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ORIGINAL PAPER

Biocertification and Neurodiversity: the Role and Implications of Self-Diagnosis in Autistic Communities

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Abstract Neurodiversity, the advocacy position that autism and related conditions are natural variants of human neurological outcomes that should be neither cured nor normalized, is based on the assertion that autistic people have unique neurological differences. Membership in this community as an autistic person largely results from clinical identification, or biocertification. However, there are many autistic individuals who diagnose themselves. This practice is contentious among autistic communities. Using data gathered from Wrong Planet, an online autism community forum, this article describes the debate about self-diagnosis amongst autistic self-advocates and argues for the acceptance of the practice in light of the difficulties in verifying autism as a 'natural kind.' This practice can counteract discriminatory practices towards and within the autistic community and also work to verfiy autistic self-knowledge and self-expertise. This discussion also has important implications for other neurocommunities, neuroethical issues such as identity and privacy, and the emerging field of critical autism studies.

Keywords Autism spectrum disorder · Self-diagnosis · Neurodiversity · Scientific realism · Neurocommunities · Online communities

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We are collectively becoming "cerebral subjects" [1: 6], increasingly considering our behaviors, personalities, and temperaments as situated within, or, at the very least, deeply connected to our neurological structures and wiring. Largely associated with the "Decade of the Brain", there has been a dramatic rise in neuro-markets, marking what can be called a new "neuro-age" [2: 1162]. This age has permeated academic and professional worlds, generating such fields as neurolaw, neuropsychoanalysis, neuroeducation [1], and neurotheology [2]. These fields reflect a larger cultural trend of connecting selfhood with neurology, which leads to statements such as "we are depressed," rather than "we are feeling depressed." We *are* our brains, rather than we *have* our brains [1–5].

One outcome of framing identities in this way is the creation of neurologically similar communities. This approach is perhaps most prominent in the neurodiversity movement, which promotes the idea that autism,[1] and similar neurological conditions, are a natural part of the human community and should be accepted as such. Alongside this argument is a rejection of the need to normalize autistic behaviors and discover cures or remedies for autism. Thus, neurodiverse adherents often argue against the clinical perspective, which relies on a narrow medical model interpretation of autism as a tragic condition in need of a curing or alleviating rather than acceptance [6, 7]. Many members of

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[1] Autism Spectrum Disorder (ASD), or autism, is a developmental disability characterized by differences in communication, social behaviors, and self-management. It is highly variable in presentation; there is a wide range of expressions of all features of autism among autistic individuals.

the neurodiversity movement, namely autistic self-advocates and their supporters, grapple with an important feature of autistic identity—that of diagnosis. Autism is a complex condition that is difficult to diagnosis due to its highly variable expressions and constellations of traits. It is commonly identified in childhood by clinicians who support a biomedical perspective of autism. However, there are some individuals who, for various reasons discussed below, diagnose themselves. Some autistic self-advocates are apprehensive about this practice, often to the extent that they fully question all self-diagnoses or even choose not to recognize individuals who self-diagnose as part of the autistic community. Others, however, fully accept self-diagnosis, noting that those who recognize themselves in descriptions of autism are welcome into the autistic community.

In this article, I examine the role of self-diagnosis in neurodiverse communities by analyzing a range of reactions to this practice made on an online forum for and by autistic people called Wrong Planet. In particular, I am interested in exploring how self-diagnosis is discussed by autistic people and how it challenges biocertification—a process by which social identities are acknowledged and confirmed through medical, governmental, or psychiatric practices and documentation [8]. Those in the neurodiverse community define membership as related to a particular neurological profile, which is most often confirmed by professionals who rely on a model of autism that self-advocates reject. This tension leads to questions addressing the role of self-expertise in the autistic self-advocacy movement; whether and how professional diagnostic practices can be used in concert with a neurodiverse perspective; and autism within the realm of scientific realism. This research has implications for neuroethical issues related to foundations of neuroidentities, stigmas related to neurological difference, and professional authority.

By examining discussions of self-diagnosis on the well-known online autism forum Wrong Planet [9] within Ian Hacking's concept of making up people and the looping effect [10, 11] as well as Miranda Frickers' work on testimonial injustice [12], I propose that autistic self-diagnosis is a necessary feature of autistic communities and neurodiversity. These concepts, which are more fully described in the conclusion, frame my argument that self-diagnosis is a response to the inability of science to confirm autism as natural kind and is an act that is devalued because of the presumed unreliability of autistic voices. Furthermore, it is an act that directly contradicts widespread notions that autistic people are unable to be autistic self-experts. As a result, biocertification can be used as a means to verify self-expertise to the wider public, becoming "both external imposition and internal desire" [8: 149]. However, an insistence on biocertification is impractical because of the dynamic nature of autism-related definitions and concepts, which contribute to real challenges in obtaining adult diagnoses and diagnoses for less apparent manifestations of autism.

After contextualizing these issues within the history of defining autism and neurodiversity as well as a brief overview of biocitizenship and biocertification, I present data from Wrong Planet to demonstrate arguments for the acceptance and rejection of self-diagnosis. This data will then be discussed and situated within debates on broader neuroethical issues related to neuroidentity and the role of the patient as a self-expert as well as within the emerging field of critical autism studies.

Diagnostic Histories

Currently, autism, or Autistic Spectrum Disorder (ASD), is diagnosed based on professional observation and/or parental developmental report of a variety of social, communicative, and behavioral traits. Previous editions of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM) included a category called Autism Spectrum Disorders comprised of several separate diagnoses, including autistic disorder and Asperger's syndrome. The current DSM 5 has collapsed this category into only one diagnosis, Autism Spectrum Disorder. ASD has lists of traits placed into two categories: social communication and interaction, and restricted, repetitive behavior and interests. The traits must be present in early childhood [13]. Since the 1940s, autism spectrum disorders have cycled through various iterations of diagnostic criteria, becoming broader and including people with varied behavioral and cognitive profiles [14].

