Discourses of Disability, Narratives of Community: Reclaiming an Autistic Identity Online

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As increasing rates of autism diagnosis generate media interest, the autism community is bombarded with various disability discourses. Using netnographic methods, I explored how members of one online community, Aspies Central (AC), engaged these discourses to communicatively (re)claim a positive autistic identity. By assessing 561 posts on AC’s forums, interviewing 10 individuals who frequent online communities, and interacting extensively with two informants, I located reclaiming discourses that allowed community members to shift their understanding of autism from a biomedical to a cultural perspective. Through these discourses, community members reclaimed (a) normalcy, (b) symptoms, and (c) agency. In this paper, I discuss implications for the narrative construction of disability identities and the activation of self-advocacy movements.

Keywords: Autism; Disability Discourses; Identity; Narrative; Othering; Reclaiming

When my cousin was first diagnosed with autism, my family scoured the medical literature in the hopes of developing a clearer picture of Michael’s future. What we read was discouraging. According to biomedical definitions, autism is a developmental disorder characterized by social skill and communication deficits, as well as self-stimulatory behaviors (Newschaffer et al., 2007). People with autism are less likely than members of the typical population to pursue secondary education, live independently, have a romantic relationship, or hold a job (Barnhill, 2007; Levy & Perry 2011). Those who do work often experience malemployment, taking jobs that are below their intelligence and skill levels (Barnhill, 2007). Additionally, while some people with autism desire friendship, they struggle to find and retain friends (Jantz,
These difficulties can lead to poor mental health outcomes (Levy & Perry, 2011).

Eventually, I stumbled upon Bagatell’s (2007) ethnographic study of a teen with Asperger’s syndrome (AS)—a milder version of autism. Here was a completely new perspective. Bagatell (2007) wrote of the “Aspie” community: people with AS who had begun to view autism as a viable culture, standing in contrast to what they termed “Neurotypical” society. Aspies, and other members of the autism community, have worked to counteract the biomedical understanding of autism by exchanging it for the discourses of neurodiversity—a sociopolitical movement that has pushed for people with autism to embrace their autistic identity as an alternative viewpoint (Bagatell, 2010; Bumiller, 2008; Cascio, 2012; Jaarsma & Welin, 2011). Self-advocates have objected to stigmatizing depictions of autism circulated by the media, most of which frame people with autism as pitiable victims (Sarrett, 2011). Since the 1990s, neurodiversity proponents have developed several self-advocacy organizations, including the Autism Self-Advocacy Network (ASAN), the Autism Network International (ANI), and the Global and Regional Asperger Syndrome Partnership (GRASP) (Bagatell, 2010). These groups criticize organizations that focus on finding a cure for autism. For some, the “cure movement” draws attention away from resources that would help Aspies to succeed on their own terms. For those with more extreme viewpoints, the cure movement represents a eugenics program, engineered by Neurotypicals to eliminate the threat of an Aspie culture (Cascio, 2012).

Aspie self-advocacy efforts were unsettled by the fact that, in May 2013, AS was eliminated from version five of the APA’s Diagnostic and Statistical Manual (DSM) (APA, 2013). Aspies were absorbed under a new diagnostic term, Autism Spectrum Disorder (ASD), alongside more severely affected members of the autism community. In reworking its diagnostic categories, the APA highlighted the evolving conflict between descriptions of autism as a biomedical label and interpretations of autism as a cultural category.

Studying the conflict between autism as biomedical label and autism as culture has practical implications. Currently, while organizations like Autism Speaks and the APA aim to make life easier for people with autism, the biomedical discourses they perpetuate can actually make it more difficult for individuals to deal with their diagnosis in positive ways. Studying communication circulated within the Aspie community addresses the need to bridge the divide between the practical concerns that are the focus of biomedical approaches to autism and the identity concerns at the core of a cultural approach. My research is driven by the following research question: How do online spaces facilitate the communicative construction of an autistic identity? Although not directly pursued in this piece, this research question gives rise to related questions: what effect does this autistic identity have on an individual’s sense of well-being?; what impact might shifts in diagnostic categories and criteria have on both identity construction and well-being? In this netnographic study, I explore autistic identity construction by studying one online community: Aspies Central.
Life at the End of the Spectrum

In the DSM IV, Asperger’s syndrome (AS) referred to the mildest condition in a range of autism spectrum disorders (ASDs). People with AS adopt a particular communication style: “they often indulge in monologues; use stilted words and expressions; offer excessive details; and show problems with prosody and intonation” (Ghaziuddin, 2010, p. 1147). They find it difficult to interpret nonverbal cues, and tend to take figurative language literally (Orsmond, Krauss, & Seltzer, 2004). In addition, people with AS fixate on areas of intellectual interest and find it difficult to take others’ perspectives, making it challenging for them to socialize (Ghaziuddin, 2010; Orsmond, Krauss, & Seltzer, 2004). This sense of isolation is magnified by the fact that ASDs are extremely complex and vary from person to person, making them difficult for both researchers and the lay public to understand.

Communicating Disability: Representation and Self-Advocacy

As members of a larger disability community, people with ASDs are influenced by oppressive and empowering discourses of disability.

Oppressive Discourses of Disability

Coopman (2003) explicated three oppressive disability communication metaphors: (a) disability as a medical problem, (b) disability in culture, and (c) disability as cognition. Approaching disability as a medical problem can have a number of negative consequences. Biomedical discourses situate disability as an individual problem, ignoring social and political influences (Coopman, 2003; Linton, 1998). As a result, “adversity is not depicted as lack of opportunity, discrimination, institutionalization, and ostracism; it is the personal burden of their own body” (Linton, 1998, p. 25). Biomedical discourses author the concept of normalcy, “which centers and privileges certain types of behavior, functioning, and appearance” (Linton, 1998, p. 6). Individuals with disabilities are assumed to be weak, helpless, suffering victims who strive to overcome their condition, and who are always the recipients of support (Chew, 2008; Fine & Asch, 1988; Zola, 1993). Essentially, biomedical discourses frame disability as deviance.

