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# Diagnostic Domain Defense: Autism Spectrum Disorder and the *DSM-5*

Kristin Barker<sup>1</sup> and Tasha R. Galardi<sup>2</sup>

<sup>1</sup>University of New Mexico and <sup>2</sup>Oregon State University

## ABSTRACT

A central mechanism by which medicalization occurs is through domain expansion, wherein an existing diagnostic definition widens to include cases beyond its original scope. This has been especially commonplace with respect to mental illness diagnoses. In contrast, there are few clear instances of domain contraction. The controversy surrounding the revisions to autism in advance of the publication of the fifth edition of the *Diagnostic and Statistical Manual of Mental Disorders (DSM-5)* is thus of considerable importance. Many autism advocates feared the new definition of autism would exclude a significant number of individuals who are already diagnosed. We examine lay claims making to this perceived instance of domain contraction through a content analysis of online reader comments to a high-profile *New York Times* article reporting on the *DSM-5* autism criteria. Our analysis points to an amorphous group of social stakeholders who express a variety of concerns about unabated medicalization. We also identify the stance of *diagnostic domain defense*, which is an oppositional response by laypeople with a personal connection to a diagnosis to a real or perceived challenge to the definitional boundaries of that diagnosis. Our analysis explicates the dimensions of diagnostic domain defense, which include its grounding in experiential certainty and anguish, and the accrual and deployment of diagnostic resources. We make a case for the utility of this concept for theorizing the relationship between lay claims making, diagnoses, and medicalization. We also make a case for the use of online reader comments as a way to unobtrusively study lay claims making related to pressing social problems in the Internet era.

**KEYWORDS:** autism; medicalization; diagnosis; lay experts; online reader comments.

The long-awaited fifth edition of the *Diagnostic and Statistical Manual of Mental Disorders (DSM)* was released in May 2013 at the American Psychiatric Association's (APA) Annual Meeting. The *DSM-5* represents the first major revision since 1994 to what is informally called the "Bible" of mental disorders. The revision process was rigorous and protracted. The document represents eight years of labor on the part of more than 1,500 mental health experts (Jeste 2012). The revision process was also publicly contentious. Not only were there well-publicized professional disagreements, but there was

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also public outrage over various proposed changes to the *DSM* (Anspach 2011; Whooley and Horwitz 2013).

The conflict surrounding the revisions to autism was among the most contentious. One controversial change in the *DSM-5* involves the collapse of several separate autism disorders listed in the *DSM-IV* into the single diagnostic category of autism spectrum disorder (ASD). At issue here is the elimination of the widely applied diagnostic labels of Asperger's disorder and pervasive developmental disorder not otherwise specified (PDD-NOS), by reclassifying them as part of ASD. The new diagnostic criteria are also restructured in a manner that significantly reduces the number of ways to be diagnosed with autism. Specifically, there were 2,027 different symptom combinations in the *DSM-IV*, but only 11 ways to be diagnosed in the *DSM-5* (Ferris 2012). Well before the criteria were formalized with the publication of the *DSM-5*, members of the autism advocacy community voiced their concerns that these changes would exclude many individuals who were already diagnosed and deny them access to needed treatment and services. The disquiet created around the autism revisions reveals just how much is at stake when it comes to how mental illnesses are defined in the *DSM*. It also reveals a larger story about the character and consequences of diagnoses as they relate to contemporary medicalization trends in U.S. society.

Sociologists have studied the medicalization of deviance and social problems for more than four decades (Bell and Figert 2012; Zola 1972). Medicalization is the process whereby human experiences come to be defined or treated as medical in character (Conrad 2005). The creation or discovery of a new diagnosis is one key way in which medicalization occurs (Jutel 2009; Zola 1972). But medicalization also occurs through domain expansion, wherein an existing diagnostic definition widens to include cases far beyond its original scope. The latter process has been especially commonplace with respect to mental illnesses (Conrad and Potter 2000; Horwitz 2002). In contrast, there are relatively few instances of contraction, where a diagnostic definition narrows in ways that effectively exclude some previously diagnosed cases. There are a handful of transient mental illnesses that appeared in particular places and times only to disappear entirely (e.g., fugue); and, a few diagnoses have been removed from the *DSM* altogether (e.g., homosexuality) (Bayer 1987; Hacking 1998). Nevertheless, demedicalization via diagnostic contraction appears to be infrequent and, as such, has been rarely studied by scholars.

Herein lies the importance of the autism controversy preceding the publication of the *DSM-5*. The public dispute affords an occasion to examine how concerned constituencies respond to a perceived instance of domain contraction. A naturally occurring opportunity for just such a study arose when an article appeared in *The New York Times* with the title, "New Definition of Autism Will Exclude Many, Study Suggests" (Carey 2012). The article, which was published more than a year before the publication of the *DSM-5*, drew considerable public attention. Among other things, it generated several hundred online reader comments. These comments are illustrative of the types of claims and counterclaims (Best 1987) laypeople make vis-à-vis the prospect of demedicalization.

In our analysis we highlight two sides in the often-heated debate within *The New York Times* online reader forum: an amorphous group of social stakeholders who discussed the costs of medicalization to society more broadly, and individuals whose lives have been personally affected by autism who argued for the importance of the existing diagnosis. We also identify the stance of *diagnostic domain defense*, which is an oppositional claim on the part of laypeople with a personal connection to a diagnosis, to a real or perceived challenge to the definitional boundaries of that diagnosis. Professionals and other market entities with a vested interest in promoting a diagnosis also engage in defending diagnostic boundaries (Conrad 2005; Lane 2007). However, our conceptual focus is on the opposition that emerges from laypeople's "experience-based expertise" (Collins and Evans 2002). Through this analysis, we explicate the dimensions of diagnostic domain defense, including its grounding in experiential certainty and anguish, and the accrual and deployment of diagnostic resources. We make a case for the utility of this concept for theorizing the relationship between lay claims making, diagnoses, and medicalization.

## BACKGROUND AND CONCEPTUAL FRAMEWORK

### The Autism Epidemic and the DSM

Individuals diagnosed with autism-related disorders exhibit mild to severe levels of impairment associated with their ability to interact and communicate with others (National Institute of Mental Health 2012). The disorder is sometimes first detected by parents or educators, but it is formally diagnosed by medical professionals (e.g., pediatricians, neurologists, psychiatrists, or psychologists) (CDC 2014). Although there is no known cause or definitive biomarker for autism spectrum disorder, the current biomedical understanding is that it is “a complex neurological and developmental disorder” that “affects the structure and function of the brain and nervous system” (National Institute of Child Health and Human Development 2014), which may have an underlying genetic basis (National Institute of Neurological Disorders and Stroke 2014). There is currently no cure for autism, but it is treated using pharmaceutical, educational, and behavioral therapies (CDC 2014). In sum, autism is defined by, studied by, and falls within the jurisdiction of medical researchers, clinicians, and therapists. That having been said, current autism expertise has been “co-produced” by a host of medical and nonmedical experts in tandem with parent experts (Eyal 2013; Silverman 2012).