Of note, these diagnostic iterations and most literature about autism have historically been and continue to be focused on autistic *children*. There are many reasons for this, including the fact that adults with developmental or intellectual disorders are difficult to identify in communities once they have aged out of the school system, which, in the U.S., is at 21 years of age. With little scientific or academic literature on autistic adults, diagnosing this population remains difficult, particularly in cases where diagnosis was missed in adulthood and in lower income families [15], and has contributed to the unique phenomena of autistic self-diagnosis.

Neurodiversity

Neurodiversity is connected to the wider disability rights movement and the field of disability studies, which "explores the social, cultural, and political dimensions of the concept of disability and what it means to be disabled" [16: 2]. A large part of this exploration is the preservation, rather than eradication, of disability and difference, or human biodiversity [16]. Disability scholars and advocates reject the rhetoric from medicine and science that define disability as a flawed aspect of an individual in need of fixing or curing [17]. This perspective, often referred to as the medical model, defines disabilities like autism as an individual problem that needs to be remedied by clinical and medical professionals. Autistic people[2] have something 'broken' about them that must be fixed [18–20].[3]

Neurodiverse and disability rights advocates reject this perspective in favor of some iteration of cultural and social models of disability, which consider disabilities, including autism, as cultural communities of individuals whose bodies and minds mis-fit with physical and social surroundings constructed for the "normate" [23: 8]. The disability, then, is located in the interaction between particular types of bodies and minds and their wider milieu rather than in the individual [21]. Supporters of neurodiversity consider autism to be situated in neurological differences; autistic brains are different but not deficient. These differences, adherents argue, should be neither cured nor normalized but accommodated, accepted, and made more visible to non-autistic individuals and communities [6, 7, 22]. Because neurodiversity relies on defining autism as a distinct kind of brain, this movement demonstrates a particular kind of neuroidentity, one that is dissimilar from 'neurotypical,' or non-autistic, brains and, therefore, people.

The notion that autistic people have definitive, yet unknown, identity-forming neurological differences relies on an acceptance of cerebral subjectivity. Interestingly, this perspective takes a concept often thought to be individually reductive—that our selfhood can be controlled and determined by the structures of an, albeit important, organ: the brain—and turns it into a rights-based model and framework for participation in a neurological community [4, 23]. This strategy is employed as a way to strengthen identity and self-understanding while also reducing stigma and creating new social connections and a shared set of values. There is, however, a threat of homogenizing what is known to be a highly heterogeneous community by narrowing the spectrum of who is considered autistic through necessitating some sort of neurological profile [23, 24].

The difficulty in defining a highly variable group to generate a collective effort for social justice and acceptance is an issue the wider disability rights movement has struggled with for many years. Disability advocates and scholars continue to propose how to best define disability [25–27]. Some advocates assert the universality of disability, noting that everyone will experience disability in their lives, and others focus on definitions that include specific impairments and biological states of being. Definitions depend on one's overall aim: gaining specific accommodations based on type of disability or developing a large, unified front with a powerful voice [26]. For example, there is a split between people with physical disabilities and those with psychiatric or intellectual disabilities. Often, individuals with physical disabilities do not want to be associated with the stigmas connected to psychiatric and intellectual disabilities and those with psychiatric and intellectual disabilities find that efforts towards infrastructural modifications to improve access to space does little to address their needs [22, 28]. The difficulty of defining who belongs in the autistic community, and how to represent the diversity within, emerges in the online discussions on self-diagnosis compiled for analysis here.

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[2] Autistic self-advocates find autism to be central to identity formation and thus prefer to use the phrasing "autistic person" rather than "person with autism." The latter phrasing reflects the well-known and oft preferred phrasing of people first language, which attempts to linguistically represent a person as more important than a disability by saying "person with schizophrenia" or "person with mobility impairments." Although this phrasing is still often used in reference to other disabilities in the disability rights movement, autistic self-advocates reject this phrasing noting, again, the importance of autism on identity and that person-first language seems to reflect a need to remind others that autistic people are, in fact, people [6, 7]. In this article, I use language reflective of neurodiversity and so will be relying on the phrasing preferred among autistic self-advocates: 'autistic people.'

[3] Philosopher Ian Hacking discusses this model as it relates to the popular and widespread use of the puzzle piece as a symbol of autism hacking [52].

Similar to the notion that everyone is disabled, a proposed neurodiverse spectrum, one that includes all human neurological outcomes, including neurotypicality, may address the concern that a concept of autism based on neurological difference will result in a restrictive and reductive community. Within a neurodiverse spectrum, autistic people can be positioned as a specific and distinct group with a set of values connected to the group's identity and needs. In this way, autistic individuals concurrently utilize both narratives of alignment with and distinction from the wider human population [4]. A similar approach is used in self-diagnosis; some autistic self-advocates simultaneously utilize the validity of professional diagnostics and question the approach of the very professionals who provide these assessments, or biocertifications.

Biocitizenship, Biocertification

Biological citizenship, or biocitizenship, is a relatively new term that emerged to describe the phenomena of linking biological features to personal and social identity, most often in efforts to claim rights and support. The term was coined by anthropologist Adriana Petryna in her research on Ukrainian survivors of the Chernobyl nuclear disaster. She used biological citizenship to describe the utilization of the biological damage resulting from radiation exposure as "grounds for social membership and the basis for staking citizenship claims" [32: 5]. Here, classic citizenship failed to provide support for basic biological survival and so affected individuals realigned their social identities to demand medical, scientific, and legal recognition of and compensation for biological injury.