The metaphor of disability in culture is more subtle in its ability to oppress. Disability in culture highlights how “cultural definitions of illness and health underscore the evaluative dimensions of disability” (Coopman, 2003, p. 259). By emphasizing the conceptual co-construction of disability, these discourses focus on how individuals with disabilities can influence how disability is defined. However, in reality, cultural understandings of disability are generated by large media organizations, to which individuals with disabilities have little access. Linton (1998) described the predominant media portrayal:
Disabled people are rarely depicted on television, in films, or in fiction as being in control of their own lives... More often, disabled people are depicted as pained by their fate or, if happy, it is through personal triumph over their adversity. (p. 25)

Autism, in particular, has been framed in a number of potentially oppressive ways. Several tropes have consistently appeared in depictions of autism. The first is the idea of fragmentation: the autistic individual is a broken person who must be fixed (Sarrett, 2011). A second trope perpetuates the idea that autism is the imprisonment of the normal child (Broderick & Ne’eman, 2008; Sarrett, 2011). A final trope is the metaphor of the “alien”: individuals with autism are so different that they belong to another world (Broderick & Ne’eman, 2008). This trope blends with the idea of the person with autism as a superhero, a savant, or a noble savage. While this characterization seems empowering, it propagates unrealistic expectations.

The metaphor of disability as cognition provides a third oppressive discourse. Disability as cognition applies a lens metaphor to understand how perceptions of disability are filtered through individuals’ attitudes and personality traits (Coopman, 2003). This metaphor invokes modified labeling theory (MLT):

When people are labeled, they are placed into a cultural category that makes the category’s stereotypes salient and personally relevant. Labels carry cultural meaning that can be activated in diverse settings, which can make them difficult to dispute, ignore, or hide. (Smith & Hipper, 2010, p. 411)

Stigmatizing labels discourage people from identifying as disabled (Scotch, 1988). Fear of stigma causes those with less visible disabilities to attempt to “pass” as typical, causing physical and emotional strain (Davidson & Henderson, 2010). “Stigma coaches” discourage loved ones from telling others about their condition (Smith & Hipper, 2010). Thus, disability as cognition firmly entrenches individuals with disabilities in the position of “Other.”

Othering involves the consolidation of power and technology by a dominant group, which distances itself from a subordinate group by portraying its members as morally inferior, pathological, and deviant (Jensen, 2011; Marzorati, 2013). Members of the subordinate group perpetuate othering by engaging in defensive othering: “reinforcing the power of stigmatizing labels by arguing that the label is true for other members of their social category, but not for themselves” (Ezzell, 2009, p. 114). Othering can also be resisted. Through capitalization, individuals appropriate some of the stereotypes associated with their position as Other (Jensen, 2011). Thus, people with disabilities can actively generate resistant discourses.

**Empowering Discourses of Disability**

Coopman (2003) identified three disability metaphors that empower individuals with disabilities: (a) disability as culture, (b) disability as politics, and (c) disability as community. Disability as culture points to the language, narratives, rituals, and symbols adopted by individuals with disabilities as they create co-cultures.
Disabilities develop into cultures by emphasizing “shared experiences, celebration of values different from the majority culture, and integration of difference into a positive self-concept” (Caldwell, 2011, p. 316). Disability as culture draws from Orbe’s (1998) co-cultural theory, which examines how marginalized groups leverage their outsider-within position to navigate oppressive dominant forces within organizations. The disability as culture metaphor highlights discrimination, but still classifies people with disabilities as members of a marginalized community.

Disability as politics stresses issues of power and voice, critiquing “ableist” viewpoints and highlighting the importance of self-definition in identity construction (Coopman, 2003). Reclaiming disability as a social/political category allows individuals to unite around a political constituency that can lobby for its own interests (Linton, 1998). Disability as politics taps into feminist standpoint theory (Dougherty & Krone, 2000; O’Brien Hallstein, 2000) to emphasize how the unique viewpoints of those with disabilities provide valuable social critique. Through counter-narratives, people with disabilities can destabilize widely-accepted norms and create space for alternative stances. However, collective action only takes place when people with disabilities feel that they are members of a community (Beart, 2005).

This need for connection is captured in the final disability communication metaphor: disability as community (Coopman, 2003). Communities form as individuals engage with each other on a more personal level. The Internet has facilitated this community building, linking geographically isolated individuals and providing access to “public and private discourses often not possible in face-to-face communication” (Coopman, 2003, p. 377). Consequently, the Internet has become a powerful catalyst in a growing self-advocacy movement.

The Significance of the Internet

The advent of the Internet and computer-mediated communication (CMC) has had an important impact on the autism community in several ways. First, CMC has created a comfortable communication environment. Because CMC is text-based, it avoids nonverbal cues that are difficult for people with ASDs to process (Davidson, 2008). In addition, CMC allows individuals to communicate from the security of their homes, where they can control anxiety-causing stimuli (Jordan, 2010). Further, the Internet has contributed to a growing sense of empowerment within the disability community at large. On the Internet, people with disabilities gain visibility and invisibility at the same time—claiming a voice without having to claim a body (Zubal-Ruggieri, 2007). The anonymity of the Internet also allows individuals to reveal a stigmatized identity without fear of judgment (Weiser, 2001). As a result, CMC can increase self-confidence and encourage individuals to network with others.