In recent years, there has been a precipitous rise in the number of children diagnosed with these disorders. As reported by the Centers for Disease Control (CDC 2014), 1 in 88 children has an autism diagnosis, which represents a 78 percent increase between 2002 and 2008. Results from the National Survey of Children’s Health, based on parental reports, found a prevalence of diagnosed autism of 1 in 50 school-aged children (Blumberg et al. 2013). The extent to which this trend reflects better case ascertainment as a result of increased awareness and access to diagnostic services or a real increase in the prevalence of autism disorders remains unknown (Liu, King, and Bearman 2010).

There is some concern that the autism epidemic is, at least in part, an artifact of the widening definition of the disorder (Chamak 2007; Eyal et al. 2010). In 1943, the American psychiatrist Leo Kanner identified 11 children with a cluster of unusual behaviors, including “autistic aloneness,” “belated echolalia,” and “insistence on sameness.” Although the term “autism/autistic” appeared in the *DSM-I* and *DSM-II*, it was classified as a manifestation of childhood schizophrenia. So defined, it was exceedingly rare (Eyal et al. 2010). Infantile autism, a condition closer to that described by Kanner, appeared in the publication of the *DSM-III* in 1980 under the new class of pervasive developmental disorders (PDD). Even though the parameters of infantile autism were defined more broadly than the condition identified by Kanner, some experts argued that the criteria were still too stringent (Volkmar et al. 1992). Thus, with the publication of the *DSM-III-R* in 1987 the criteria were further expanded under the diagnostic label of autistic disorder. The new criteria dropped the requirement for early onset of symptoms and also permitted diagnosing individuals with only mild cognitive impairments, thus paving the way for a broad spectrum of “atypical” children to be diagnosed and the exponential rise in autism that quickly followed (Eyal et al. 2010).

Ultimately, the criteria for autistic disorder came to be seen as having low specificity. That is, the criteria resulted in many false positives. The revisions to autism in the *DSM-IV* were an attempt to address this problem. However, the *DSM-IV* criteria created new problems. Among them was a menu of symptom options resulting in many different possible permutations of symptom manifestations. The outcome was that these criteria were “overly inclusive and confusing” (Mahjouri and Lord 2012:741). The addition of Asperger’s disorder, a condition that overlaps with autism but lacks delays in language and cognitive development, to the list of pervasive development disorders also contributed to the diagnostic muddle. Consequently, there has been considerable variability in when and how the diagnoses are applied among different practitioners and across different settings (Baker 2013).

At the same time, a broader definition of autism has been considered a great success by those in the autism advocacy community, who were, in fact, key actors in the development of the expanding definition of the disorder (Eyal 2013). As more children have been diagnosed, including those with a

broader and milder set of symptoms, so too has there been a corresponding expansion in the range of services for those in need. Autism is one of the 13 primary disability categories defined by the Individuals with Disabilities Education Act (IDEA), thereby guaranteeing children with the diagnosis access to special educational resources at no cost (Silk et al. 2000). Individuals diagnosed with autism can also qualify for Supplemental Security Income, disability benefits, and Medicaid. The Affordable Care Act includes mandatory autism screening for infants and improves access to medical and developmental health services for those with autism (AMCHP 2012). Even as states have different guidelines about what types of services they are required to provide, individuals with autism receive benefits as a result of these federal laws and policies. The upshot has been an enormous demand for supplemental educational and therapeutic services (Ganz 2007).

The changes to the *DSM-5* criteria are the next step in the historical development of the autism diagnosis. Like previous changes, the new diagnosis is thought to address the limitations of its predecessor. According to the *DSM-5* Neurodevelopmental Disorder work group, the entity responsible for revising the autism criteria, the new criteria “better reflect the state of knowledge about autism” (American Psychiatric Association 2013). As mentioned, one key change collapses several of the diagnoses listed as pervasive developmental disorders in the *DSM-IV*—including autistic disorder, Asperger’s disorder, and pervasive developmental disorder not otherwise specified (PDD-NOS)—into the umbrella category of autism spectrum disorder (ASD). The rationale given for this change is that these conditions have similar symptoms that fall along a continuum of severity. The work group favored this approach over keeping separate categories, arguing that preserving the distinct labels is not justified by the current state of medical knowledge. As vividly explained on the *DSM-5* website, the *DSM-IV* criteria are “equivalent to trying to ‘cleave meatloaf at the joints’” (American Psychiatric Association 2012). This change also addresses the widespread use of PDD-NOS. Not otherwise specified (NOS) classifications were meant to apply to only a small number of individuals with hard to classify symptoms, but the PDD-NOS label had been widely applied.

The second major change involves reorganizing symptom categories and changing the symptom threshold. The *DSM-IV* has three sets of symptoms: social interaction, communication, and repetitive/restricted behaviors or interests. The new criteria merge deficits in social interaction and communication into a single domain, on grounds that people with autism usually exhibit both of these types of symptoms (Ferris 2012). There is also less flexibility in terms of the symptoms required to meet the diagnostic threshold. Thus the new criteria create a more streamlined framework for clinicians by reducing the number of possible symptom combinations at their disposal (Baker 2013). As summarized by a member of the work group, the rationale for the changes can be described thusly: “Our aim is to acknowledge the widespread consensus that Asperger syndrome is part of the autism spectrum, to clean up a currently hard-to-implement and contradictory diagnostic schema, and to do away with distinctions that are made idiosyncratically and unreliably” (Happé 2011).

To a considerable extent, the public controversy surrounding these changes can be traced to research conducted by a group at Yale University, led by the well-known autism expert Fred Volkmar. In January 2012, the Yale team reported that a significant number of the people currently diagnosed with autism would no longer qualify under the new criteria. It is worth noting that Volkmar resigned from the *DSM-5* work group overseeing the revisions on grounds that the draft criteria were excessively stringent. Eventually the Yale team published their research (McPartland, Reichow, and Volkmar 2012) and their study’s methods and findings were denounced by many mental health experts, but not before bringing national attention to the matter and creating a firestorm within the autism community.

The unfolding controversy caught the eye of Benedict Carey, a regular science writer at *The New York Times*. In the aforementioned article, Carey (2012) summarized the results of the Yale study. He reported that roughly three-quarters of those diagnosed with Asperger’s, 85 percent with PDD-NOS, and perhaps a quarter with classic autism would not meet the new diagnostic criteria. Not only did the article generate hundreds of online reader comments, but dozens of bloggers and online

forums in the autism advocacy community picked up on the story and began reporting that well over half of all autism patients would lose their diagnoses overnight with the release of the *DSM-5*. The anxieties of individuals directly impacted by the diagnostic upheaval foreground key themes that reside at the junction of the medicalization and the sociology of diagnosis literatures. We now turn our attention to that intersection.

### Medicalization Trends and What Diagnoses Do

Medicalization involves defining or treating human experiences as medical in character that were not previously defined or treated as such. Instances of medicalization are widespread. We have witnessed the reframing of a host of deviant behaviors (e.g., drug use and sex offending), natural life experiences (e.g., pregnancy and aging), everyday problems of living (e.g., sadness and daytime sleepiness), and forms of social malaise (e.g., child mistreatment and domestic violence) as medical problems (Davis 2009). The persistent march toward medicalization, or overmedicalization, has itself been identified as a social problem (Clarke et al. 2003; Illich 1976; Zola 1972). That being said, medicalization is bidirectional (Conrad 2013): there are instances of demedicalization, wherein a problem once recognized as medical is no longer construed as such. Masturbation and homosexuality are the most frequently cited examples.