Later, sociologists Nikolas Rose and Carlos Novas discussed the term's historical application as any instance in which human beings have linked themselves with others based on some concept of a "biological existence" [33: 440]. Here, biocitizenship is described as a tactic that is simultaneously "individualizing and collectivizing" [33: 441]. As it collects individuals into biologically similar groups, biocitizenship relies on an individual's ability to deeply know their somatic selves. Rose and Novas outlined the differences in creating biological citizens from above and below. The former strategy, that of relying on clinical definitions and treatments of biologically linked groups, finds scientific authorities unproblematic. The latter strategy introduces, and often emerges from, doubt in these authorities [29]. It is this latter strategy on which the neurodiversity movement is built. By questioning the pervasive clinical and scientific belief that autism is a condition requiring normalization, cure, and eradication, groups of autistic individuals have found a community that is reliant on their common neurological identity and their common desire to question the practices of the hegemonic medical authorities asserting those claims.

Interestingly, however, it is often these authorities who determine membership in certain biological communities. One must be officially diagnosed as biologically harmed (as in the case of the Ukrainian victims of the Chernobyl disaster) or biologically different (as in the case of autism). In other words, an affected person must attain some sort of biocertification to gain services and, often, access to a community as a biocitizen. Disability scholar Ellen Samuels defines biocertification as the requirement of official documents "to authenticate a person's social identity through biology, substituting written descriptions for other forms of bodily knowledge and authority" [8: 122]. As I demonstrate in my analysis, it is the latter half of this statement, the disregard for self-knowledge, that becomes important to the issue of self-diagnosis of autism.

Self-Diagnosis

The role of biocertification in autism is critical to, at the very least, clinical and medical authorities but how this practice fits within neurodiversity and self-diagnosis continues to be debated. Self-diagnosis is relatively unique to autism within the realm of chronic conditions of the mind (i.e., psychiatric, developmental, and intellectual disabilities). A brief exploration of an online community for people with schizophrenia—which is comparable to Wrong Planet in terms of attitudes towards medical authorities by people with a life-long, identity forming condition of the mind—revealed self-diagnosis not to be an issue. As one poster stated in response to my introductory post (described below), "Sz [schizophrenia] is hard to diagnose on one self. Usually you don't think there is anything wrong with you when you become ill." Additionally, although people often self-diagnose or identify as depressed or anxious, this type of self-diagnosis rarely results in aligning oneself with an active rights-based movement like neurodiversity or, in the case of schizophrenia or similarly significant psychiatric conditions, the Mad Pride Movement.

Self-diagnosis among autistic individuals primarily occurs in adults. Online forums and public statements made by autistic self-advocates list a variety of reasons adults may self-diagnosis, including misdiagnosis or a lack of diagnosis in childhood; unawareness of a childhood diagnosis; lost or destroyed childhood records; fear of workplace or insurance discrimination; financial, geographic, class or race-based barriers to diagnostic practices; and/or distrust of the psychiatric profession or, similarly, not considering autism as a 'disease' that requires a diagnosis [30]. These sentiments are shared by many of the posters on Wrong Planet who support self-diagnosis.

The issue of self-diagnosis is an unresolved and controversial one within the neurodiversity movement and among autistic self-advocates. As one poster noted in response to my introduction on Wrong Planet: "[T]he subject of self-diagnosis is a perennial one here and generally causes heated discussion." These discussions reflect the tension between self-advocates two aims: on the one hand, the desire to create accepting, judgment-free safe spaces for autistic people to meet and be themselves; and, on the other hand, the need to ensure this safe space is not exploited or infiltrated by the very people from whom autistic people wish to be protected.

Wrong Planet: Methods and Results

Wrong Planet was created in 2004 as an online community developed by and for autistic people. It can be assumed that autistic people who seek out a site like Wrong Planet do so after feeling somewhat dissatisfied with their connections in their home lives and, often, the attitudes about autism encountered in daily life. Finding a community that accepts and celebrates autism is often the result of disliking common attitudes about autism in one's community along with a desire to find and connect with people who share the autistic experience. Wrong Planet meets these needs by hosting forums for discussions on a wide range of issues important to the autistic community as well as areas for articles, videos, and information about employment, schools, and parenting [9, 14]. In an effort at full transparency, prior to combing through Wrong Planet and Schizophrenia.com for conversations on self-diagnosis I posted a message announcing my presence as an autistic advocate and researcher interested in self-diagnosis. I included a brief description of biocitizenship and biocertification to give context to my research and offered to answer questions and take comments. This announcement not only ensured that I would not be secretly exploring these sites but also led to some insightful comments and a tip on a recent thread from June, 2015 that specifically addressed the issue of self-diagnosis. It was from this thread that the majority of the data presented here was found as it reflects the most current thoughts from this population on the topic of self-diagnosis. Interestingly, the thread was started by an autistic woman asking: "Why is there a lot of hatred towards people who self-diagnosis themselves with Aspergers or autism?"

Using this thread and a forum search for "self-diagnosis" (and "self diagnosis"), I read and categorized comments into three primary sections: accept self-diagnosis, reject self-diagnosis, and middle of the road. Comments in each section were further separated into similar themes; I will focus on three themes in the reject and accept sections in order to explore the more common attitudes and approaches to self-diagnosis. Those rejecting self-diagnosis argue for the need for professional training to diagnosis autism, not wanting self-diagnosed individuals to represent autistic people, and the influence of the media to motivate scammers. Those who accept self-diagnosis primarily focus on being a self-expert, rejecting the medical model, and the infeasibility of obtaining a diagnosis in the adult years.