One of the most significant contributions of the Internet is its ability to link people in networks: “informal, abundant and redundant ties between people and the organizations they make up” (Olsson, 2008, p. 663). By networking, people establish the connections necessary to form a collective identity. Collective identity is the
evolving, emergent result of networked interactions that uncover and produce shared interests (Polletta & Jasper, 2001). Researchers have theorized that collective identity is a prerequisite for the development of social movements (Diani, 1992). The Internet, by breaking down geographical barriers and by networking individuals, allows collective identities to form (Lomicky & Hogg, 2010) and has been credited with shaping and facilitating modern social movements (Van Laer & Van Aelst, 2010), including the neurodiversity movement.

Neurodiversity is a social movement whose advocates push to reframe autistic traits as a healthy part of the autistic individual (Bagatell, 2010; Bumiller, 2008; Cascio, 2012). Neurodiversity involves understanding autism as a natural variation in ability that should warrant equal respect (Bumiller, 2008). The development of the neurodiversity movement is closely tied to the advent of the label “Asperger’s syndrome” (Bagatell, 2007). This label helped higher functioning individuals to group themselves around a collective identity, building an “Aspie” culture that proudly distinguished itself from larger, “Neurotypical” (NT) society (Bagatell, 2010). However, not everyone in the autism community embraces this viewpoint. Some argue that neurodiversity privileges the experience of higher functioning individuals at the expense of those who experience a greater degree of struggle. For some, developing treatments and finding a cure represent laudable goals, while accepting autism as a positive identity seems like an impossible task. Thus, the discourses of neurodiversity may appear just as oppressive as those of biomedicine. Given this complicated web of identity politics, this essay addresses the research question: How do those with high functioning autism and Asperger’s syndrome communicatively construct an Aspie identity on the Internet?

Method

A netnographic approach is ideal for addressing this research question. This research design was approved by my institution’s Institutional Review Board, and all interview participants’ names were replaced with pseudonyms to protect their anonymity. The following sections provide a description of the Aspie online community, a rationale for netnography and the process of collecting text-based interactions, the interviewing protocol, and an account of the strategy of data analysis and representation.

The Aspie Online Community and Netnography

The Aspie community has a significant online presence. Several sites organized by people with ASDs explicitly encourage online community building, including Wrong Planet and Aspies for Freedom. I analyzed the interactions between members of a single online community: Aspies Central (AC). I chose AC for several reasons. First, AC is a smaller community with a contingent of regular users. Second, because AC’s founders attempt to build and maintain an inclusive environment that discourages “Neurotypical bashing,” I believed I would be welcomed despite my status as an NT.
A netnography is a type of ethnography conducted over the Internet (Bowler, 2010; Kozinets, 2010). Netnographers recognize that “online communities form or manifest cultures, the learned beliefs, values and customs that serve to order, guide and direct the behavior of a particular society or group” (Kozinets, 2010, p. 12). They target, as I have, online communities that are relevant to their area of interest, meet regularly, are interactive, include a heterogeneous mix of participants, and offer rich data (Bowler, 2010). Unlike traditional ethnography, netnography includes the collection of participants’ text-based interactions (Kozinets, 2010). Thus, the majority of my data comes from online posts.

Data collection was limited to public sections of the AC site. All forums from “The Spectrum” section of the AC site were selected for study because “The Spectrum” was devoted to interpersonal issues—the types of issues from which discussions of identity might emerge. From each forum, I collected posts written between July 2012 and October 2012. Although the choice to begin in July was arbitrary, the choice to end in October was driven by the sense that my emerging categories were theoretically saturated. In choosing specific threads to analyze, I only selected posts that received 10 or more replies, ensuring that these posts generated discussion. For each of these posts, I collected the first 20 substantive threads, where participants had contributed a new idea. Table 1 summarizes the data-set.

I remained a complete observer to avoid disrupting normal interactional patterns. However, I was able to interact with participants during interviews.

**Interviewing**

Interviews provided a means of interacting with my participants to co-construct understanding. I posted a request for interview participants on the “Introductions” forum, providing a description of my research and directing interested community members to contact me. I also sent private messages to moderators. While I focused on Aspies Central for most of my data collection, I also interviewed members of other online Aspie communities to get a general sense of why individuals with autism use them. My interviewees included users of Wrong Planet, Aspies for Freedom, and Spectrumville. Interviews were scheduled via telephone, Skype, instant messenger, or

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email. These options allowed me to both reach far-flung participants and to accommodate varying levels of comfort with nonverbal cues. Interviews used an interview guide, but developed freely through probing questions. Questions asked participants to describe similarities and differences between Aspie and Neurotypical (NT) communities, discuss difficulties Aspies face, and describe passing and disclosure strategies.

I conducted 10 interviews, which included six female and four male participants with an average age of 35. One interview was conducted via telephone, one via Skype with the video feature enabled, four via Skype without sound or video, one via Facebook chat, and three via email. Interview data produced 66 single-spaced pages of transcription. I also recorded the type of diagnosis each individual had and how long they have considered themselves to be an Aspie. An “official diagnosis” refers to a diagnosis given by a medical professional. A “semi-official” diagnosis indicates that the individual has been told by a medical professional that they most likely have Asperger’s syndrome. A “self-diagnosis” refers to the individual’s belief that they have Asperger’s syndrome (see Appendix 1 for a demographic description of participants). While online observations and interviews provided me with a wealth of information and insights, two informants helped shaped my personal understanding of ASD.