There are a number of important caveats and nuances when it comes to medicalization. For example, medicalization-demedicalization is a continuum, not an either/or category (Conrad 2005; Halfman 2012). This is made evident by instances of partial demedicalization: male circumcision has become increasingly less common in the United States, but it maintains legitimacy as a medical procedure (Carpenter 2010); some members of the deaf community celebrate their rich culture and reject the notion that deafness requires a medical fix (Lane 1995); and, breastfeeding resides betwixt and between being medicalized and demedicalized in response to recent efforts on the part of lactation consultants (Torres 2014). These particulars also make evident that medicalization can take place at different levels (e.g., conceptual, organizational, and microinteractional) (Conrad 2013) and has different dimensions (e.g., discourses, practices, and identities) (Halfman 2012). A problem can be medicalized at some levels or dimensions but not at other levels or dimensions. A problem can also be characterized by greater or lesser degrees of medicalization within each of these levels and dimensions.

In practical terms this means that a problem can be defined as medical (i.e., diagnosed), treated as such, and come to constitute an illness identity, even without a biomarker or the widespread endorsement of the medical profession. This is the case with contested illnesses such as Fibromyalgia Syndrome (Barker 2005). Or, a problem can be defined as medical and endorsed as such by the medical profession although it is “treated” with nonmedical interventions by nonmedical personnel, which, parenthetically, describes the case with autism (Eyal et al. 2010). In sum, medicalization is a complex, multifaceted, dynamic, and ultimately “sociocultural process that may or may not involve the medical profession, lead to . . . medical treatment, or be the result of intentional expansion by the medical profession” (Conrad 1992:211).

There are also multiple and competing forces, both inside and outside the institution of medicine, contributing to and resisting medicalization, and these forces have changed and continue to change over time (Rose 2007). Whereas physicians were more influential in instances of medicalization during much of the twentieth century, technoscientific practices, corporate entities, medical markets, and lay consumers have become crucial players in the new regimes of medicalization (Clarke et al. 2003; Conrad 2005; Furedi 2004). Peter Conrad (2005) refers to these changes as the “shifting engines of medicalization,” whereas Adele Clarke and colleagues (2003) suggest the term “biomedicalization” better captures the technoscientific intensification and transformation of the process of medicalization. Despite its changing character, and in the face of some emerging pockets of resistance and countervailing forces (Conrad 2005; Light 2010), the trend toward medicalization and/or

biomedicalization represents a significant social development in contemporary Western societies (Barker 2014; Bell and Figert 2012; Clarke et al. 2003).

Medicalization is especially apparent in the case of mental illness. Not only do the rates of mental illness continue to rise, but there has also been an increase in the number of diagnostic categories over the life course of the *DSM* (Angell 2011). The growing size of the *DSM* itself provides material representation of medicalization. Whereas the *DSM-I* listed 106 diagnoses in its 130 pages, the *DSM-IV* lays out 297 diagnoses in 866 pages (Mayes and Horwitz 2005). In addition to new diagnoses, another source of medicalization is found when an existing *DSM* category expands to include cases far outside of the original diagnostic boundaries. The inclusion of adults under the diagnostic rubric of attention deficient hyperactive disorder (ADHD), which was formerly limited to children, and the incorporation of other victims of violence and trauma (e.g., sexual and political) within the diagnostic parameters of post-traumatic stress disorder (PTSD), a category originally adopted to recognize the suffering of Vietnam veterans, are cases in point (Conrad and Potter 2000; Scott 1990). Another example involves the significant broadening of the definition of depression from a relatively rare affliction to a common condition (Horwitz 2011). The removal of the “grief exclusion” from the *DSM-5* (i.e., removal of the stipulation that depression cannot be confirmed in the period following the death of a loved one) will even further expand depression’s diagnostic applicability. The concept of domain expansion, borrowed from the social problems literature (Best 1990), captures this tendency.

The dynamics behind domain expansion are myriad. Here we gain key insights from the sociology of diagnosis literature. Some of the conceptual tasks of the sociology of diagnosis include charting the social contexts from which diagnoses emerge and examining the considerable social consequences of having a particular diagnosis (Jutel 2009). As such, both the medicalization and sociology of diagnosis literatures have a keen appreciation for the various benefits that diagnoses afford individuals and key stakeholders. In this regard, Annemarie Jutel (2009) describes the multiple types of work diagnoses do:

Diagnosis is integral to the system of medicine and the way it creates social order. It organises illness: identifying treatment options, predicting outcomes, and providing an explanatory framework. Diagnosis also serves an administrative purpose as it enables access to services and status, from insurance reimbursement to restricted-access medication, sick leave, and support group membership and so on (p. 278).

The research on emergent or contested illnesses provides additional insight. Specifically, when individuals doggedly search out diagnostic labels for their debilitating but medically elusive conditions, they do so in search of the personal validation and concomitant medical and social services that diagnoses afford (Barker 2002). As aptly described by Joseph Dumit (2006), these are “illnesses you have to fight to get.” Sometimes *laypeople* become activists and play a pivotal role in the discovery of a disease category itself as they collectively seek to legitimate their suffering and gain access to secondary benefits (Brown 1995). Given that diagnoses have such a significant and largely beneficial impact on individuals’ lives, we would expect to see sufferers act in ways that promote medicalization, whether through advocating for contested illnesses or diagnostic expansion.

Conversely, in light of the positive benefits associated with “putting a name” on a disorder (Jutel 2009) there are few clear cases of diagnostic domain contraction. The case of homosexuality warrants special mention. In the 1970s, gay activists asserted that their sexual identities were not a disorder in need of medical intervention (Bayer 1987). In the eyes of those labeled, the diagnosis was a liability rather than an asset. In response to pressure from gay activists, the diagnosis was removed from the *DSM* in 1973. This ended the era of defining homosexuality as a mental illness in and of itself (Jutel 2011); however, the *DSM-II* and *DSM-III* did introduce new, albeit rarely used, diagnoses for individuals who were distressed by their sexual orientation.

There are also a few contemporary examples of groups who resist being diagnosed with a mental illness. Pro-Ana groups and some individuals who engage in self-injury, for instance, contend that anorexia and cutting respectively are personal choices and core features of their identities, not medical disorders (Adler and Adler 2007; Boero 2012). In an effort to avoid the stigma of mental illness, a faction of transgender activists wants any reference to transgender disorders to be removed from the DSM (Burke 2011). There are also people aligned with the neurodiversity movement who consider a host of mental illness categories, including autism, to be natural and potentially beneficial human variations. This includes those who derive value from the “Aspie” identity but do not seek medical treatment or other resources afforded by the diagnosis (Armstrong 2010; Singh 2011). Some individuals within these above noted groups see themselves fighting the same battle fought by gay activists 40 years earlier. They eschew diagnostic labels and call for demedicalization.

