culture through the creation of multidimensional and positive identity narratives. The social media users examined here are contesting established narratives about autistic people and building community narratives by co-creating community and individual narratives.

### *The Importance of Self-narrated Accounts*

Autistic voices, thoughts, and feelings are often excluded from scholarship and frequently dismissed within activist spaces in favor of family and medical-led discourses (Barnett, 2014; Egner, 2019b). While work on autism from both autistic scholars and from the perspective of autistic participants has become more common, the vast majority of research is conducted by non-autistic scholars and frequently relies on the perspectives of teachers, educators, therapists, and family members rather than of autistic individuals themselves. Medical and deficiency-based discourses permeate even “inclusive” activist and academic work (Egner 2017, 2019b). However, CAS scholarship works both to highlight the perspectives of autistic people and reject academic and cultural pathologizing of autism.

Some recent scholarship has focused on social media to examine autistic people’s self-storying, identity, and experiences (see Benham, 2015; Egner, 2019b; Karusala et al., 2019; Welch et al., 2020a, 2020b; Zolyomi et al., 2020). Welch et al. (2020a, 2020b) uses blog data, and both Benham (2015)

and Zolyomi et al. (2020) use Twitter data to elucidate autistic social media users' construction of identity narratives through the rejection of stigmatizing, medicalized, and negative framings of autism. Similarly, I found (Egner, 2019a) that neuroqueer social media users resist their exclusion from autism narratives and want their voices to be forefronted. This project works to foreground the perspectives of autistic social media users by highlighting their activity on Twitter as both activist work and academically relevant. Self-narrated accounts in research are especially important when examining emerging and marginalized communities as they have the ability to challenge dominant group power, reject oppressive discourses and promote self and community reliance (Bradford & Clark, 2011, p. 180).

Narratives present in media help make sense of our experiences, identities, and how we understand the world. Today, we are not lacking narratives about disability and there is certainly autistic representation in media. Indeed, 2017 was coined the “year of autism inspired TV” (Hickman, 2017). However, disabled and autistic people are often tokenized, stereotyped, and oversimplified (Egner, 2019a; Hevey, 1993). One need look no further than their own Netflix queue to see examples; hit TV shows such as *Parenthood* and early seasons of *The Good Doctor* and *Atypical* portray autistic people as undesirable, emotionally stunted, or difficult to love (notably, they are almost always depicted as white boys or men). A lack of positive representation contributes to exclusion, stigmatization, invisibility and oppressive stereotyping (Dahl, 1993; Hartnett, 2000). Through self-narratives, communities construct individual and community identity, make claims about their oppression, and advocate for social change (Bradford & Clark, 2011; Loseke, 2007; Melucci, 1995; Polletta, 1998a, 1998b).

Autistic people lack positive, nuanced and accurate representation, and are therefore either excluded from popular narratives and representation or they are frequently inundated with stories of stereotypical representation that reinforces stigmatization, thus rendering accurate portrayals invisible and inaccessible. Both stereotypical depictions and a lack of representation of specific (often marginalized) identity implies that autistic identities should be hidden, overcome, changed, and avoided. As the majority of academic research, activist work, and media representation tend to ignore the perspectives of autistic people and rely on deficiency-based models, it is imperative that we examine autistic self-narratives (Gillespie-Lynch et al., 2017).

## **Methodology**

Disabled and autistic people's perspectives have been historically and culturally silenced (Barnett, 2014; Egner, 2019a; Yergeau, 2018). Using social media to examine personal narratives allows researchers to explore the thoughts, ideas, and feelings of autistic communities that have been

historically ignored. Online media platforms are also particularly useful in addressing disability and autistic experiences, as digital technologies are able to relieve some communication barriers that are often present in face-to-face communication (although they do present their own communication challenges) (Egner, 2019b). Drawing on feminist disability research methodology (Garland-Thomson, 2005), research involving disabled people who often experience marginalization should be emancipatory. The purpose of this project is to highlight a group of self-advocates and bring further attention to their creative work. My objective is not to coopt and authoritatively interpret their stories, but rather to bring mainstream academic attention to their important perspectives. Moreover, as an autistic scholar, I have a personal investment in the perspectives of autistic social media users and I wish to bring academic attention to the way autistic people resist deficit-based medical models of disability and construct positive self-stories through virtual community building.