Nick. When I began this research, everything I knew about autism came from the perspective of a care provider. I had helped my toddler cousin with his ABA therapy, interviewed therapists about their relationships with their clients, and volunteered at a center that took children and teens with autism on community field trips. Nick was the first person I interviewed for this piece. He was also the first person who helped me to realize that my past studies had depicted people with autism as passive recipients of care, rather than as active participants in the management of their own lives. After I initially interviewed Nick, he began to reach out to me via Skype and Facebook chat. After chatting for 7.5 total hours between October 2012 and February 2013, Nick shifted from being my participant to being my friend. In between sharing his passion for literature, art, travel, and cats, Nick linked me to articles and sites devoted to generating acceptance of the Aspie culture. A moderator for AC, Nick reviewed my work and checked that it accurately reflected the community’s dynamics.

Paul. My final participant, Paul, served as a foil to Nick’s sunny outlook. In his interview with me, Paul disclosed that he had intended to commit suicide several months earlier. Joining an online community and reaching out to me were his attempts to find a healthier way of approaching his diagnosis. In addition to the interview, Paul shared 18 diary entries—a total of 28 single-spaced pages. His writings gave me an intimate look at the darker moments some Aspies may experience. His writings made me more conscious of the ethical danger of trampling roughshod over Aspies’ personal experiences with a simplistic analysis.
Analysis and Representation

In analyzing this data, I applied Charmaz’s (2006) grounded theory approach, where categories are produced inductively through constant comparison between data, emerging categories, and the literature. For each entry, I used open coding to create first-level codes based on the general topical content. I also identified en vivo codes, selecting keywords or phrases expressed by the participants (Olson, 2011). I continually compared these first-level code categories with linking, axial codes to identify emergent categories (Charmaz, 2006). When I felt I had reached theoretical saturation, I pulled out key quotations from both the forum posts and the interviews, organizing them according to my developing categories. Categories included (a) reframing, (b) reclaiming, and (c) (re)negotiating an Aspie identity. In this essay, I have focused on reclaiming. Reclaiming is the process by which Aspies transform a biomedical understanding of ASD into a cultural one. Reclaiming was particularly fascinating to me because it captured processes by which individuals with autism move from simply accepting their Aspie identity to advocating on its behalf. I pulled from 48 key quotations, coded into the subcategories described in the following results section.

Reclaiming: Defending a Spoiled Identity

Neurotypical (NT) biomedical discourses pathologize autism, emphasizing the idea that those on the spectrum are the unfortunate victims of their own abnormalities (Coopman, 2003). Online communities provide a space where geographically-isolated Aspies can unite in reframing Asperger’s syndrome positively. Reframing “involves intentionally renaming what is happening to you” (Foss, Domenico, and Foss, 2013, p. 21). For Aspies, reframing moves beyond simply altering a perspective to reclaiming elements of their identity. Aspies reframe their identities through discursively reclaiming: (a) normalcy, (b) symptoms, and (c) agency.

Reclaiming Normalcy

The first concept Aspies reclaim is the idea of normalcy. Macro discourses about Asperger’s syndrome emphasize the fact that those on the spectrum are not normal. Paul’s diary revealed the impact of this:

I read that people with my condition are usually able to live normal to near-normal lives. This statement implies that people like me are not normal. I didn’t think that I wasn’t like everybody else at the time... That, however, was rapidly changing, as I looked to fix this disorder of mine. (personal diary, June 11, 2012)

Paul’s statement reveals two issues. First, it points to the socially-constructed nature of normal; Paul did not think of himself as abnormal until he was assigned this label by others. Second, it highlights how damaging spoiling discourses can be. As Paul’s diary progressed, he focused more and more on discourses that place him outside the
normal. For example, in thinking about texting, Paul wrote “Pretty much every human American teenager does it” (personal diary, September 25, 2011). From this first thought, Paul produced the following rationalization:

> the word “teenager” was meant to exclude the very young and very old people who don’t need to do it. The word “American” was meant to exclude the people in developing nations, who might be too poor to need texting capabilities. And perhaps worst of all, the word “human,” other than animals, was meant to exclude myself... My overall thought was that because of this lack of a desire to text, and because of the mental problems that led to that lack of a desire, I wasn’t fully human. (personal diary, September 25, 2012)

In order for members of online Aspie groups to embrace Asperger’s syndrome as an identity, they must first distance themselves from the idea that it represents an inferior way of being. To accomplish this, they must reclaim the word “normal.” AC community members repeatedly described those with Asperger’s syndrome as being “differently wired,” “on a different wavelength,” and “differently-abled,” rather than abnormal or disabled. These descriptions produce a more neutral “we are simply different” stance. Indeed, referring to those not on the spectrum as Neurotypicals achieves the same goal in that it avoids assigning these people “normal” status, and, by default, assigning Aspies “abnormal” status. Instead, these discursive approaches leave room for different versions of “normal.”

Once community members established that their Aspieness is not inferior, simply different, many worked to normalize that difference. For instance, one AC community member noted that “everyone is supposed to be an individual and therefore will have quirks... I don’t understand why it matters if it’s AS or not.” Thus, Aspie quirks are part of a normal and expected range of difference that encompasses both Neurotypicals and Aspies. Similarly, the difficulties faced by Aspies were normalized: “every human being is challenged either by their own shortcomings or those of the world around them. That’s why I endorse... saying ‘differently-abled.’” Thus, any differences, even challenging ones, are a typical part of life.

Some members of these online communities pushed beyond normalizing Aspie differences to suggest that those differences give them an edge over Neurotypicals. This is evident in expressions of personal pride: “I think of it as everyone else is just a normal factory car, but I have been tuned for something much better; “it’s awesome being very intelligent and a one of a kind person! Instead of a regular where you don’t do as interesting things as an Aspie would do!” These individuals opposed the idea of “curing” autism, fully embracing it as a defining element of their identity.