Crusades for demedicalization on the part of affected laypeople are the exceptions rather than the rule. They are “islands of resistance reacting to a tidal wave of medicalization” (Conrad 2013:209). And yet, their very existence provides an important clue about the elemental relationship between diagnoses and contemporary medicalization processes and the rising influence of laypeople therein. Existing research demonstrates that laypeople can act as an important “engine” of medicalization when they push for the creation or expansion of a diagnosis (Barker 2002; Brown 1995; Conrad and Potter 2000). What we demonstrate is that laypeople can also fight to defend hard won diagnostic ground when they perceive such ground to be under threat. We refer to this as diagnostic domain defense. We unpack the concept by showing its manifestation in the public debate concerning the perceived contraction of the autism diagnosis.

#### DATA AND METHODS

This study utilizes a novel source of data—a reader comment forum to an online newspaper. Although online reader comments are relatively new, they have become widespread and popular. In 2006, *The Washington Post* was the first newspaper to allow reader comments to appear following a news story. *The New York Times* followed suit in 2007, and other leading papers were only a few steps behind. Of the top 100 newspapers in the United States, the share that accept article comments jumped from 33 to 75 percent between 2007 and 2008 (Santana 2011). In 2010, 92 percent of the top 150 U.S. newspapers accepted online comments (Santana 2012).

More Americans read news online than in print; this makes news not only more portable, but also more participatory (Purcell et al. 2010). Reader comment forums are an important part of the new world of participatory journalism. In online forums, readers from across the country register their opinions on the current events of the day. According to Pew researchers, 25 percent of Internet users report posting a comment to an online news story or news blog (Pew Research Center 2012). Reader comments are simultaneously a response to a given article and a dialogue between those who comment. One can think of comment forums as a hybrid of “letters to the editor” and an electronic bulletin board. As such, reader comments represent an “index of operative social values” (Santana 2012:1). While there is a tradition in social science of analyzing both letters to the editor and electronic bulletin boards (Barker and Galardi 2011; Perrin and Vaisey 2008), online reader comments represent a novel data source for assessing a broader range of public sentiments and claims making (Croteau 2006).

There is no systematic information concerning the social characteristics of readers who post comments to online newspapers in general or to *The New York Times* in particular. Hence, we cannot say that the tenor of a reader forum is representative of public opinion generally. Only those with an active interest in a given news story and the inclination to comment will be represented. In the case of *The New York Times*, however, reader comments do represent the claims of individuals from across the country to a story that appeared in a leading national newspaper. Reader forums provide an opportunity to explore the various claims key stakeholders make about issues of great interest to them.

But, they also allow for relatively “disinterested” parties (i.e., those with no direct connection to the issue) to contribute to the discussion. As data, they capture a range of positions vis-à-vis the subject of a news story, as well as an active engagement between individuals who represent these positions.

Two additional points must be made about the data. First, the substantive focus of the newspaper article, which reported on the new autism criteria’s potential to exclude many individuals, likely influenced who decided to post a reader comment in the first place and the content of the reader comments themselves. Second, and relatedly, the reader comments are not responses to the *DSM-5* criteria per se. Instead they are responses to the newspaper article’s description of the changing criteria (i.e., narrowing the definition of autism) and the possible consequences of such changes.

We analyzed these comments using qualitative content analysis, which allows researchers to make valid inferences based on the systematic study of qualitative data (Schreier 2012; Weber 1990). The advantage of studying texts like these reader comments is that they are naturally occurring data. Therefore, the presence of researchers does not influence the data itself (Weber 1990). The goal of content analysis is the systematic study of texts, which is achieved by classifying the data as “instances of the categories of a coding scheme” (Schreier 2012:1). We provide a systematic analysis of reader comments with an eye toward ascertaining, presenting, and analyzing their key thematic content.

To code the data we used NVivo, a computer-assisted qualitative data analysis software program. All three members of the research team independently read the comments. We discussed our general impressions concerning patterns in the data and then created a working set of codes using these patterns. The basic scaffolding for our coding scheme included a category for position on narrowing the definition of autism (e.g., support or oppose) and subcategories based on the rationale given for support or opposition. We also coded the comments in terms of the reader’s relationship to autism (e.g., parent of autistic child, person with an autism-related diagnosis, concerned citizen, etc.). In addition, we identified common types of exchanges between readers as captured within the above-described coding scheme. Because it is an especially effective way of presenting the overarching thematic content, we showcase the most common types of exchanges, which we identify as *points of contention*. These points of contention are also analytically important because they highlight the existence and character of diagnostic domain defense.

Reader comments to Carey’s article were accepted on the *Times* website for three days, during which time 393 readers posted 642 comments. The overwhelming majority of individuals posted one comment ( $n = 317$ ). However, 76 individuals posted more than one comment, one of whom posted 35 comments. Approximately 47 percent of the comments came from readers who live in eastern states ( $n = 184$ ). Readers living in the West ( $n = 93$ ), South ( $n = 43$ ), and Midwest ( $n = 32$ ), as well as international readers ( $n = 20$ ), also commented. We were unable to determine residency for 21 individuals. Somewhat surprisingly, the majority of those who posted a comment could not be identified as key stakeholders in the debate. Sixty-eight percent ( $n = 269$ ) of the readers who commented did not specify any personal or professional relationship to autism. It is also the case that these individuals posted the most comments (66 percent). Conversely, 20 percent ( $n = 80$ ) of those who commented had a family member diagnosed with autism, 4 percent ( $n = 14$ ) identified as having an autism-related disorder or meeting the diagnostic criteria, and 8 percent ( $n = 30$ ) claimed to have professional expertise related to autism (e.g., doctor, therapist, special needs teacher).

## ANALYSIS

### The Dimensions of Diagnostic Domain Defense

The central focus of Carey’s *New York Times* article was that the *DSM-5* criteria for autism were slated to become significantly more stringent. The resulting tenor of the comments was passionate and the dialogue often confrontational. Family members, individuals with an autism-related diagnosis, and those with professional expertise in the area of autism overwhelmingly favored the existing diagnostic criteria. In contrast, roughly half of the readers who lacked a personal or professional

connection to autism supported narrower criteria, while others in this camp were either silent or ambivalent on this particular matter. There is a caveat with respect to this divide: six people with a family member with severe autism and five people who met the *DSM-IV* diagnostic criteria also favored narrowing the diagnosis.

What the data most clearly illuminate is a debate between those who supported a more restricted definition of autism and others who defended the existing diagnosis. Ultimately, the reader comments reflect a debate about medicalization. The debate unfolded as follows: Someone in the former group would posit, “It’s about time the diagnostic criteria change because . . .” and then go on to detail their concerns about the potential social costs of broadly defining autism. At that point, someone in the latter camp responded with the moral authority of their own experience to explain just how important it is to keep the *DSM-IV* diagnostic criteria in place. We identify these exchanges as points of contention. We present the most common points of contention and foreground how those on the side of the diagnostic status quo engaged in diagnostic domain defense.