### *Data Collection*

I collected data through periodical data scrapes (at two-week intervals) of Twitter, using qualitative data collection and analysis software NVivo 12, between August 2019 and December 2020. Twitter is a social network platform in which users connect via quick, short (maximum 280 characters), and frequent communications or micro-blogging called tweets. Twitter users have a profile page they can update with information about themselves and they connect with others via their feed/timeline. The timeline displays the tweets of the users one follows as well as the tweets they like. Users can retweet others' posts, retweet and add their own content, comment on tweets, and like tweets. They can search and save hashtags so that they are able to follow specific topical conversations. Using NVivo, I searched the hashtags #ActuallyAutistic and #AskingAutistics and downloaded every public original tweet and retweet as a data file to be examined within the software program. Each data scrape of these two hashtags together amounted to between 10,000 and 20,000 tweets and retweets.

I am interested in how autistic people use social media to build collective narratives. Therefore, I applied virtual ethnographic methods (such as following field connections to examine user interactions) in order to gain a more complete picture of the data. By following field connections (Hine, 2000) of particularly popular and relevant tweets that used the above hashtags, I downloaded sets of comments on tweets as individual data files. Virtual ethnographic methods treat the internet as both culture and cultural artifact, thus it is particularly valuable in examining the way the internet is socially meaningful (Hine, 2000).

The data examined here is entirely open access, none of the accounts referenced are private, and tweets were visible without a Twitter account.

Many of the autistic Twitter users referenced in this paper are autistic advocates, activists, and scholars with highly public Twitter presences. As such, and because I believe that the work of these Twitter users deserves recognition and understand that citation can be a powerful tool in deciding what knowledge is valuable,<sup>4</sup> I do not provide pseudonyms for the quoted material throughout this paper and refer to the majority of Twitter users by their Twitter name or handle. Many of the users employing these hashtags make a living from their social media presence and many of them are activists or academics using Twitter to author, promote, and disseminate their work; they deserve credit for their ideas and thoughts. If, however, their Twitter presence appears to only be personal (and not used for activist, academic, or professional work) I have not included their handles, and if the tweet was easily searchable I only paraphrase, consistent with many recent academic conversations about the ethics of using publicly available social media data (Benton et al., 2017; O’Callaghan & Douglass, 2021; Townsend & Wallace, 2017; Williams et al., 2017). From my perspective, to quote or paraphrase the work of autistic activists and authors without providing proper citation could be unethical, and therefore I make a distinction between public profiles and personal profiles by examining follower counts, number of retweets and likes, and profile statements. This project was approved by my institutional internal review board. There is a short history of academic manuscripts citing the social media work of activists and scholars (Brown et al., 2017; Cole, 2021; Egner, 2019a). Williams et al. (2017) argues that scholars should contend with the ethical considerations of the use of data from Twitter in ways that consider users’ expectations and behaviors. Since the majority of users referenced here use Twitter to disseminate their work, I promote and give credit. I argue that academic audiences should engage with the work that scholars and activists are producing on social media in their own right (not just with the academics who reference them) (Egner, 2019a).