Reject Self-Diagnosis

The most frequently stated reason for rejecting self-diagnosis was the need for professional training to accurately diagnosis someone with autism. As one poster explained:

> I dislike when somebody diagnoses themselves [*sic*] and then expects everyone else to take it the same way as if it came from a doctor. What gives them the idea that their opinion on this matter has any more weight than it would on any other health issue? Doctors go to school a long time to learn to diagnose and treat things, and if it were as simple as an internet test and asking people what they think they have, and they could get an accurate dx [diagnosis] that way, why wouldn't they just do that then?

At first blush, it seems this statement directly contrasts with the overall purpose of many disability-related online communities, which are often "set up independently from, or even in direct defiance of, the health profession" [35: 421]. However, despite the frequent rejection of professional approaches, many in the autistic community recognize that diagnosis is a complex issue, one that can be clouded by self-bias. In other words, diagnosis may be acceptable while normativizing practices and attempts at cures are not.

Though autistic self-advocates assert their experiences as an autistic person as more informed than the researchers and professionals who claim to be experts about autism, for some in the community, the road to being an expert on your own condition begins with confirmation from the outside; it begins with biocertification. "The autism traits are to be matched with individual traits from the outside," one member explains, "not the inside, so self-diagnosis of matching outside autism traits with inside individual traits is misuse of diagnostic criteria." Several posters noted a "substantial amount of training, experience and an 'outsider' viewpoint [as] necessary for a diagnosis" and others go so far as to explain that, without this diagnosis, people are not and cannot be autistic. If the autistic traits of those who self-diagnosed have not caused enough distress to warrant a professional diagnosis, some argue, the person does not really have autism. This is a belief expressed in many arguments against self-diagnosis.

Self-diagnosis is sometimes compared to instances in which self-observation is accurate enough to treat illnesses with over-the-counter medicine, such as colds, lice, or the flu, and, thus, is not serious or complex enough to warrant professional intervention. In this way, many find self-diagnosis "make[s] the label illegitimate to those who need it." Until a professional diagnosis is obtained, many self-advocates argue that the label is just a guess, similar to how people often guess that they have the flu or a migraine.

Additionally, many posters pointed out that it is nearly impossible to set aside one's own bias towards oneself to accurately judge the presence or absence of autism. One poster stated: "Self diagnosis contains the risk of self confirmation bias. The idea is that the self diagnoser wants an explanation will sub consciously [*sic*] find reasons why they have autistic traits. More generally it is felt an outside observer can be more unbiased observer of yourself then you can." Another poster shared a similar sentiment, comparing self-diagnosis of autism to one of chest pains:

> I believe its because of the rule that psychologists go by "You cannot diagnose yourself nor can you diagnose your family". As people we either think too highly of ourselves or we think too lowly. It would be like someone who said "I feel pains in my chest so that means I have heart problems" when really if they were properly diagnosed they would find out they really had heartburn problems which isn't related to the heart at all. Same concept with someone self-diagnosing with Autism or any other disorder.

By comparing the leap from heartburn to heart problems, this poster is also suggesting that those who self-diagnose are exploring traits or symptoms of something much less significant than autism. The argument that professional experience is necessary for correct diagnosis is wrapped up in beliefs that one is biased about oneself and that autistic traits that have not garnered professional or personal attention until adulthood must be features of some other, less significant condition. Or of no condition at all.

Thus, some self-advocates not only question if people who self-diagnose actually have autism, but also openly question whether they even have autistic characteristics. One poster stated:

> i [*sic*] have seen people on this board who have argued that the diagnostic requirements for asperger [*sic*] system should be changed because they personally do not fit them. they [*sic*] assume completely that they have asperger syndrome and complain that they are socially successful, have abundant empathy, no sensory issues and an advanced theory of mind along with many other traits that are antithetic to the diagnostic requirements.

Like previous comments, this statement reflects the need for a certain level of impairment and life-long difficulties in order to be granted membership in this autistic community, something that self-diagnosis supporters argue strongly against. Questioning the legitimacy of someone's diagnosis demonstrates the difficulty in creating and defining a unified neurodiverse community. Because of the wide array of autistic manifestations, many autistic people find it difficult to relate to other autistic people who have dramatically different autistic profiles. There is a wide range of lived experiences among the autistic community, making it difficult to develop, or even support, a unified autistic position on issues of accommodation needs, stigmas, and navigating the neurotypical world. Although the topic is beyond the scope of this article, the issue of how or whether people with various manifestations of autism can accurately represent one another is an important one. As noted below, indications of this concern exist throughout conversations about self-diagnosis.

Representation and illegitimacy are central to the other primary concerns self-advocates have with self-diagnosis: a disconnect with self-diagnosed individuals and the presence of scammers. Some posters expressed no real problem with self-diagnosis until those who self-diagnose, as one member put it, "try to be ambassadors to lay people who they misinform about the subjective experience of being AS [autistic]." In other words, individuals who suspect that they are autistic, but are not professionally confirmed to have autism, should not advocate as an autistic person for the autistic community. One poster likened this to speaking "for autistics who are very low functioning and say[ing] that I'm speaking for them from the same place they are coming from." Some autistic people who reject self-diagnosis see something fundamentally different between suspecting oneself to be autistic and the experience of carrying the professional diagnostic label, which, here, is the equivalent of truly being autistic. Again, underlying this statement is the recognition of a wide variability of autistic manifestations and, consequently, the consequences this variability has for who can represent the community and exactly what rights, needs, and values are most important.

Questioning the level of impairment of people who self-diagnose is also evident in statements regarding the possibility that people are claiming to have autism for secondary gains. Despite disability-related stigma, many self-advocates feel as though, as one member put it, "some people WANT to has [*sic*] AS or ASD [autism] as some people think it would make them special. […] Some people also seek a diagnosis simple [*sic*] because of welfare or disability pay." While some people who self-diagnose are suspected of doing so for these benefits, including the benefit of accessing a supportive online community, people with an official diagnosis are legitimated because autism is complex and difficult to reliably fake in front of a trained professional.