### Point of Contention: What is Normal and What Counts as Disease?

One point of contention emerged around the inherent problem of drawing a line between normal and abnormal. A number of readers proposed a narrower definition of autism as a way to limit the trend toward diagnosing slightly odd or quirky children. As pointed out by some readers, the category of “normal” has become increasingly narrow. “It is about time. Every slightly strange kid is labeled on the spectrum and considered ‘defective’ and in need of some type of ‘treatment.’ Those strange kids often grow up to do great things. Leave them alone already!”<sup>1</sup> One reader complained, “Everyone who acts outside ‘normal’ gets to claim a disease. Oh, may we one day look back on this as the dark days of conformity.” Others warned of the potential harm caused by creating pathology out of minor personality or behavioral differences:

- Why do you need to make up diagnoses for diseases that don’t even exist? No one is denying that so-called “Aspies” have problems. But slapping a label on them doesn’t help . . . This is a sociocultural zeitgeist in American life now—to pathologize differences. As if there’s some kind of shining “normal” grade that you either do or don’t make, and anything below that grade, is a disease.

Also related to the inherent problems associated with delineating normality from abnormality, a number of readers raised concerns about the highly arbitrary diagnostic categories in the *DSM*. The following comments are cases in point:

- The *DSM* is notoriously broad. Did you ever look at the definition of addiction? Under that definition, I am addicted to yellow cake with chocolate icing. In any event, some studies say 1 in 11 children have some form of autism. That seems very high based on my experience. It is good to tighten up the definition.
- This would be an interesting move, considering that the *DSM* has a reputation for pathologizing everything—i.e. turning vague or normal-range symptoms into diagnosable disorders or diseases.

These readers shared a general concern about the consequences for society at large when we narrow the limits of what is considered “normal” by expanding the definition of abnormality via medical diagnoses.

1 We present the reader comments verbatim, except in a few instances where the content was unclear without minor grammatical or spelling changes. Our minor alterations are presented in brackets. We use ellipses to denote the omission of some segment of reader comments.

These claims elicited heated responses from family members asserting that autism is a *real* medical disorder with debilitating symptoms. Their child is not just a quirky kid who, if left alone, could get by on his or her own. As expressed by one parent, “Changing the criteria for inclusion on the autism spectrum will not make these issues go away.” Another parent elaborated on this point and, in so doing, captured the sentiments of others:

- To actually say that the overwhelming majority of persons diagnosed with some form of autism in the last two decades will no longer be considered autistic is Orwellian . . . Goodness if we parents of autistic children knew that was the way to do it, we would have asked for this definition change decades ago. . . . Unbelievable. . . the psychiatric community changes the definition and our children have no more problems. . . who knew.

To family members, the line between normal and disorders on the autism spectrum is crystal clear. “It is true no one is normal, but trust me, there is such a thing as abnormal. If you had an autistic or developmentally disabled kid you’d know it.” Using their own relationship to autism as the basis of privileged knowledge, these lay experts deflected a critique of the medicalization of difference advanced by some concerned readers.

But for parents there is more at stake than philosophical debates about the arbitrary and excessively broad character of *DSM* categories. What matters to them is that the diagnosis confirms their reality: their child is not normal. The disorder is not “phony” and, sadly, their child is proof. Parents, family members, and those diagnosed with an autism-related disorder shared personal stories of how the diagnosis represented a form of validation. A grandmother described the “relief” she felt when her granddaughter was diagnosed because she “knew something was different with her.” Another reader explained that his mother, who “is on the high-functioning end of the spectrum” was “relieved to be diagnosed as an adult and to find out why she always felt ‘different’ from everyone else.” Although there were only a small number of reader comments from those with an autism spectrum diagnosis, a 23-year old woman expressed her alarm about the removal of Asperger’s from the *DSM*: “I cant believe they would do something like this. . . I was diagnosed with Aspergers when i was 11 years old. . . I couldnt imagine how things would be if i wasnt diagnosed with Aspergers.”

The diagnosis renders a complex and troubling set of experiences meaningful. Parents shared their accounts of how a vast array of their children’s problems, including troubles at school, awkward social skills and encounters, frequent tantrums, sensitivities to noise, incessant teeth grinding, head banging, and obsessions with things ranging from the Titanic to Greek mythology, were made coherent by a diagnosis. One father provided a powerful description of how the diagnosis fit his direct observations:

- We initially resisted the diagnosis when the mental health pros at school proposed it—but after 5 police visits to the house because of violent behavior, 2 psychiatric hospitalizations, and more learning on our part, we accepted it because it made sense of what we were observing and experiencing and offered a path forward for a very troubled child.

In turn, a coherent story validates the diagnosis. Jutel (2009) describes the simultaneous “interpretive and organizational” character of diagnoses as follows: “It [a diagnosis] provides structure to a narrative of dysfunction, or a picture of disarray, and imposes official order, sorting out the real from the imagined, the valid from the feigned, the significant from the insignificant” (p. 279). Family members shared personal stories of their child’s hardships to substantiate the reality of autism, deflect accusations that they are medicalizing quiriness, and defend a broader set of diagnostic criteria. From their privileged vantage point as lay experts, narrowing the diagnostic criteria would be irrational insofar as the *DSM-IV* criteria are merely the natural expression of the disorder itself. These parents and

family members supported the medical framing of autism and resisted any movement toward its demedicalization.

### Point of Contention: Parental Blame versus Parental Absolution

Many of the comments addressed the causes of autism and the reasons for the sharp increase in the number of children with these disorders. Several readers accused parents of “causing” autism through permissive parenting. “Thank god, too many of these so called ‘autistic’ children are what we would have called brats.” Another reader explained that some parents seek out an autism diagnosis when they “cannot accept they have a discipline problem.” Mocking the notion that autism is the result of a neurochemical abnormality, one man explained, “I was a kid with similar problems in the early ‘60s: the remedy was I got sent to a military school, my brain chemistry got sorted out really fast.” He continued, “[m]ore discipline and structure in children’s lives are what’s needed, not the enabling and reinforcement of social pathology through contrived biological diagnoses.” Like these readers, many others suggested that the real problem is parents who indulge and coddle their children. This constituency argued that there are significant social costs when parents abdicate personal responsibility for their child’s behavior by seeking a medical solution.

Parents and family members of children responded to these accusations with intense anger. Parents joined together to vehemently deflect attacks on their parenting. Comments such as “we parents” or “speaking for us parents . . .” created an *us* versus *them* dynamic. Parents defended their children and themselves, and some grew downright hostile, calling their critics “ignorant,” “stupid,” “mean,” and “clueless.” Family members asserted that they, better than anyone else, know what autism is really like. After all, they live with it every day of their lives. Readers who suggested that their children’s problems are a matter of discipline were simply deemed to be misinformed, if not mean spirited. One parent suggested that critics should, “Walk a mile in my shoes. Or five feet in those of my son. It is easy to look through windows of someone’s home—understanding what you see is more difficult.” Another derided the “brilliance” of people she encounters in the grocery store when her son is “mid-meltdown” who say “he needs a nap,” or worse, ‘he needs a spanking!’ . . . Wow! Naps and spanking cure AUTISM!??? Alert the press!!!”

Although not unique to autism, the disorder is characterized by a disjuncture between troubling symptoms and a normal outward appearance. Just as there is no biomedical test for autism, there are often no visual indicators to differentiate an autistic child from a “normal” child. This is especially pronounced in the case of high-functioning autism (Gray 2002). Consequently, when children appear normal but behave abnormally, both children and parents experience social stigma (Farrugia 2009; Gray 2002). A child’s autistic behaviors, such as tantrums in the supermarket, are often interpreted as a reflection of parental incompetence. One father described how he believes people view his son, who was reprimanded for making “nervous noises” at school: “Some of you think . . . he is just a brat with bad discipline. You see a normal looking kid from a distance. He doesn’t look like a ‘spaz’ or a ‘retard.’” A diagnosis comes with exemptions (Parsons 1951): parents are absolved from blame and there is a reason for their child’s unusual behavior. In the face of such harsh indictment of their parenting, coupled with the urge to defend their children from unkind labels, it is no surprise that parents cling to the vindication provided by an autism diagnosis.