### *Data Analysis*

This paper utilizes virtual data collection methods in combination with Narrative Analysis, practicing Loseke’s (2012) approach to analyzing formula stories. The data in this article are treated not as inanimate texts, but rather as interactional, cultural resources artfully employed by Twitter users. Although narratives are often skillfully employed by individuals, they shouldn’t be oversimplified as only personal stories. Narratives are “simultaneously about the personal, the social, and the cultural” and they inform and are informed by private life, “public social processes, social forces and societal institutions” (Loseke, 2019, p. 85). This methodological

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<sup>4</sup> Moreover, American Psychological Association, American Sociological Association, and Modern Language Association style guides all require the in-text citing of tweets.

approach requires the researcher to begin the analysis by situating the contexts of stories via asking reflective questions and considering the authors, claims, and audiences (Geiss & Egner, 2021; Loseke, 2012). After compiling all the data into NVivo for analysis I began by asking: Who are the authors? Who is their audience? What type of story are they attempting to tell? I then examined the common and prevalent narratives to gain an understanding of the central themes of the stories. I took note of the particularly popular tweets to better understand what narratives are evaluated as important by the social media users. In subsequent passes, I re-coded, using lumping and splitting techniques (Zerubavel, 1996) to begin generating common thematic categories. I used these categories and codes to pull out the narratives that were common across all the tweets from different social media users. The final step of this analysis was to systematically analyze the symbolic codes (cultural ways of thinking) and emotion codes (cultural ways of feeling) embedded in the data (Loseke, 2012) by asking further guiding questions, such as: What knowledge about the world does this statement assume? What would I need to believe about the world for this statement to be believable and important? What specific values are being reflected/transmitted (Loseke, 2012, p. 262)?

A Narrative Analysis of Twitter is especially useful as comments, liking, and retweeting allows a researcher to examine what narratives are evaluated as valuable and taken up by a specific community (Egner, 2019a, 2019b). Recent scholarship has utilized virtual methodology to explore narratives in the digital world (Busby & Laviolette, 2006; Geiss, 2019; Underberg & Zorn, 2013), and I have recently examined how narratives are constructed, employed, modified, and imparted in virtual spaces (Egner, 2019a, 2019b, 2019c, Geiss & Egner 2021).

## **Findings**

Most narratives and media representations about living life as an autistic person are oversimplified, highly medicalized, rely on stereotypical depictions, and present autism as a series of deficits. Autistic people are thus using Twitter to try to make meaning of their experiences that are not represented within these very medicalized notions of what it means to be autistic by establishing virtual learning communities. The findings section below will begin with a brief analysis of how autistic social media users utilize Twitter to establish learning communities. The remainder of this section will address five narrative tactics autistic Twitter users employ to reject medicalized inaccurate depictions and construct new self and community affirming resistance narratives.

### *Establishing a Virtual Learning Community*

Autistic social media users utilize Twitter to build virtual learning communities in which they collectively recognize the lack of representative and relatable circulating stories that accurately depict their experiences in recognizable ways. Throughout the data there were hundreds of posts from autistic authors criticizing and discussing poor and stereotypical representation. For example, users expressed frustration and anger with the portrayal of autistic girls in musician Sia's recent movie project and her response to autistic self-advocates criticizing these portrayals via Twitter. Notably, in this set of tweets ChiariChey (an activist writer with over 5,000 followers working at the intersection of disability and race) describes how stereotypical portrayals of autism can have real life implications for autistic people.

Why is Sia still talking? Why? We're still being compared to a man from a movie that came out before I was even born & he wasn't even #ActuallyAutistic!... It's wrong af and you don't get why. #SiaStop #SiaDoesntSpeakForUs... Now a whole generation of nonspeaking girls will hear ignorant bull for the rest of their lives just like we still hear Rainman. (Nov. 27 2020)

ChiariChey elucidates what many scholars of narrative have explained: culturally recognizable stories (however inaccurate) can have severe implications for personal identity construction as narratives are our most powerful resource for making sense of the self and others (Atkinson, 2006; Egner, 2019b; Loseke, 2011, 2017; Melucci, 1995).