Many posters relate this phenomenon to contemporary media representations of autism, which often exoticize autism and autistic people. Unfortunately, media representations are rarely accurate and, as with most representations of disability in the media, serve purposes other than showing the presence of autistic individuals in our communities, such as soliciting pity (and money) from the non-disabled viewer or existing as an interesting plot point [20, 22, 31]. Autistic characters are frequently portrayed as quick and easy moments of comedic relief and as individuals who can, at least occasionally, be cured by love [32]. These are the types of representations that self-advocates believe contribute to the motivations to 'fake' autism. As one poster explained:

> In the last 15 years have been [*sic*] fictional television portrayals of high functioning Autistics/Aspies's [*sic*] as socially awkward funny geniuses. That has led to a feeling there are many Aspie wannabees. People that read a few things about autism on google [*sic*] decide they are autistic because they think it is cool or trendy or to use Autism as an excuse for bad behavior.

Celebrities who have recently 'come out' as autistic are also pointed to as reasons people may claim to be autistic without an official diagnosis or without actually having autism. In recent years, popular media outlets have reported that Daryl Hannah [33], Dan Aykroyd [34], and Jerry Seinfeld [35] have all claimed to be autistic (although Seinfeld later retracted that statement [36]) and many have proposed that other celebrities, such as Bill Gates, Mitt Romney, and Dennis Rodman, could be autistic [37]. The popularity of autism is evident in modern media, leading to a rise in recognition of the term and a new, albeit narrow, perception of what autism entails. Some self-advocates believe that increasing representations in the media demonstrate that autism is a current psychiatric fad and this new attention has contributed to a rise in people claiming to be autistic.

Other reasons stated for rejecting self-diagnosis included comments suggesting that the process of diagnosis is a rite of passage for the autistic world, that diagnosis is useful for obtaining accommodations, that diagnosis is useful for confirming what is already felt/known, and that self-diagnosis is just plain disliked. Most of these categories are fluid, running into and overlapping with other categories. However, there are strong arguments in favor of self-diagnosis, including the importance of self-expertise, the rejection of the medical model, and barriers to getting a diagnosis. These arguments are primarily responding to, or generate responses about, the need for training and experience to accurately diagnosis autism.

Accept Self-Diagnosis

The most common response to those who challenge self-diagnosis is a strong suspicion of medical and therapeutic professionals and the wider scientific community. This is one of the primary motivations for the creation of online communities like Wrong Planet and is important in considering the acceptance of people who self-diagnose. One poster states:

> I think people become deeply conditioned to believe that 'the experts' know it all. The problem is such 'expertise' is very often normed on a certain set of people, and if you do not belong to that category, no matter how much you feel your reality, it becomes harder to get official validation for it.

This poster went on to compare this situation to a history of misogynistic and colonialist scientific practices and attitudes. Other posters agree, stating that, "[n]o diagnosis is guaranteed to be accurate," "I don't exactly trust that the 'experts' have it all together," and that professional psychological diagnoses are "just guesses most of the time." There are two primary features to this argument: (1) that clinicians are no better at diagnosing autism than autistic people and (2) that autism diagnoses are so variable that they are, or might as well be, guesses. This attitude is connected to the anti-psychiatry movement that began in the 1960s and 1970s [38, 39] and is reflected in neurodiversity and Mad Pride Movements, which find modern psychiatric and scientific practices in mental health suspicious and lacking in input from patients and their families [28].

An official statement regarding self-diagnosis signed by several prominent autistic self-advocates on autistics.org expresses full support for people who self-diagnose. Recognizing the many challenges presented to adults (and some children) in obtaining a diagnosis, they state: "What ties us [the authors] together is that we believe a person is equally autistic whether or not they have a piece of paper, that autistic people can have the knowledge and insight to understand we are autistic just as non-autistic people understand that they are non-autistic…" [30].

This statement expresses another common argument in support of self-diagnosis: that of the autistic self-expert. Most self-diagnosed autistic adults find that, after learning about and researching autism, they have the self-awareness to state confidence in having autism. Engaging in informational biocitizenship, or the process of gaining knowledge about one's condition, is central to this process. Rose and Novas described informational biocitizenship as a process integral in becoming a biocitizen, however their description situates this process as occurring after diagnosis [29]. In the case of self-diagnosis, informational biocitizenship precedes and allows for the self-determination of an autism diagnosis. Thus, unlike officially diagnosed individuals who are often diagnosed in childhood and learn about autism and neurodiversity after obtaining the label, those who self-diagnose flip the process by learning about autism then deciding the label appropriately describes their lived experiences.

The information garnered through the process of informational biocitizenship combines life experience and self-knowledge to enable autistic self-advocates to assert themselves as experts on autism, more so, many argue, than the professionals studying, diagnosing, and treating autistic people. The figure of the self-expert is often placed in direct contrast to the construction of the flawed professional expert. "I would venture to suggest" one poster explained, "that people with autism know more about it than mental health professionals. Professionals can only see the symptoms, we know about the experience." Another Wrong Planet member stated: "People know themselves far better than any psych [*sic*] could ever know them and given the right information are in a much better position to diagnose themselves than a psych [*sic*] would be." This particular poster went on to explain that she actually obtained a diagnosis and that, although it was useful in confirming what was already known, she received "nothing concrete out of it in terms of help." Again, distrust (or, perhaps, distaste) for the professional community is evident in this comment.