This sense of pride can easily shade into a sense of superiority. In reading AC community members’ posts, I learned of other sites whose members focus on establishing their own version of “normal” as the best way, vilifying Neurotypicals and criticizing their viewpoints, skills, and social norms. This outlook could be detrimental to Aspies’ well-being, as they must still live in a predominantly Neurotypical world where success is determined by adherence to NT norms. AC’s
coordinators opposed this extreme viewpoint, stating “we have a zero-tolerance policy for all forms of Aspergers, Autism and even NT Supremacy.”

Community members wrangled with their need to express pride in their own viewpoints, acceptance of Neurotypical/Aspie differences, and frustration with the mistreatment and misunderstanding they receive at the hands of some NTs. One member expressed his concern that the site was allowing “NT bashing”:

Having been here a few days, I have found that it is easy to be sucked into the US and Them argument-I have been rejected, misunderstood, maligned, bullied, and disregarded by many Neurotypicals over the course of my life. However, I do not wish to do the same to them.

Others echoed this sentiment: “In recent weeks there has been a rise in Neurotypical put downs, expressed anger, elitism, pretty much just disguised bigotry in general.” In light of the possibility that embracing their Aspieness might degenerate into vehemently rejecting Neurotypicalness, Aspies employed the same strategy of normalizing difference: “I don’t think that the Aspies/Neurotypical thing has to always be adversarial... there’s no denying that we are very different. Difference, however, doesn’t have to be a bad thing.” Clearly, community members try to occupy the middle ground of acknowledging that difference is both normal and valuable. This stance allows them to reclaim a second aspect of autism: symptoms.

Reclaiming Symptoms

The second element Aspies worked to reclaim was symptoms. In light of autism’s pathologization, all of the characteristics assigned to those with the “disorder” tend to be cast in a negative light. Characterized as symptoms, these features are discursively stripped of any potential value. Contrastingly, many of my participants and members of the AC community worked to reclaim the “symptoms” of their diagnosis as positive elements of their identity.

A first “symptom” of autism is the individual’s obsession with particular interest areas. On the AC forums and in my interviews with participants, this obsessive interest in detail was reclaimed as an “Aspie superpower.” Nick, a 33-year-old man with a semi-official diagnosis, clearly illustrated this reclamation process: “A therapist I was seeing once criticized me for having ‘narrow interests,’ I prefer to look at it as having my nice little niche and as being ‘deep’ rather than ‘wide’” (personal communication, October 22, 2012). Others elaborated on the productive benefits of having “narrow interests.” For instance, Anne observed that, while focusing intensely on one thing may be considered a fixation, that focus allows Aspies to get very good at their particular interest areas. Elle Cee reported, “I program visual basic in Microsoft Excel, and it allows me to hyperfocus on working, because Excel is one of those areas I’m obsessed with” (personal communication, November 11, 2012). Matilda, a 51-year-old woman with an official diagnosis, framed this viewpoint in more colorful terms:
I truly believe, were it not for Aspies in the community, with our incessant curiosity and drive to find out how things work, that humans would still be sleeping up in the trees at night... (personal communication, January 21, 2013)

Praise for the Aspie ability to “hyperfocus” was often linked with applause for a second “symptom”—the Aspie’s extremely logical, unemotional approach to problem solving. Members of AC recognized that this “symptom” has been negatively labeled: “Rather than seeing our straightforwardness, logic and precision as positive traits, all they’ll think Asperger’s=Autistic=unstable=dangerous= ‘retarded’ =NUTS!!!” (AC, n.d.). However, AC community members reclaimed this “symptom” by discussing how their logical mindset helps them outperform NTs in everything from speculating on the stock market to dissecting the problem of a rising divorce rate. Combined, these reclaimed traits are used to explain how Aspies can be valuable, contributing members of society: “In our increasingly tech dependent world, Aspies are making their mark in mathematics, engineering, robotics and every aspect of computer sciences” (AC, n.d.). Matilda reclaimed famous historical figures as members of the Aspie community: “Einstein, Marie Curie, Newton, da Vinci, none of these could really be called ‘Neurotypical’ by any means. And see what they achieved!” (personal communication, January 21, 2013). This type of reclaiming discredits the idea that those with autism are in need of “fixing,” and instead asserts that they can be successful precisely because of their autistic traits.

In addition to emphasizing their potential productivity, many of my participants and the members of the AC community reclaimed their “symptoms” to demonstrate their value as morally respectable people. One “symptom” of Asperger’s syndrome is the individuals’ reduced ability to recognize or produce sarcasm or lies. Aspie community members reclaimed this as a virtue: “the lack of duplicity is one of the more endearing qualities many Aspies share.” Similarly, an inability to innately grasp the social norms of NT culture was reclaimed as beneficial:

A Neurotypical person might feel that something is socially awkward, but not be able to tell you why. I can give you the reason behind it... for social situations, I had to “learn the rules” and so I can explain it better than a Neurotypical.

This “outsider-looking-in” status is reinterpreted by members of AC as being able to “not follow the herd” and to provide a much needed alternative viewpoint.

Finally, my participants reclaimed the alienation, bullying, and misunderstanding they face as Aspies by illustrating how those difficult experiences made them more empathic. Pella explained:

NTs talk about how rude Aspies are or that we are selfish. Then I see the Aspies on AC trying so hard to make sure that they didn’t offend anyone... we know how much it hurts when someone says something that offends us ... that’s what empathy is, feeling what others may be feeling, and for people who have difficulty with... [empathizing], I think it is that much more meaningful when we do. (Personal Communication, January 19, 2013)
Similarly, Anne described one of the positives of being an Aspie as “being able to identify with and have compassion toward people who are different” (personal communication, November 3, 2012). This kind of empathy for other stigmatized groups becomes even more apparent as members of online Aspie communities reclaim their agency as self-advocates.