In response to these inaccurate depictions, autistic people turn to Twitter to build a virtual learning community in which they collectively write new resistance narratives. They employ common community hashtags as valuable communication tools to purposefully interact with and learn from other autistics. As Autistic Architect explains in a tweet: "The #ActuallyAutistic tag means that the person writing the tweet is actually autistic. It's how we identify each other. Also #AllAutistics. The #AskingAutistics tag will bring replies from the #ActuallyAutistic community" (Sept. 22, 2020). Users engage with these hashtags to construct self-understanding and self-identity that they are not able to build within established medicalized and cultural narratives about autism. This is evident when one Twitter user explains:

Navigating the #ActuallyAutistic community has taken me to my lowest ebb And it's also taken me to my highest. Because it's been a self-awareness & education my diagnosis didn't give & no amount of research can offer I can honestly say I'm thriving Thanks to meetin[g] all of you.

As there are few in-person communities of autistic people and the majority of information about what it means to be autistic relies on deficit-based models,

social media users turn to Twitter. In doing so, they are constructing a virtual community and establishing identity narratives.

### *Rejecting Medicalized Cultural Narratives*

Autistic Twitter users reject current cultural narratives of autistic personhood (often embedded with medicalized and stereotypical notions) by employing five resistance strategies: (1) building autistic identity beyond medical conceptions, (2) recognizing shared experiences of marginalization, (3) debunking stereotypes, (4) flipping both negative stereotypes and pathologized evaluations of their “deficiencies” into positive self-stories, and (5) contesting medicalized perspectives that autistic bodyminds should be cured, rehabilitated, and avoided.

*Building Autistic Identity Beyond Medical Conceptions.* First, autistic Twitter users utilized the hashtags #ActuallyAutistic and #AskingAutistics to connect with other autistics and relate their experiences to each other outside of and beyond medical conceptions of what it means to be autistic. There were many tweets in this dataset in which users shared and asked other users to share how they understand, perceive, and make sense of a variety of different experiences related to their identity. Autism Health and Wellbeing (an autistic activist Twitter account centered on wellbeing) explains that they love stimming and autistic movements as well as asks how other autistic hashtag users understand autistic wellbeing.<sup>5</sup> They write in a thread:

...I am #AutisticWhileBlack (with some added sprinkles) & love to wiggle!  
 ...Some of the things that I am a nerd for are stimming/expression/movement & general beingness (especially autistic beingness). If you're interested in seeing what some of that looks like you can check out: Dancing Is Existing, & Something that I have been curious to know since I joined this blog... if anyone reading would be so kind to help me explore, is: As an autistic, what does wellbeing mean to you? (Dec. 1, 2020)

Users like the account referenced above are perception-checking their own experiences with other autistics, recognizing that they experience the world differently than allistics and use Twitter as a place to explore what these differences look like and what it means to be autistic (outside of deficit-based models). They are establishing, confirming, and reaffirming autistic self and collective identity. This is evident when one autistic user asks “Do any other #ActuallyAutistic folk sometimes have such intense emotions that it overwhelms you in a very problematic way? #AskingAutistics cause I made a friend recently but I am now an absolute mess. Any suggestions on...

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<sup>5</sup> Stimming refers to self-stimulating behaviors such as repetitive movements or noises.

managing this?” Commentors on this tweet reaffirmed this experience and shared advice on how they navigate similar situations. Commentor RoseMCarreiro (an autistic and mental health advocate with over 3,000 followers) states “Me. I try to figure out what exactly is stressing me out and try to find solutions to remove or decreasing the trigger.” Another user confirms that they experience this too and encourages others to recognize that just because feelings are *different* doesn’t make them *wrong*.

Importantly, these narratives extend well beyond diagnosis criteria and common medical and cultural conceptions of autism. Users frequently employed these hashtags to describe their perception of, or feelings associated with, an experience that they viewed as uniquely autistic (or mostly unique to autistics). This is evident when ChairyChey writes about (what they refer to as) autistic scripting:

#ActuallyAutistic scripting: Coming up with every question and answer relevant to a situation that could possibly be asked at any point in time, although it may never be... ever. I’ll probably forget the most important ones & still end up looking like an unprepared failure tho.

Commentors affirmed this, explaining that they do it “outloud” and “with different tones.” ChairyChey and some commentors expressed that, through Twitter interactions, they have realized that this might be part of being autistic. ChairyChey responds “yes! I’m reading these like ‘It’s not just meeee???’ Like I know we all script, but I have a whole play in my head with every scenario possible lmao.”