### Point of Contention: Unfair Benefits versus Diagnostic Entitlements

Similar to accusations of bad parenting, some readers claimed that the autism epidemic is in part the result of parents’ attempts to garner unfair benefits for their children. As one reader grumbled, “There is a very strong incentive to be diagnosed with ‘autism,’ Asperger’s, or any number of other psychological illnesses—a diagnosis can mean access to disability benefits (free money) and advantages in our educational system.” Some readers even accused parents of “shopping” for an autism

diagnosis to access these benefits, going from doctor to doctor until they find one that is willing to diagnose their child.

Others emphasized the idea that many parents no longer accept anything less than an exceptional child. Instead, they are quick to diagnose mediocrity in an attempt to get special services to enhance their child's academic performance. One reader complained, "I personally know someone who insisted her child was autistic so she could get him into a special school. The only thing wrong with him was that he was stupid and spoiled." An educator from the Silicon Valley commented on the high number of children in his part of the country with special accommodations and suggested that "rich parents" have manipulated the system to compensate for their children's inability to compete. The following comments express similar concerns:

- [P]arents have to accept the fact that their son or daughter may not be the perfect little being they expect; it's not a medical condition if you happen to be the least sharpest tack in the box or dim bulb; we shouldn't be medicalizing everything.
- I also think that parents have an almost insatiable desire to see their children as exceptional, and this take the chuckles out of the Lake Woebegone effect. No one has an average, good kid anymore.

Yet another reader charged parents with autistic children of being "helicopter parents" who "want society to coddle their 'special snowflake' from birth to death with subsidized housing, specialized schooling, and of course, a support check monthly along with food stamps." These types of claims are interesting in light of the fact that autism prevalence rates are positively associated with family socioeconomic status, and states and regions with higher rates of wealth have higher rates of autism disorders (Eyal et al. 2010; King and Bearman 2011). In various ways, these comments capture a concern that some individuals make strategic use of a diagnosis to accrue advantage in a competitive society.

Parents and other family members defended themselves and their children in the face of these comments. The following parental retort captures a common response: "No one wants their child to be 'exceptional' by being labeled with a developmental disorder. Come on now." Another parent declared, "I would like my daughter to be TYPICAL like my other two." Rather than wanting an "exceptional" child, parents explained that their child needs services in order to merely function in the world. Some expressed their hopes that interventions now would help their child achieve independence in the future.

- [W]e as parents took out loans in order to help our daughter with therapies. Yes some of those therapies have helped. Is she cured? No she is not. Will she be able to live on her own, hold down a job, lead a fulfilling life? We do not know these answers. . . Please no flames for me here, I am a tired parent, who just needed to vent, and trying the best to help my child survive.

While it is true that a diagnosis is generally the key that opens the door to many resources and services, family members and individuals with an autism diagnosis were quick to challenge accusations that the diagnosis is merely a device to garner benefits.

- [C]ome live with our Asperger's/PDD-NOS child for a while and then tell me that my wife and I are helicopter parents who have made up this diagnosis to get government benefits. . . Without medication and the intensive help given in a therapeutic school, this mid-teen might well be in jail by now if past behavior patterns had persisted. Our child is not retarded (IQ tests in the normal-high range), but does have a medical condition that needs pharmacological, therapeutic and educational interventions to make independent functioning, perhaps, possible in adult life. The help given now—some of it government funded—makes larger societal, not to mention personal, costs, less likely. I'm trying very hard to be polite so this comment will be

posted, so I'll just say you have no idea what you're talking about. I'm thinking the same thing in much ruder words as I write.

Parents expressed intense fear that under narrower diagnostic criteria, many children would be denied the very services that are necessary for hope of a better future. The following comments are exemplary:

- As the parent of a 13-year-old boy who has Asperger's, I'm eternally grateful to the dedicated professionals who have aided him as the result of the diagnosis. To deny the diagnosis and so the aid is to condemn him and those like him the help they need to become successful adults.
- I can't explain the feeling of initial despair followed by radiant hope that seeing your child learn to speak and interact with the world means. [My son] only got his therapy because he was diagnosed.

Other parents told similar stories of successful therapeutic interventions and warned readers about the catastrophic outcome of denying the very diagnosis that granted access to those interventions. These comments expose a belief, promoted by various entities in what has been called the "autism matrix," that there is a "critical window of opportunity" wherein an atypical child can receive timely treatment with potentially transformative results (Eyal et al. 2010). The autism epidemic has, in no small measure, been fueled by this therapeutic optimism and its concomitant rhetoric of hope. Parents and family members desperately tried to convey how more restrictive criteria would deny many children, including their own, a path forward. In light of this sentiment, they are unlikely to abandon the hopeful prospects that a diagnosis affords their child.

#### **Point of Contention: Finite Resources versus Necessity of Treatment**

As foreshadowed in previous reader comments, another point of contention involved the financial limitations of providing services for every person diagnosed on the autism spectrum, especially given the country's current fiscal crisis. Although some people were sympathetic to the needs of those diagnosed, they nevertheless pointed out that we live in a world of finite resources. The following comments describe the difficult but necessary task of drawing a line in the financial sand:

- As a society we can provide some compensation to help the most affected, but we can't afford, for example, rent assistance to everyone who has a hard time renting because they don't know when to make eye contact. We do not have infinite resources.
- Personally, I want to make certain the limited funds and services that society has set aside for autistic patients are going to patients who actually have the illness, not just the diagnosis.

The last comment decouples the illness from the diagnosis. As such, it is in line with a concern expressed by other readers that resources for genuinely disabled children are being diverted to those with "trivial" problems. They maintained that a narrower definition would create a more rational allocation of costly assistance:

- It is about time that some discipline was applied to the liberal naming of all sorts of young people as autistic, having ADD, or other categories of mental issue. This has . . . diverted attention away from the most serious cases in a blizzard of dubious cases.

Although family members overwhelmingly supported the diagnostic status quo, a small number shared concerns similar to those expressed above. As one parent explained, "I have a 16-year-old also

with classic autism and have been shocked at some of the kids who have the label and are getting services as I can barely detect anything out of the ordinary.” Another family member favored more stringent criteria in order to avoid putting children with significant disabilities “in fierce competition for resources with kids who are ‘autistic-ish.’”

For many readers who held this opinion, a narrower set of diagnostic criteria would be a welcome response to run-away government spending. This is seen, for example, in the comment posted by “Concerned Citizen” from Anywheresville, USA: “It’s time for a more specific set of diagnostic tools, and time to get a lot of greedy people off the government dime. We can’t afford this any longer.” Additional comments revealed similar opinions: “This is long overdue. Our country has become a place where everybody gets a diagnosis, a pill, a disability check and an excuse!”; and, from another reader: “I for one don’t want to follow the path of the Greeks and forever just assume ‘somebody else’ will pay.” Yet another reader warned that providing free care to everyone who wants it will “continue the bloodletting of our ailing economy and dwindling power.”