**Reclaiming Agency**

Agency was the final concept Aspie community members reclaimed. Agency refers to the perception that one is capable of influencing or changing important aspects of one’s life (Foss et al., 2013). Labeled with an autistic diagnosis, Aspies can be perceived as hapless victims of their own abnormalities, in need of help from Neurotypical experts. Instead, my participants worked to position themselves as their own advocates. In order to reclaim agency, Aspies first reframe the source of their difficulties and then align with others who have overcome similar difficulties.

In their attempt to reclaim agency, Aspies first reframed the source of their difficulties. Instead of focusing on their own struggles to adapt to Neurotypical society, they focused on Neurotypical society’s unwillingness to adapt to them: “Why can’t people try to understand if you say you’re different? I’ve been reading Neurotypical literature all my life; would it kill you to read this pamphlet about Asperger’s syndrome?” In doing so, the members of AC associated themselves with other groups who have successfully demanded that Neurotypical society treat them more kindly. Some took the viewpoint that Neurotypicals are simply ignorant to alternative points of view. One AC community member discussed wheelchair-hostile buildings as an example:

> When NTs designed and built these structures, they weren’t intentionally trying to harm people in wheelchairs, they just were thinking from a majority normative perspective. Unless these issues get raised, the world will remain a difficult to navigate place for Aspies as well.

Others’ arguments were more inflammatory, claiming blatant discrimination. One AC member compared the pathologization of Asperger’s syndrome to similar attempts to pathologize Blacks, Jews, and the LGBT community by Nazi Germany. Similarly, one AC member compared Neurotypical efforts to assist Aspies to colonialists’ misguided attempts to educate indigenous people. Another AC member compared the depiction of the nerdy TV Aspie to stigmatizing representations of Blacks, Latinos, and Asians. NTs were perceived as a threat to Aspie culture: “Our people and our culture... has been criticized, pathologized and picked apart by well-meaning (and not so well meaning) Neurotypical experts. Efforts continue to dismantle our culture.” Whether participants claimed that Neurotypical society actively discriminates against them or inadvertently does so, they repeatedly aligned their experiences with those of traditionally marginalized groups. Consequently,
Aspies reclaimed their right to act as change agents, rather than passively accepting Neurotypical norms. One community member wrote:

What are you apologizing for? Are you apologizing for being an Aspie? Like it was your choice somehow? Does a person in a wheelchair apologize for not being able to walk? Does he ever say “I’m sorry you had to build this ramp for my wheelchair?” No he doesn’t. He'll probably demand the ramp to be built. He will demand “understanding.”

Clearly, by emphasizing that Aspieness is not a choice, but a way of being, this community member establishes the idea that Aspies are entitled to understanding.

Not only do these discourses function to reclaim Aspies’ rights to act as change agents, they also claim a unique ability to create that change. My participants and the AC community members emphasized the value of “seeing from different angles” and “not following the herd.” They pointed out that Neurotypical society is far from ideal: “NTs themselves are being driven batty by the world they’ve played the lead role in creating.” Thus, they established a need for their own perspectives. For example, one community member wrote that his purpose is to “turn what’s considered normative on its head and force the mass cultural discourse to examine, critique and improve itself through looking through Aspie eyes.” Online communities like AC provide Aspies with an opportunity to act as change agents by sharing their perspectives.

Discussion

Through the process of lacing together participants’ descriptions of their autistic identity, I have drawn several conclusions about the process of identity construction. This discussion section addresses implications for the processes of (a) naming versus labeling, (b) narrative identity construction, (c) coalition building, and (d) othering/selfing.

Naming versus Labeling

Framing disability as culture, politics, and community can significantly impact individuals’ perceptions of an Aspie identity. This impact is most clearly illustrated by contrasting the effects of passively receiving a biomedical diagnosis versus actively naming oneself as a member of the Aspie community.

A label is imposed upon a person. Labeling reflects the medicalization of Asperger’s syndrome, which “casts human variation as deviance from the norm, as pathological condition, as deficit” (Linton, 1998, p. 11). Consequently, being labeled with Asperger’s syndrome is accompanied by denial, resistance, and resentment. Labeling undermines the individual’s ability to take an active part in shaping identity.

In contrast, naming is an active process where individuals seek out an explanation that fits their personality and experiences. When individuals choose to name themselves as Aspies, they are not assenting to a medical diagnosis. Instead, they are choosing to identify with a cultural group that fits their experiences. Participants
who expressed a more positive view of their Aspieness tended to be self-diagnosed, or strongly suspected that they had an ASD before they sought diagnosis. This explains why, while my interview participants’ average age was 35, many had only received their official diagnosis less than two years prior. These people had many years to notice their own quirks and struggles in comparison to their NT peers, which propelled them to search for something that would explain these differences. Thus, naming is associated with an empowering moment of self-recognition.

The process of naming is empowering in several ways. First, because naming is the result of an individual’s own actions, it encourages the individual to be proactive in negotiating what the name Aspie means for them. Thus, people who name themselves may be more likely to seek out and produce reclaiming discourses. Because naming is preceded by research, individuals who name themselves have an opportunity to encounter the more positive narratives expressed in online communities such as AC before they take on an Aspie identity. As a result, rather than retroactively reconstructing their Aspieness in a positive way, they start out with a more positive perception of ASD.