Because the majority of medical and therapeutic advice about problems many autistics experience are embedded with negative evaluations of autism and are almost entirely constructed by non-autistics, users turn to Twitter to help name and recognize what they are going through and get advice from fellow autistics in how to manage a variety of concerns and situations (such as responding and dealing with over-stimulation, coming out as autistic, negative comments from peers or family, and experiencing meltdowns) in non-medicalized ways. Lilrariah – an autistic activist with over 21K followers who advocates specifically for the recognition of autistics who are Black, Indigenous, people of color – writes in a thread:

I realize that I (still) have a really limited understanding of meltdowns, as I’ve seen a few examples over this past month or so of meltdowns being prolonged (full day?) events. For my body, when I think of meltdowns, I think of what is essentially a seizure. Can people help me understand how this can differ for their bodies? (Nov. 30. 2020)

In turning to other autistics for advice users are not (or not *just*) reaching out to “experts” on autism (such as healthcare providers, therapists, educators, and allistic family members) for help. It is likely that the day-to-day experiences of being autistic and what it means socially to identify as such

are not part of medicalized communications and prominent cultural narratives. For instance, there are dozens of tweets with long comment threads detailing stories of autistic meltdowns, indicating that what it actually feels like and means to experience an autistic meltdown is not communicated by “experts” nor are recognizable stories of meltdowns present in dominant narratives. These conversations suggest that autistic people utilize Twitter to construct these narratives for and with each other outside of medicalization.

*Autistic Identity as Shared Marginalization.* The second tactic autistic Twitter users employ is the use of these hashtags to story their identities through common experiences of stigmatization and oppression. Many posts detailed the ways in which societal and medical understandings of autism, autistic behaviors, and autistic communication devalue autistic people, rely on negative evaluations of autism, and contribute to marginalization of autistic people. Autistic Twitter users commiserate together and cast the “problem” of autism as societal prejudice rather than individual inability or lack. This is illustrated when AntiLeven writes,

People tell me I just like to label myself. To that I always say: ‘Society has labeled all kinds of inaccurate negative labels on me, long before I did anything. Now I have an accurate positive label. It’s society’s labels that are the problem, not my actual label.’ (Nov. 28, 2020)

Cultural narratives about autism portray autistic people as insensitive, as lacking an ability to understand and communicate with others, as rude, as unable to pick up on jokes or as lacking sense of humor, among a variety of other misconceptions. These conceptions of autism ask autistic people to change, hide, and “overcome” their autistic behaviors. When autistic Twitter users tell their stories of stigmatization, they construct their experiences as valid and valuable and resist both stereotypical portrayals of autism and the notion that autistic people should change. This is evident when Hopper (an autistic activist) depicts neurotypicals (opposed to autistics) as insensitive: “The three primary types of neurotypicals: 1. The ones that are demeaning cause I’m different. 2. The ones that tell me I’m not different. 3. The ones that do both simultaneously.” This is further elucidated in the following exchange between AutisticWookiee and commenters as they provide positive self-stories:

*AutisticWookiee:* Since “coming out” as #ActuallyAutistic at work people send me details of learning events about autism (this weeks favourite is “reasonable adjustments & practical support for People Living With Autism”). What’s an NT approved way of pointing out it’s not me that needs training?

*Beautidivergence:* It’s so cute when they think they can educate us on Autism. Just tell them you’ve been put through a complete, immersive experience, that is the best available training in the world.

*Autistic wookiee:* And that I am in fact one of those “persons” therefore they could try doing something radical like... just listening to me! Save the course fee and believe people who live it daily!

*SparkleClass:* I often use deliberate misunderstanding with NTs, especially when they send me info with no bloody context or action. “Thank you for this, is this something you’re planning to attend or are you asking me if it’s suitable for your needs?”