Self-knowledge is privileged over professional knowledge even when an official diagnosis is later sought. Like the member quoted above, many people who obtained an official diagnosis after self-diagnosing felt a sense of confirmation, which some posters placed higher value on than others. Similar to Brownlow and O'Dell's work on online autistic communities, many posters here recognize the power of an official, professional diagnosis even while placing a higher value on self-knowledge and self-diagnosis [40]. Outsider, professional knowledge and biocertification are used largely as confirmation of self-knowledge to other outsiders, including, when necessary, other autistic self-advocates.

Clearly, a belief in the credibility of one's expertise in autism via lived experience is closely associated with distrust of the psychiatric and medical professions. Just as those who reject the ability to self-diagnose claim that autism is too complex to be self-identified, those who accept self-diagnosis claim that the lived experience is more important and complex than clinical assessments. So much so that self-diagnosis is not only acceptable but, to some extent, preferred. One poster even suggests that many professionals accept the validity of self-diagnosis: “I’ve read plenty from autism experts and many of them think many times if someone comes to think they have autism chances are they do, I mean I’ve heard that so much its almost like a catch phrase.” Thus, the expertise of autistic individuals becomes validated even within the medical model paradigm being rejected by the community.

As noted above, self-diagnosis in the autism community is likely tied to the focus on children in autism-related diagnostic and direct care professions. This is the third commonly cited reason for accepting self-diagnosis. As is the case with many bio-communities, medicine and health care is inaccessible to all but the biocitizens with the means and, sometimes, prestige to access care [41]. Similarly, autism diagnoses in adulthood are often geographically or financially inaccessibly. This is particularly true when coupled with the challenge of finding a professional who can and will diagnose adults. One poster explained: “It is not always so easy once you are an adult and no longer a cute little kid. If you don’t have insurance most therapists won’t even talk to you. That’s IF you can find an autism specialist. They are all in the big city and I can’t handle city traffic…” Another member agrees, stating,

> Autism is so child-focused and Aspergers so relatively new and underdiagnosed that there just aren’t adult specialists. I’ve just read several comments about all of the behavioral traits being identified by a psychologist but the diagnosis missed. The professional community simply isn’t capable of the type of Aspie diagnosis and support that is needed, especially outside of major metropolitan areas and top-tier medical/psychological campuses.

Other posters pointed out the expense of obtaining a diagnosis, especially when insurance does not cover these very expensive assessments. This is particularly salient in a community that has difficulties obtaining and sustaining reliable employment [42, 43]. Further, many posters stated that obtaining an official diagnosis may prevent future employment opportunities. Discrimination based on an autism diagnosis is a significant concern.

> I’ve also read that diagnosis as an adult Aspie can be dangerous, and based on recent experience I believe it. It can lead to discrimination where there would be none if you disclose to an employer or have a diagnosis in your medical records. You could be fired, passed over for a deserved promotion or charged more for insurance.

Self-diagnosis is a considerable alternative for adults who are looking for an explanation for lifelong feelings of alienation and misunderstandings with their communities. Many advocates of self-diagnosis assert this reason as the driving force behind looking into autism and deciding to self-diagnose. As one poster aptly explained:

> Self-diagnosing has given me some peace of mind about my own behavior and “quirks” (for lack of a better term). That’s all. No one else “has to” accept that it’s “really true” - it’s simply “true enough” for myself. I am not looking for “special treatment” - in fact, quite the opposite: having “labeled” myself with AS enables me to “check” myself and adapt to daily living far better than if I didn’t “know.”

For many, the value of self-diagnosis lays largely deepening self-knowledge. Other reasons for not obtaining an official diagnosis—distrust of the medical model, belief in one’s self-expertise, and the inaccessibility of getting diagnosed in adulthood—add to the motivation for self-diagnosis.

Discussion

The data presented above provides the foundational arguments for and against the acceptance of self-diagnosis in the autistic community. As of now, this particular issue is far from resolved. One side claims that, not only must one be a professional to adeptly identify autism, but those who self-diagnose cannot accurately represent the autistic community to the outside world. There is also a heavy emphasis on the legitimacy of those who self-diagnose autism. The other side claims that those who self-diagnose are seeking better self-understanding and that professional diagnoses are not only highly inaccessible, but frequently wrong.

This debate is closely connected to discussions on the validity of scientific realism. This is the notion "that scientific theories correctly describe the nature of a mind-independent world" [44]: 4]. In other words, the things that science describes are real things that exist outside of human construction. Perhaps more related is the newer concept of neuro-realism, which asserts neurological findings make certain phenomena real and objective, especially in the public imaginations [45]. There are various ways these concepts are implemented and there are significant criticisms of them. As it applies to autism the question becomes: is autism a 'real' thing? Or, as social theorist Ian Hacking asks: are autistic people subject to the process of making up kinds of people and the looping effect? His framework for how kinds of people are made up begins with the classification of people. Once classes of people are delineated, individuals become considered as situated in and extensions of these classes; they become labeled. There must also be institutions that interact with these classifications and knowledge created about these classes, or kinds, of people. And finally, there must be experts who study, classify, and treat the classified people [11]. This framework clearly applies to autism, which has generated a host of experts, clinics, and diagnosed individuals since the naming autism in the 1940s [14]. Thus, the 'realness' of autism as a natural kind is in question [10]. This is not to say that autism is not real in the sense of lived experiences, rather this framework suggests that autism is an unstable category created by humans and is alterable by time, information, and the individuals who are identified or who identify with the label.