These claims drew an impassioned response from the majority of family members. They argued that all children on the spectrum deserve support. Some worried that efforts to narrow the definition of autism point to a larger, troubling agenda: “I fear this re-defining of the diagnosis is part of the coming wave of cost cutting and dumping of the values of caring for others. Where is the Village that it takes to raise a child?” Parents were especially offended at the suggestion that there is an abundance of free services for children on the autism spectrum.

- The people who think there is some kind of gravy train for the handicapped don’t realise just how stingy those services really are, and how many hoops you must jump through to avail yourself even of what little there is, and how great the humiliation and stigma can be (particularly in the ignorant, arrogant view of many of the posters here who have not got a clue).

Drawing on the notion of “a window of opportunity,” other parents made the case that helping children now is a cost-saving strategy in the long term and warned against economic short-sightedness. As in this comment, they reminded skeptical readers about the intersection between compassion, therapeutic outcome, and cost savings.

- We must be particularly careful, in an era of strained public resources, not to make a penny-wise and pound-foolish decision on that score. Doing what we can to see to it that children with disabilities receive the aid they need to lead as productive, independent lives as possible is not only the humane thing to do, it’s the most cost effective.

In response to the heated anti-government rhetoric, some family members stressed that the problem was the government’s priorities rather than the role of the government per se. The following comment is illustrative:

- Yeah, as long as it’s not your kid, we’re wasting money. . . The trillion bucks we spent in Iraq is what “blood-let” our economy and power, not helping children and their families to live with a set of problems that are in no way their fault.

These exchanges reflect the basic philosophical scaffolding that guides political debates in the United States—the role of the state in the lives of individuals and the essential character of a good society (Lakoff 2002). Indeed, diagnoses are necessarily influenced by large-scale social, economic, and political processes (Anspach 2011; Jutel and Nettleton 2011). While the neoliberal agenda is not new, during the last several decades the politics and ideology of fiscal responsibility (i.e., austerity) have become more culturally salient. In theory, this should create a climate that is more favorably disposed toward demedicalization via diagnostic contraction. This is especially true with respect to

autism given that current interventions include a costly and comprehensive array of medical, behavioral, and developmental health services, as well as a host of other benefits that often extend into adulthood (AMCHP 2012). A point of contention in the autism debate is that in a welfare state, however atrophied, the work diagnoses do for some citizens is made possible by other citizens. As such, diagnoses create interest groups along a diagnostic divide: beneficiaries and benefactors. The diffuse opposition of benefactors signifies the possible existence of a “countervailing force” (Light 2010) that is concerned about the larger social costs of unrestricted medicalization. But, as we have demonstrated, the beneficiaries have significantly more to lose and gain when it comes to diagnostic change.

## DISCUSSION

Online reader comments provide a unique and naturalistic way for sociologists to study lay claims making related to pressing social problems. Internet forums for national newspapers, like *The New York Times*, bring together people who are separated geographically and ideologically to engage in public discourse about newsworthy issues of our day. Some who participate in these forums have a personal connection to the issue being reported and are stakeholders in the conventional sense, but many others simply take the opportunity to contribute to a public discussion. We are not exactly sure what motivates these social stakeholders to participate, but their actions, like those of conventional stakeholders, represent some level of civic engagement. What is more, this type of civic engagement on the part of both conventional and social stakeholders is increasingly common due to the large number of national newspapers that accept online comments (Santana 2012). Because reader comments capture a broad range of public sentiment on any and all topics covered by the news media, we encourage sociologists to put this rich and publicly available data source to use in their research. Reader forums are themselves a strategic new site where stakeholders attempt to influence how public issues are framed. Stakeholders are actively exploiting these forums; so too should sociologists who are interested in understanding the politics of public discourse.

Despite these benefits, there are also limitations associated with using this type of data, which may have skewed our findings. It is certainly the case that the readers who commented are a self-selected sample and their views likely differ in significant ways from those of the population in general. We also know that several autism advocacy groups encouraged people to post critical comments in response to Carey’s article. If those aligned with these groups represent a significant number of the reader comments, their presence likely shaped the conversation in a particular fashion and may have inflated the sense of homogeneity among those on their side of the debate. Internet “trolls” may have also posted incendiary comments. Although *The New York Times* does delete reader comments it deems uncivil, trolling and contributing to forums with the explicit intent of causing discursive mayhem is known to occur (Bishop 2014).

With these cautions in mind, our analysis of the online reader comments demonstrates that a diagnosis can be “a kind of focal point where numerous interests, anxieties, values, knowledge, practices, and other factors merge and converge” (Jutel and Nettleton 2011:798). Readers skeptical about the “autism epidemic” pointed to a number of social factors contributing to the sharp increase in the disorder, including permissive parenting, the inclination on the part of many parents (and society) to diagnose quirky children or children whose social and academic skills fall below parental (and societal) expectations, and the desire on the part of some parents to use the diagnosis to give their children a competitive edge. Although they do not have a direct, personal stake in how autism is defined, they framed the issue in terms of the larger social costs associated with diagnostic expansion. The social stakeholders raised broad concerns: how society should define “normal,” who should be responsible for the behavior of children, whether it is acceptable for individuals to use a diagnosis to gain an unfair advantage in a competitive society, and the appropriate allocation of finite, taxpayer-supported government resources. In sum, by speaking to the troubling social consequences of medicalization (Conrad 2013) they advanced a compelling argument in favor of a shift toward demedicalization via

diagnostic domain contraction. Social stakeholders challenged the medical definition of the problem, its scope, and its solutions, as championed by the majority of autism advocates.

Readers with the most at stake in the diagnostic upheaval vehemently countered these challenges. Their debate with social stakeholders exposes the dimensions of diagnostic domain defense. Diagnostic domain defense is an oppositional claim on the part of laypeople with a personal connection to a diagnosis to a real or perceived challenge to the definitional boundaries of that diagnosis. This opposition is grounded in first-hand experience with autism and a concurrent certainty that autistic disorders are not “made-up” artifacts of less stringent diagnostic criteria. The everyday lives of these lay experts confirm the existence of the disease. This group of individuals challenged their critics, whom they deemed clueless and hurtful, to staunchly defend the diagnostic status quo. Diagnostic domain defense is fortified by the anguish of the illness experience. In the case of autism, the anguish that emanates from parental love is particularly noteworthy (Silverman 2012). Parents experience personal distress and mourn for their child who may not live the life of their hopes and dreams. This emotional gestalt and a rational quest for some palliative are elemental to diagnostic domain defense. Diagnostic benefits further motivate a defensive stance. For parents, the diagnosis validates their parenting, provides a coherent framework to account for their child’s problems, serves as a tool to convey to others that their child has a disabling illness, and grants them access to services that provide support and hope. Those with an autism diagnosis also access these services, albeit from a different position. For all these reasons there is little cause for diagnostic beneficiaries to lay down their diagnoses and disband. Said differently, diagnostic domain defense represents a formidable barrier to demedicalization.