*Debunking Stereotypes.* Third, autistic Twitter users employ these hashtags to combat stereotypical representations and beliefs about autism. Extremely common threads (like the following) work to educate readers about what “it is really like to be autistic.” Commafficionado (an autistic writer with over 47K followers) asks “Autism mythbusters - let’s get rid of some of those incorrect stereotypes. Please share - educate folk today!” (Nov. 30. 2020). Commafficionado follows up with their own thread of examples of debunking stereotypes, such as: “Autistic people can have friends... Perhaps a smaller number? Maybe, but not necessarily.” This post had 27 replies, over 600 retweets, and over 900 likes. Kinkybaron rejects more stereotypes in a thread of replies containing a list of things that *can* be true of autistics:

Autistic people can be the most sarcastic, jokey people and often are the life of the party when around people who the[y] are comfortable with in social settings we can understand... Autistic people think of “communication” as more than just speech. For most of us, our idea of communication is actually very broad and considers many other forms of communication that Allistics often overlook... Autistic people make amazing friends. We are deeply loyal, fair, empathetic, open, honest, compassionate, accepting, and consistent.

*Flipping Negative Narratives into Positive Stories.* Fourth, many Twitter users utilized these hashtags to flip negative narratives into positive stories, by re-inscribing “deficits” as beneficial. For instance, autistics are often criticized for lacking “good” communication skills (they’re often deemed tactless or too blunt), and Irisdyoung describes autistic styles of communication as preferable when they write, “I find it so much easier and more comfortable to communicate with autistic people on average. I like communicating directly and literally, and I prefer writing over speaking.” In another example of citing the cultural problems of autism and reframing them as positive another user writes, “so many allistic people insist on framing autistic traits in negative ways. Even when they clearly recognise something in us that they can’t pass off as terrible, they still force negative connotations onto it.” They continue with a thread of examples in which they reframe behaviors that are often evaluated as problems into skills and advantages:

People will sometimes acknowledge that autistics often like order and routine, but they’ll call it ‘a lack of imagination’ and ‘rigid thinking’ and try to force us to be

‘more creative’ (as though no art was never made of neat lines, as though poetry is never structured)... Here’s an idea: autistics are great at finding patterns in a chaotic world, and we’re great at creating them! You don’t need to pressure us to think like you, and we can’t do that anyway, ‘cause we’re us!..., People will sometimes acknowledge that autistics can spend a lot of time thinking, but they’ll call it ‘being slow’ (or worse, the R word) or ‘self-absorption’ or ‘refusal to engage socially,’ and try to force us to spend less time thinking and more time talking... Here’s an idea: autistic people are largely introspective, and maybe the world would be better if everyone spen[t] a bit more time thinking and a bit less time talking.

In reframing autistic associated behaviors that are culturally devalued and deemed problematic into positive stories and advantageous skills, autistic Twitter users are contributing to the construction of more recognizable individual and collective autistic identity narratives. I want to be clear here that autistic Twitter users are not employing these script-flipping tools in ways that resemble inspiration porn.<sup>6</sup> They do not position their skills as a way to “overcome” autistic behaviors nor do they cast themselves as autistic savants (so often depicted in popular media). Rather, they are self-narrating complex, multifaceted, recognizable, and relatable positive stories of autistic personhood.

*Rejecting and Providing Alternative Narratives to Cure.* Fifth, users resist medicalized narratives by rejecting notions of rehabilitation and cure. Medical model conceptions, that are deeply embedded in our cultural beliefs, understand disabled bodyminds as problems that need fixing and therefore employ tactics to force disabled people to conform to normative expectations of bodies, behaviors, and practices (Berger, 2013; Conrad & Barker, 2010; Egner, 2017; Oliver & Barnes, 2012). The autistic Twitter users referenced here reject the idea that autistic behaviors and bodyminds, frequently understood as deviant, are an individual problem in need of fixing. Rather, they recognize that the problem is located within cultural and medicalized narratives that devalue bodily and mental diversity. In other words, autistic social media users are doing important social movement work by resisting eugenic notions that autistic people are “less valuable” (Stoll & Egner, 2021) and by contesting normalizing narratives that perpetuate destructive medical model discourses of cure. For example, stimming is a common autistic behavior that has been highly medicalized and stigmatized and is often recognized by many medical professionals, educators, and family members as a problem in need of fixing. Autistics are frequently encouraged or taught not to stim. Many posts focused on stimming as a natural behavior with a variety of benefits. In one tweet NeuroRebel (an autistic writer, public speaker, and educator with over 36,000 followers) asks followers to fill in the blank on