It is widely accepted that the way autism is defined and diagnosed has changed over time. Hacking's looping effect, which states that when knowledge about a group of people changes so does that population, can be and has been applied to autism [4]. In other words, the way autism is defined impacts the population being classified which, because of variable autistic expression and development, alters the definition of autism. The role of self-diagnosis, which is significant, can be seen as either a negative or positive contribution. Those who assert that a person is not likely to be truly autistic if one's autistic traits are not significant enough to warrant professional attention and diagnosis may also see self-diagnosis as endangering the definition of autism, making it overly inclusive and broad. Advocates in favor of self-diagnosis who argue that professionals still do not know enough about autism to understand all expressions of the condition (or, likely, conditions), especially among adults, would argue that self-diagnosis is acting to further refine the definition of autism by presenting cases that medicine misses. Thus, because there is no confirmation of autism as a real thing, or as a natural kind, the looping affect changes the way autism is defined and conceptualize, thus opening up the possibility of self-diagnosis being as valid as a professional diagnosis.

Rose and Novas' concept of "ethical pioneers" [29]: 450], or biocitizens who collectively develop "a new informed ethics of the self—a set of techniques for managing everyday life in relation to a condition, and *in relation to expert knowledge*," [33: 450; emphasis added], describes the way the neurodiverse community is redefining itself. As neurodiversity grows, autistic self-advocates are increasingly asserting themselves as *the* autism experts and so must decide how to contend with the more widely accepted experts, i.e., the doctors, therapists, academics, and researchers who speak about, and often for, autistic communities, but who, as neurotypicals, cannot fully understand the lived experience of autism. As demonstrated above, even those who accept self-diagnosis still recognize the influence and authority of official diagnoses while accepting that, because autism is not a 'natural kind' with infallible or definitive identification measures or definitions, there are many who fall outside of currently used professional biocertification methods.

For now, autistic ethical pioneers are contending with the values and uses of available professional practices, such as diagnostic measures. Given the influence of professional authority, autistic self-advocates can either (a) use outside authority to both ensure and express their stated expertise or (b) point out the hegemony and discriminatory practices of outside authority and fully reject required engagement with these practices. These options lead to important questions such as: can one obtain credibility as an autistic self-advocate without utilizing the tools imposed by the professional community to affirm one's membership in autistic communities? And, should official diagnoses be used to situate autistic self-advocates as the experts they claim to be? These are the questions that must be addressed when exploring the option to rely on professional diagnoses to affirm membership in the autistic neurocommunity.

Reclaiming and using diagnosis for the needs of an advocacy community is one way to promote the requirement of official diagnoses within a neurodiverse community. In other words, self-advocates may rely on diagnosis to validate placement in the autistic community and still, post-diagnosis, resist other normativizing practices and definitions. This practice would be an attempt to overcome testimonial injustice, the phenomena in which individuals are deemed incredible because of prejudice from outsiders [12]. This practice is a primary threat to respect for self-expertise and, thus, self-diagnosis. Due to the fact that autistic people are considered to have difficulties with self-awareness, a generalization that inaccurately describes autistic people, their ability to self-diagnosis is automatically questioned, necessitating, for some, expert opinion.

Once one's self-expertise is verified and asserted without the need for biocertfications, and testimonial injustice is overcome, there may be a cultural shift towards widespread acceptance of autistic individuals as valued, self-aware members of the human community whose specific needs and accommodations will be respected. To reach this goal, some may argue for initially relying on biocertification to verify self-diagnoses to encourage respect for the self-expertise of autistic individuals and reduce stigmatizing attitudes. It could also be argued that this practice would address the issue of who can represent the community. Those who reject self-diagnosis feel uncomfortable allowing those without official diagnoses to speak for the community because the community may not listen unless they have first been vetted by outsiders. In other words, some autistic individuals reject self-diagnosis not because they consider autism to be a natural kind identifiable only by experts, but because the general, normative community does. Perhaps regular confirmation of self-diagnosis with current diagnostic practices would lead to more tolerance of the practice outside of autistic communities, leading to more acceptance within autistic communities.

On the other hand, it is evident that many self-advocates feel as though employing the diagnostic techniques of the medical and scientific community regenerates the discrimination and abuse being fought against with neurodiversity. The official position from autistics.org cited above notes that, regardless of the verification official diagnoses may provide, it remains a personal decision that requires a consideration of the various barriers to obtaining a diagnosis. Additionally, "… it invades our privacy to request our medical records. We believe it would be discriminatory on the basis of disability, culture, income, social class, and age, to view someone's status as suspect on these grounds." Here, the imposition of an official diagnosis is a form of internal discrimination. Generating more stigma related to autism is counter-effective towards generating more accepting attitudes towards ASD. And, as the data from Wrong Planet exemplified, there are significant barriers to obtaining a diagnosis in adulthood, when most self-diagnoses need to occur. While official diagnoses could, on the one hand, lead to wider acceptance as an autistic self-expert, when required within neurodiverse communities, it can replicate the very measures the community is designed to combat.

Limitations and Future Directions

These opposing perspectives are connected to deeply held beliefs about the ways in which autism has been dealt with and constructed in professional and clinical paradigms. The role of and attitudes towards self-diagnosis is a largely understudied issue, but one that reflects the important perspectives of autistic self-advocates and the neurodiverse community more broadly, particularly attitudes towards professional practices. Future research needs to be conducted to clarify these positions throughout the autistic community, particularly how they relate to other social identities such as class, race, gender, and sexuality that effect access to diagnostic practices as well as health care, education, and employment opportunities.

Although Wrong Planet is accepted as a site to assert autistic rights and as a location where autistic people can find a common community, it is also publically available so anyone can create an account and post in the forums. Thus, a range of attitudes towards professional practices is present. A deeper exploration into associations between attitudes towards self-diagnosis and other professional approaches, including behavioral or educational interventions and theories would provide important information about the nuances between diagnostic and other biomedical practices. Additionally, understanding how self-diagnosis relates to notions of having different neurological structures would clarify the process of self-identifying as this particular kind of cerebral subject as well as highlight desires for a neurodiverse spectrum and a distinct community with definitive borders and limits. In other words, learning more about the role of self-diagnosis within a community founded on the notion of a shared neuroidentity could lead to important information about how cerebral subjectivity is formed, defined, and used by bio- or neuro- citizens. This work will provide a more nuanced framework for the relationship between identity politics and neurology beyond simple acceptance or rejection of the brain as central to autistic, and neurotypical, personhood.