Naming and Narrative

The concept of naming draws on narrative understanding of identity, where identity is understood as “a continually unfolding story that develops new characters and twists in plot, and can be understood only discursively” (Canary, 2008, p. 439). Identity narratives are produced in everyday interaction with others, involving the kind of collaboration facilitated by online community such as AC (Harter et al., 2006; Holstein & Gubrium, 2000; Rapley, 2004). An Aspie designation has biological underpinnings. However, the difference between Aspie and Neurotypical cultures, between “normal” and “abnormal” ways of viewing and interacting with the world, is a socially constructed, binary distinction. Aspies who focus on binary narratives of normalcy continuously focus on their own “abnormal” nature. However, forums like AC provide opportunities to breakdown the binary distinction between normal and abnormal. After joining an online group, Aspies may choose to attend only to narratives that resonate with the group’s ideology of neurodiversity, exchanging narratives that emphasize “abnormality” for narratives that emphasize “difference.”

Culture, Community, and Coalition

My findings indicate that online communities are important sites for coalition building. Aspies communicatively establish links between themselves and other members of the Aspie community by establishing that they share similar experiences, viewpoints, and goals. In doing so, they draw on discourses that frame disability as culture, community, and a political entity.

First, by interacting with Aspies from around the world, members of online communities establish that they are part of a larger group of similarly thinking and acting others. Subsequently, they draw on discourses of culture. By reclaiming
symptoms as positive elements of an Aspie identity, Aspie online community members identify elements of an Aspie culture of which they can be proud. Indeed, Aspies themselves describe their community in cultural terms: “Our people and our culture... has been criticized, pathologized and picked apart.” The “our” in this last quote shows how closely a cultural understanding of autism is linked to understandings of disability as community (Coopman, 2003).

After establishing themselves as members of both a culture and a community, the members of AC felt that they could mobilize other members in a coalition for political action: “Only if we unite, then we will have the power to change a lot of things.” However, political coalition building moved beyond simply establishing connections among Aspies. Through their communication in online communities, Aspies align themselves with members of other groups whose biological differences have caused them to suffer oppression. In aligning with other maligned groups, such as physically disabled communities, ethnic minorities, and the LGBT community, Aspies assert that, while they are biologically different, this difference should receive acceptance and accommodation just as it has in these other populations. Coalition building with other groups adds legitimacy to Aspies’ attempts to advocate on their own behalf.

Othering/Selfing

In many ways, AC community members use reclaiming discourses to capitalize on their Other status (Jensen, 2011). For instance, by reclaiming symptoms, the members of AC select those aspects of Asperger’s syndrome that single them out as the Other and transform these into positive traits. By reclaiming agency and building coalitions with similarly marginalized groups, the members of AC frame Otherness as morally superior to the oppressive Neurotypical majority. However, capitalization still preserves the binary produced by Othering, creating a new dichotomy between Aspie and Neurotypical.

Interestingly, the members of AC actively tried to discourage this dichotomy by focusing on reclaiming normalcy. Members discouraged “Neurotypical bashing” while focusing on difference as a positive and expected element of the spectrum of humanity. This finding reinforces criticisms of othering, which challenge its binary nature. “Selfing” has emerged as an alternative understanding of the othering process. While othering is an extraverted process of disidentification, selfing is an introverted process of fitting a history of personal experience into a cohesive “sense of goodness, uniqueness and continuity” (Gulerce, 2014, p. 245). While selfing inevitably involves othering, both occur as part of a dialogic process that recognizes the fuzzy boundaries between Self and Other. This recognition is particularly important for members of the AC community, whose mental and physical well-being is closely tied to their ability to function well in a Neurotypical-dominated community. Embracing a rigid and antagonistic division between Aspie and NT is impractical. Instead, AC community members maintained a hybrid identity, residing “neither in a position of independence nor interdependence, but of interdependent independence”
They continually shifted between embracing an Aspie self and trying to function well from the NT perspective. It is the online community that allows AC members a space where dialogues of resistance, in the form of reclaiming symptoms and agency, are tempered by dialogues about reclaiming normalcy. This function of the online community, along with the others noted above, has several practical implications.

**Practical Implications**

This project reveals the potentially vital importance of online communities. By circulating reclaiming discourses, online communities counteract the repressive effects of biomedical discourses by constructing narratives that reframe “abnormality” as “difference.” Additionally, these online sites encourage individuals to understand autism as a culture, and to rally together behind self-advocacy causes. As evidenced by Paul’s experience, where joining an online community helped to combat suicidal thoughts, membership in communities like AC can have a powerfully positive impact on individual’s psychological well-being.

Of course, online Aspie communities may produce potentially negative impacts. For instance, while AC attempts to be egalitarian in its treatment of both Aspie and NT cultures, other communities may construct a more antagonistic view of NT society. Members of Aspie communities may become so attached to Aspie culture that they grow to resent NTs. This viewpoint would undermine an individual’s ability to be successful in an NT-dominated world. It is important to consider the ideological underpinnings of a particular online community when trying to determine whether it will have a beneficial impact on psychosocial well-being.

These findings have several practical implications for friends and family members, for medical practitioners, for the APA, and for nonprofit organizations. First, family and friends must recognize that autism is not something that happens to a person, but something that is part of a person. Friends and family members must realize that treating autism as a *disease* category prevents an autistic person from viewing it as an *identity* category, one that can be (re)fashioned to focus on positive difference. Based on this understanding, there are several things that friends and family can do to help people with autism to develop a positive autistic identity. First, they might recommend visiting sites like AC to engage with others who have found a way to deal with the difficulties associated with autism. Second, rather than treating symptoms, family and friends should focus on providing strategies for functioning in an NT-dominated world. Framing assistance in this way recognizes practical needs without belittling the Aspie perspective or reifying a normal/abnormal dichotomy. Moreover, family and friends must work to recognize the Aspie perspective, and actively acknowledge some of the uniquely positive attributes tied to their loved one’s autism identity. Visiting sites like AC, which welcome questions from curious NTs, can facilitate the process of developing respect and empathy for a person with autism.