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<sup>6</sup> Inspiration porn is the portrayal of disabled people as inspirational solely based on their disability, typically presented to and for able-bodied audiences (see Young, 2014).

their experiences and beliefs about stimming, writing: “Stimming is \_\_\_\_\_?” Comments included answers such as “Autocomplete says: stimming is a good time I have nothing to add”; “part of me”; “relaxing and calming. Also natural”; “a reclamation of self”; and “Automatic! I don’t even realize I’m doing it most of the time. When I do notice, it can be hard to make myself stop, and the second I stop paying attention it’ll start happening again.”

Twitter users resist the idea that disabled bodyminds are passive objects on which the medical or cultural agendas of others should be enacted, and recognize that the reinforcement of normative behavior can have detrimental effects. One user explained that they used to receive enjoyment from their stimming but they were trained out of stimming and that they actually stop breathing, stating “I can’t stim so I hold my breath. My husband still has to remind me to breathe. THAT’S how screwed up people get when you don’t let them stim. It’s super f\*cking hard.” They counter the medical knowledge that describes stimming as unproductive, distracting, unnatural, conscious, and deviant and reclaim it as a natural and positive part of autistic identity.

Autistics use their Twitter platforms to attempt to challenge these notions of pathology. Some of the most prominent conversations in this dataset focused on not “hiding” autistic identity and autistic behaviors. Twitter users rejected the pathologized notion that autistic behaviors could be removed and unlearned through desensitizing and masking. This is evident in a conversation with an allistic social worker when they employ the #AskingAutistics to search for advice on how to explain that desensitizing is “THE WORST” and “why it’s wrong.” Commentators responded by referencing their own experiences of subjection to desensitization practices. Growing Up Autistic (who uses Twitter to share their journey with their 6,000 followers) responds:

Growing up I wanted to go to concerts but the noise/lights bothered me. After awhile I got “used” to it... or so I thought!. Years later I realised I had been masking it & eventually I felt drained. Finding ways around this is more important then getting “used” to it.

Another user elucidates that desensitization is an attempt to make someone seem more neurotypical, calling it “a flippant case of forcing neurotypicality,” and explains that just because they don’t show their discomfort doesn’t mean they are desensitized to painful stimuli. Another user articulates that attempting to suppress discomfort will have consequences sooner or later such as burnout, mental illness, meltdowns, and shutdowns. They explain that such desensitizing practices are taking someone’s mental health and “turning it into a time bomb” out of convenience to neurotypicals.

Moreover, masking is described not as rehabilitation but as covering-up and hiding autistic bodyminds in order to better fit in with preconceived

expectations of acceptable behavior. This is articulated by aspergersgirls (an autistic author with over 6,000 followers) when they write:

My masking was a result of others isolating me, manipulating me, bullying me, shaming me, and wanting me to validate their beliefs, choices, existence, and established norms. I had the choice of hiding within myself or dying. I am thankful my mask is off now and I love myself. (Aug. 6. 2019)

Often users express that without these behaviors, reactions, and experiences, autistics don't get to know who they really are. This is clear when another user writes:

I have been doing it for so long that I don't know how not to. Until I was diagnosed 6 years ago at 52 yo I felt like an imposter but I never knew why. It might have served a purpose before, but now I feel like it prevents me from knowing me.