As we have been careful to note, the diagnostic domain defense that was mobilized in anticipation of the release of the *DSM-5* is best seen as a response to a *perceived* instance of diagnostic contraction. We cannot say with certainty whether the *DSM-5* autism criteria will result in a reduction in the number of persons diagnosed or treated for autism. The *DSM-5* Neurodevelopment Disorders work group denied that their goal was to make the diagnosis more restrictive or to deprive patients already carrying autism diagnoses of their eligibility for services (Gever 2012). The commitment not to deprive existing autism patients of a diagnosis is made explicit in the text of the *DSM-5* itself: “Note: Individuals with a well-established *DSM-IV* diagnosis of autistic disorder, Asperger’s disorder, or pervasive developmental disorder not otherwise specified should be given the diagnosis of autism spectrum disorder” (American Psychiatric Association 2013:51).

Some early field trials confirm that, despite the elimination of the Asperger’s and PDD-NOS labels, nearly all existing diagnosed cases will be captured by the new ASD criteria (Huerta et al. 2012). Other research, however, suggests that the new criteria will in fact result in fewer autism diagnoses (Kulage, Smaldone, and Cohn 2014). Either way, the new criteria might better be viewed as an instance of taxonomic lumping (i.e., consolidating previously distinct diagnostic labels into a single diagnosis) than as a case of domain contraction. Additionally, there is a new diagnosis of “pragmatic (social) communication disorder,” which will be applied to those who have social and/or communication impairments without any repetitive or restrictive behaviors (Mahjouri and Lord 2012). This suggests that even if there is a small contraction in autism diagnoses there could be off-setting diagnostic growth elsewhere (i.e., diagnostic drift).

To what extent any of these details of the revised diagnostic guidelines were a direct response to the demands of autism advocates is unknown. It is the case, however, that the dynamics of diagnostic domain defense seen in the online reader comments were also integral to the widespread campaign on the part of advocates who closely scrutinized the revision process, sent thousands of protest statements to the *dsm5.org* website, and corresponded directly with the *DSM-5* Task Force to make their concerns known (Autism Speaks 2012). It is reasonable to assume that all of the work groups that made up the *DSM-5* Task Force took public comments into consideration even if only to manufacture consent. After all, the American Psychiatric Association (APA) explicitly stated that it created the *dsm5.org* website as a way to keep the public informed about the revisions and solicit their

feedback, which it did during three open commenting periods. According to the APA, members of the work groups reviewed public feedback submitted to the site and “where appropriate, revised their proposed diagnostic criteria” (American Psychiatric Association 2012). The chair of the DSM-5 Task Force describes the creation of the manual as “a remarkably collaborative process” and one in which “patients and their families, and members of the public have had a strong voice” (American Psychiatric Association 2012). The public firestorm created around the revisions to autism makes it all the more likely that the work group in charge of the autism revisions avoided, as much as possible, straying too far from the existing diagnostic domain.

The real pressures for a contraction in autism will most likely be the result of insurmountable fiscal realities. Unlike discrete pharmaceutical treatments for illnesses such as depression, managing autism can include a broad range of services over the course of a lifetime. It is estimated that the per-capita, lifetime direct cost for autism is \$1.2 million (in 2003 dollars) (Ganz 2007). Private medical insurers balk at providing those services that are not specifically medical in focus, and individual parents are unable to cover the immense costs themselves. Consequently, the burden of paying for these costs overwhelmingly falls to taxpayers. The state of California spent \$320 million in 2007 for autism interventions and the annual national costs, estimated at \$90 billion, are slated to double in the next ten years (Girion 2008). The Affordable Care Act may make controlling these costs even more difficult because it is designed to increase access to treatment services for those diagnosed with ASD and requires that all insurance plans cover free autism screening for children. At this point, it is still too early to know what effect the Affordable Care Act will have on the prevalence and treatment of ASD, especially because the current implementation allows for considerable state discretion in terms of treatment coverage.

Ultimately, insurance providers and government agencies will need to reign in autism-related costs. It may become necessary to deny services, even to some individuals who reside within ASD’s diagnostic boundaries. A particularly interesting addition to the DSM-5 criteria—and one that has yet to be the focus of public controversy—provides a means to do just that. The new criteria introduce a severity scale. Clinicians are asked to rate the severity of symptoms in terms of the amount of support needed, ranging from 3 (“requiring very substantial support”) to 1 (“requiring support”). This addition puts in place a tool for making decisions about how to allocate scarce resources should pressure build. If this comes to pass, some (but not all) of the “work” the autism diagnosis does will decline. This may indirectly promote partial demedicalization.

Thus far, we have highlighted the presence of diagnostic domain defense in the controversy leading up to the DSM-5 autism revisions. However, what we have described here is applicable in other instances where laypeople with a personal connection to a diagnosis find their diagnosis under siege. This would apply, for example, to future cases where social or fiscal pressures mount in favor of narrowing or eliminating a diagnostic category and to the current experiences of contested illness sufferers who routinely encounter questions concerning the legitimacy of their diagnoses. When the lay beneficiaries of a diagnosis encounter such attacks, they can arm themselves with experiential knowledge as evidentiary confirmation of the condition, become emboldened by the raw emotion and personal anguish of the illness experience, and defend the various types of diagnostic resources to which they are granted access. It is possible there are factors motivating lay actors to defend diagnostic territory that this case has not brought to the fore. It is also possible that the converse of what we described may transpire. That is, laypeople could defend their diagnostic domain from ongoing *expansion* (rather than contraction) if they perceive the expansion as threatening their access to diagnostic resources, including their illness identity or the legitimacy of the diagnosis itself. In other words, it may be that diagnostic domain defense could, in some contexts, act as a counter to further medicalization. We leave the exploration of these possibilities to future research.

Diagnostic domain defense is thus an important facet of medicalization processes more broadly. Once a diagnosis is established, it can readily expand, but it is unlikely to contract or be abolished unless affected laypeople support such actions. Laypeople contribute to the medicalization of their

problems not only through their demands for diagnostic discovery (Brown 1995) and diagnostic expansion (Conrad and Potter 2000), but also, as we have shown, through the defense of their diagnostic victories. The presence of diagnostic domain defense, therefore, adds to our understanding of why, in a society characterized by extensive medicalization, powerful interests stand poised to effectively ward off demedicalizing pressures.

Given this tendency, it is essential to step back and critically assess why more of us wander into diagnoses in the first place. Diagnoses have come to be seen as one of the few venues for any response to complex forms of human and social suffering. Medical solutions to entrenched social problems are politically viable in that they target individuals rather than make demands for economic or social change. In the weak U.S. welfare state, we are more likely to treat the medical needs of patients than to fulfill the rights of citizens. In such a context, diagnoses are routinely (over)summoned. No doubt the current economic crisis has accelerated this trend. This context creates forces that both favor and resist medicalization. On the one hand, patients and caregivers favor domain expansion because a medical diagnosis is one of the few means by which citizens can make legitimate demands on the state. On the other hand, the expansion of the state via mass diagnosing triggers retrenchment policies that seek to minimize governmental responsibility for “personal” problems. This dynamic is precarious and ongoing. We encourage sociologists who study the union of medicalization and diagnoses to undertake further research on this dynamic and its consequences, not only with respect to autism but in other diagnostic domains.

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