Medical professionals should also keep these approaches in mind. As authority figures, they can actively encourage people with autism and their families to gain a
cultural understanding of autism by visiting sites like AC. Moreover, medical professionals who understand the significance of autism as an identity category are better prepared to interact with self-diagnosed individuals. Although they may not officially ratify a self-diagnosis, medical professionals can acknowledge that an Aspie identity provides important self-explanatory power. Rather than completely discounting a self-diagnosis, medical professionals may encourage these individuals to engage with communities, like AC, where they can connect with similar others.

Similarly, the APA must also begin to recognize that its diagnostic categories do not just represent a “disorder,” but a culture. How might eliminating Asperger’s syndrome unsettle the identity work Aspies have done? This study suggests that decisions about altering biomedical labels must include active consultation with the communities they impact, recognizing that these labels have been transformed into names, imbued with their own cultural capital.

Finally, NT-founded nonprofits, such as Autism Speaks, must recognize that the fear appeals used to address other health issues backfire when used to advocate for autism research and resources. Undoubtedly, all members of the autism community benefit from advances that make it easier for them to function in an NT-dominated world. Certainly, there are members of the autism community who struggle so much that a cure might be an attractive goal. However, stigmatizing autism by framing it as a source of terror and anxiety curbs an individual’s ability to (re)claim it as a part of who they are.

Limitations and Directions for Future Research

This study has several limitations. First, it focuses heavily on a single community with its own ideological stance. Future studies should expand to include different segments of the autism community, capturing a more nuanced understanding of its identity politics. In addition, this study only includes data from a four month time period. Given that new scientific findings, healthcare and diagnostic policies, and public statements by prominent autism groups impact the autism community, this window cannot capture the continuously evolving nature of an Aspie identity.

Logistical issues also affected this study. Difficulties with finding interview participants kept the number of interviewees quite small. Geographical separation, as well as participant preference, caused me to conduct several interviews via email, curbing their dialogic nature. Finally, my tactics for data management and analysis allowed me to develop overarching themes, but prevented me from investigating how identity management functions as an unfolding interactional process over the course of related threads and posts.

This project opens up several areas for future research. First, further research might enhance the practical impact of this paper. A quantitative follow-up study might pinpoint how involvement in communities like AC affect empirical measures of well-being. Second, my current data suggest that this site provides a rich opportunity for developing theories of social support. A future study might investigate what strategies for providing social support are utilized by individuals...
on the autism spectrum, or how social support is elicited and received. Finally, this topic area has much to contribute to the study of self-advocacy and social movements. How do members of communities like AC move from simply embracing an autistic identity to actively advocating on behalf of an autism community? On a larger scale, future research must consider how turning points like the change in the DSM stimulate or suppress self-advocacy.

References


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Appendix 1. Participant demographics

<table>
<thead>
<tr>
<th>Participant Pseudonym</th>
<th>Gender</th>
<th>Age</th>
<th>Ethnicity</th>
<th>Communities</th>
<th>Diagnosis</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alex</td>
<td>Male</td>
<td>30</td>
<td>Caucasian</td>
<td>Aspies Central (joined September 2011) and Spectrumville (joined June 2011)</td>
<td>Self-Diagnosed in 2008; Official Diagnosis in 2012</td>
</tr>
<tr>
<td>Anne</td>
<td>Female</td>
<td>29</td>
<td>Caucasian</td>
<td>Aspies Central</td>
<td>Self-diagnosed, 8 months</td>
</tr>
<tr>
<td>Carol</td>
<td>Female</td>
<td>18</td>
<td>Caucasian</td>
<td>Aspies Central, Spectrumville</td>
<td>Official; about 1 year</td>
</tr>
<tr>
<td>Elle Cee</td>
<td>Female</td>
<td>37</td>
<td>Caucasian</td>
<td>Aspies Central</td>
<td>Self-diagnosed, 2 years</td>
</tr>
<tr>
<td>Janice</td>
<td>Female</td>
<td>56</td>
<td>Caucasian</td>
<td>Aspies Central, was part of Wrong Planet</td>
<td>Official diagnosis in 1960s seemed inadequate, self-diagnosed Aspie for 10 years</td>
</tr>
<tr>
<td>Matilda</td>
<td>Female</td>
<td>51</td>
<td>Caucasian</td>
<td>Aspies for Freedom, dissatisfied with discussions on Wrong Planet</td>
<td>Official diagnosis; 8 years</td>
</tr>
<tr>
<td>Nick</td>
<td>Male</td>
<td>33</td>
<td>Caucasian</td>
<td>Aspies Central, Spectrumville</td>
<td>Semi-official; 2 years</td>
</tr>
<tr>
<td>Paul</td>
<td>Male</td>
<td>21</td>
<td>Caucasian</td>
<td>Aspies for Freedom</td>
<td>Official diagnosis; 13 years</td>
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<tr>
<td>Pella</td>
<td>Female</td>
<td>33</td>
<td>Caucasian</td>
<td>Aspies Central</td>
<td>Semi-official; 2 months</td>
</tr>
<tr>
<td>Rich</td>
<td>Male</td>
<td>39</td>
<td>Caucasian</td>
<td>Wrong Planet, Aspies for Freedom</td>
<td>Official diagnosis, 5 months total, 3 months diagnosed</td>
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</tbody>
</table>