Twitter users position an authentic autistic identity as one that resists socialized expectations of normative bodymind presentation. This is elucidated when EmrieIrving (an autistic author and artist with over 4,000 followers) argues that we are taught to hide our autistic traits but autistics should be valued: "trust yourself more than the protocols you've used to protect yourself. When you wanted to do autistic trait as a young person you were right and valid. YOU. WERE. RIGHT. There is nothing 'wrong' with how you work. Let yourself be." Moreover, Ipiluni (an artist and blogger who uses Twitter to discuss navigating the world as autistic) sums this experience up by writing:

Sometimes my brain decides I should be masking. The internal ableism makes those days are exhausting... I mask because I think it's literally the only way to be independent/self-supporting. I think it's completely negative and exhausting. Nobody cares who I actually am. Removing the mask is difficult because masking is so often an unconscious protective mechanism for discrimination... I think you have to basically re-learn who you are, what you feel, what you enjoy, etc., because you've learned to suppress it. (Dec. 3 2020)

Central to resisting these harmful medicalized narratives is finding ways to counter and resist notions of cure and rehabilitation. Sometimes this resistance comes in the form of rejecting beliefs that stimming is unproductive or in describing forced masking as harmful. Autistic Twitter users recognize that the current medicalized cultural narratives and representation of autism subtly and overtly reinforce the notion that autistic people should be changed, avoided, rehabilitated. They contest these cultural beliefs while simultaneously constructing positive self-stories. This is clearly expressed when a user writes, "why the hell are so many people bothered about the 'causes of autism' instead of just accepting that autistic people are a

goddamn blessing to this world and being thankful for what we can actually offer you?”

## **Conclusion**

Despite the majority of cultural narratives that demean and devalue autistic bodyminds, and despite the lack of recognizable positive representation and lack of in-person community, autistic people are resiliently constructing affirming individual and collective identities through Twitter. The findings here provide insight on how people who lack positive culturally resonating identity narratives use virtual spaces to construct group identity in ways that are representative and affirming. Social media can be a useful tool in disseminating and constructing narratives that resist stereotypical and inaccurate depictions of marginalized identity. This work highlights the importance of social media in current narrative construction and the techniques that marginalized identity groups use to reinscribe their identities outside of existing stigmatizing narratives. Typical and prevalent narratives about autistic people are embedded with medicalized symbolic codes that position autistic people as problems that should be addressed through individual rehabilitation. Autistic social media users are doing important social activist work building strong autistic virtual learning communities and by constructing these resistance narratives in ways that counter current negative representation and resist eugenic notions that autistic people are “less valuable” and a problem in need of fixing.

Moreover, the autistic Twitter users referenced here construct an authentic autistic identity as one that contests socialized expectations of normative bodymind presentation. In other words, what it means to be autistic is in part a rejection of neurotypical socialization and forced normalization. To be autistic, as described by the #ActuallyAutistic Twitter community, is to share common experiences, including experiences of marginalization, but also experiences of autistic joy, autistic frustration and anger, autistic behaviors, and autistic reactions to stimuli and social interactions. Furthermore, to be autistic is to live in a bodymind that has been highly moralized and medicalized through prominent narratives and stereotypes, yet to contest that medicalization through resistance tactics. To be autistic, then, is a powerful form of social-political resistance.

## *Limitations and Considerations for Future Work*

There are many limitations to virtual social media data, one of which is that not everyone has access or the means to participate in social media. As such, this data is self-selected and limited to Twitter users who have access to both social media and the internet. Additionally, this type of media privileges

autistic people who are comfortable communicating via text, typing, and written word. Although social media can relieve some communication barriers for autistic people it also creates new barriers for some. This type of data collection also doesn't pose direct question to Twitter users and therefore future work should consider engaging with autistic social media users via interview methodology. Furthermore, due to the expansiveness of the data, many themes emerged that could not be explored in this article. Themes such as self-diagnosis, disagreements between parents of autistic children and #ActuallyAutistic people, the over-prevalence of whiteness, maleness, and cisness of autistic virtual communities and prominent narratives, and the inaccessibility of social media and formal institutions, although not addressed here, should be further explored in future work.

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