Given the ease with which individuals can access information about neurological disorders and profiles on the Internet, considering whether self-recognition of the traits found online and through conversations with diagnosed individuals is a legitimate method of identifying with a particular neuroidentity or disability is increasingly critical. As is reflected in the data presented here, accepting this method asserts individuals as experts of their own neurological experiences, however, it risks blurring the boundaries between pathology, normality, disability, and identity. Rejection of this process reinforces the authority of the medical profession, which has come under increasing criticism for over-pathologizing difference and internal biases [46]. Yet desires to identify with a neurocommunity are stronger than ever, particularly for clinical populations, who are more likely to seek out and identify with neurologically based understandings of selfhood [47].

Claiming membership in a neurocommunity may not only verify one's phenomenological experiences but also lead to a group of literally like-minded individuals who can support each other, identify common values, and argue for needed rights and accommodations. Despite this, the prospect of self-diagnosis seems to many to challenge this desired membership in a community, leaving open the possibility of blurring definitions of these communities by trusting self-knowledge and self-expertise. The autistic community is well-situated to explore these issues by identifying central positions on this topic and arguing that self-diagnosis is a process that should be taken seriously within both neurodiverse and biomedical communities.

As researchers continually attempt to verify autism as a 'natural kind' through genetic and neurological correlations, emerging findings will simultaneously challenge the ability of people to self-diagnosis and confirm the foundations of neurodiversity. Because neurodiversity relies on the assertion of distinct neurological differences from neurotypical people, the discovery of smaller, more conclusive groups of neurological profiles could disrupt the base on which neurodiversity is found. Reliance on neurological findings to support identity, or neuro-essentialism [45], is a consequence the autistic community may need to actively address. This practice could result in larger crisis of identification and force the autistic community to ask if autistic individuals should continue to band together under the behavioral traits that are currently used to refer to their distinct neurological differences even in the face of scientific findings of identifiable neurological profiles. This approach would lead to a larger group with which to support neurodiverse initiatives, but it would do so at the cost of reverting back to relying on behavior, rather than neurology, possibly undermining the very definition of neurodiversity. Further, obtaining a diagnosis that relies on the use of brain scans could make diagnosing adults easier, however it is likely to be even more financially and geographically unavailable than psychiatric and behavioral profiles. Thus, an even larger group of undiagnosed adults who relate to the autistic community yet encounter greater difficulties gaining access to it may emerge. Accepting self-diagnosis now could avoid these negative consequences of neuro-essentialism.

Wider Implications

As noted, this work has important implications for thinking about one's self-awareness and self-expertise in relation to identity and neurological status as well as for neuro-essentialism. The danger of equating cerebral subjectivity with neurological assessments communicates that individuals cannot accurately interpret their neurological experiences. This attitude discredits one's lived experience and, thus, may enhance stigmas of psychiatric disorders and prevent help seeking. Acceptance of self-diagnosis, both in the current absence of valid brain-based assessments for autism and when these assessments become available, asserts that individuals have the right and ability to evaluate their neurological profile. Doing so avoids the "solipsistic and reductionist ideology" [4; 442] that often accompanies cerebral subjectivities.

Further neurological findings related to autism means the neurodiverse community will have to face issues central to contemporary neuroethics, including neurological privacy and authority. In general, advances in neuroscience, such as brain imaging, bring both vast benefits and significant concerns. As more information is discovered about how our personalities, temperaments, and neurological diseases and disorders are structured in the brain, privacy and authority become serious ethical considerations. Who gets to control this information and whether entities such as employers, insurance companies, and educational systems can access personal neurological findings must be considered [48], particularly for something like the discovery of an autistic brain (or autistic brains), which has implications for task performance as well as interpersonal and communication styles. Although the discovery of neurological correlates could serve to validate one's experience as neurologically different, it could also suggest that autism is biologically and phenotypically inflexible [49]. Although neurological difference is central to neurodiversity and autism advocacy, increased neurorealism could bring harsher public stigmas, increase testimonial injustice and distrust of self-expertise, and increase efforts to alter or eradicate specific neurological differences found in autistic brains. Exploring how autistic self-advocates navigate these ethical concerns will illuminate the role of these issues for other psychiatric and neuro- communities.

In addition to these implications for important neuroethical issues, developing a deeper understanding of the nuanced ways in which autistic self-advocates use, reject, consider, and change professional clinical and medical concepts of autism as they relate to community membership is important to critical autism studies. This burgeoning field explores how autism and autistic people are interacting with larger power structures that have vast influences on the lived experience of autism [50, 51]. The different ways in which self-diagnosis is considered within the autistic community and how they relate to the medical and clinical professions is, thus, representative of wider concerns about the relationship between biocertification, identity, self-expertise, and psychiatric diagnostic practices.

As with many issues affecting the disability community, competing interests must exist alongside and in conjunction with each other. Neurodiverse adherents are debating how best to separate themselves as a neurologic collective while also asserting a desire to be accepted within the wider human community. Similarly, they are assessing the roles that biocertification and self-diagnosis play for those who find a home in autistic communities. Biocertification measures of a social identity often fall short [8], and even the discovery of neurological correlates carry the likelihood of false positives and negatives in addition to the challenges facing the community discussed above. It is important to investigate how the targets of biocertification are using and coping with these methods. As cerebral subjectivity becomes more relevant to personal identity, the power to discover and define one's neurological identity will have an increasingly wider impact.

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