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I. INTRODUCTION

After over a decade in development, the fifth edition of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-5) was published in May 2013.[1] It has been described as a living document and will include regular online updates and revisions (e.g., DSM 5.1, 5.2, etc.). In addition to its clinical, legal, and social significance, the DSM serves as the hub of a larger system of mental health care, research, and financing. This is to say, the DSM is very powerful.[2] Therefore, in light of recent controversies and the churn of new revisions, it is important to understand and examine the way the revision process for DSM-5 occurred and will continue to unfold.

For the first time in the history of the DSM, draft proposals were made available on three occasions for public scrutiny and comment on the APA's (American Psychiatric Association) public website, dsm5.org. This process stood in contrast to that of previous revisions, where the review of proposed categories had been confined to a select group of expert psychiatrists, psychologists, and other MD- or PhD-level researchers appointed by the APA.[3] The open invitation to the public elevated hopes that decisions about DSM categories might be made more democratically and include considerations about patient identity, their lived experiences, access to services, and other nonscientific concerns. Leaders of the revision promoted the "unprecedented level of transparency" and inclusiveness of the new process.

Others, however, including the previous DSM chair Robert Spitzer, argued that the process remained non-transparent and exclusive.[4] A growing chorus of commentators pushed for the revision process itself to become more democratic, rather than simply presenting the products of work group deliberations—that is, DSM draft proposals—for public scrutiny.[5] These critics called for a major change to the process leading to those outputs: a more transparent revision process that would include a more diverse and representative group of revisers than the present composition of mostly psychiatrists and a few psychologists and neurologists.[6]

Allen Frances, co-chair of the DSM-IV revision and a vocal critic of the DSM-5, called for an end to the APA's "monopoly" over the DSM revision process:

> All mental-health disciplines need representation—not just psychiatrists but also psychologists, counselors, social workers and nurses. The broader consequences of changes should be vetted by epidemiologists, health economists and public policy and forensic experts. Primary care doctors prescribe the majority of psychotropic medication, often carelessly, and need to contribute to the diagnostic system if they are to use it correctly. Consumers should play an important role in the review process.[7]

David Elkins, a clinical psychologist who headed the American Psychological Association's Division 32 Society for Humanistic Psychology, argued that mental health professionals other than psychiatrists and organizations beyond the APA should be included in the revision process "on an even basis" and that "because the American Psychiatric Association is so small, in comparison to all the rest of the mental health professions, I think they really need to be more egalitarian in the process of producing the manual."[8]

A number of prominent social epidemiologists and health services researchers also called for a division of powers in revising DSM categories. They proposed that the APA should share power over DSM changes with an independent review body separate from the APA that would "consist of multidisciplinary scholars from such fields as population health and the social sciences" and that would review the manual's potential social impact and economic/cultural disparities in the application of diagnoses.[9]

Combined, these proposals inventoried a long list of candidates who could contribute to changes to the manual: psychologists, social workers, nurses, epidemiologists, economists, general social scientists, patients, family members, ethicists, and forensic experts. Additional stakeholders who could play a role are third-party payers, school districts facing increases in educational disability claims, social service agencies where a diagnosis may be used as the basis to argue for welfare entitlements, or even pharmaceutical companies for whom revisions impact both profits and future therapeutic targets.

Uniting these concerns was the belief that the DSM revision process as it stands was led by a single relatively homogeneous organization, which produces a nosology of profound import, through a process that many key stakeholders view as illegitimate. This overarching criticism turns on the following set of critical questions:

1. Does the APA legitimately represent the views of professionals across the allied fields of behavioral health care?
2. Does the APA legitimately advance the interests of patients who receive DSM diagnoses?
3. Is the current revision process legitimate in the way it represents various nonprofessional stakeholders?

4. What new procedures might increase the legitimacy of future revisions of the DSM?

Questions about the legitimacy of the DSM revision have broader purchase than simply a debate about the contents of one clinical handbook. The World Health Organization (WHO), which controls revisions to the International Classification of Disease (ICD) categories, and the APA have always coordinated the two manuals' revisions, but after the surprising success of the 1980 DSM-III, these coordination efforts intensified.[10] Similarly, the APA, at the outset of the DSM-5 revision process, stated that it would work to better harmonize the diagnostic criteria to align with ICD categories.[11] Together, these two systems are the convention for psychiatric classification in the United States and the European Union, providing diagnostic codes and justifications for formularies and payment schedules.[12]

It is because of these sweeping implications that a careful examination of the legitimacy of the DSM is important. We envisage legitimacy in this context as the congruence of the outcomes and the process of the DSM revision with the prudential values of its constituents: clinicians, researchers, patients, and payers. In other words, for the DSM to be legitimate, it will advance those goods central to its constituents through a process that honors the needs and desires of constituents in a transparent way.

In addition to advancing this general notion of a legitimate DSM revision process, the notion of legitimacy we employ has two important features. First, we see legitimacy as arising from a fair process for producing DSM categories. Drawing on models of deliberative democracy, in which the legitimacy of an outcome stems from features of the process used to arrive at that outcome,[13] we focus on how the present process of revising DSM categories—in which DSM revision work groups decide on changes that affect a large and diverse set of constituents—could be made more inclusive, more transparent, and more focused on exchanging reasons for and against certain revisions with a diverse set of constituents. Second, we conceive of legitimacy as a spectrum where a process is more or less legitimate—rather than a dichotomy where a process is or is not legitimate. Again following theorists in deliberative democracy, we recognize that the DSM revision process will never be perfectly legitimate; it would be impossible to include every perspective.[14] Instead, the process should approximate the ideal of legitimacy by more adequately representing broadly held perspectives.

Philosophical inquiries about the ontology of mental disorder, sociological studies on medicalization, and policy research of the ways new categories affect health care services tend to concentrate on the products of the DSM revision. That is, philosophers have examined the DSM categories against background theories of function, health, and disease; sociologists describe how the expansion of medical categories includes behaviors that were previously considered to be idiosyncrasies or social problems; health services researchers may document how expanded diagnostic criteria affect medication utilization or identified prevalence rates.[15] These analyses focus on the *products* of DSM revisions, rather than examining the revision *process* that results in these products. Commentators have begun to address concerns about this process, such as the makeup of the DSM work groups, the basic mechanics of task force meetings, and the role of pharmaceutical funding and conflicts of interest.[16] However, a more in-depth examination of the DSM revision process and its legitimacy, to our knowledge, remains missing from the literature.

Therefore, in this paper, we begin such an analysis. In the next section, we review five potential sources of legitimacy for organizations—substantive, symbolic, formal, descriptive, and participatory—drawn from the political theory literature on how organizations should make decisions that affect a broad set of constituents. We show how these apply to the DSM revision process, and provide concrete examples of where the process has drawn upon or strayed from each source of representative legitimacy.

We then present and answer a foreseeable set of objections that theories of representative legitimacy are, in general, not appropriate for analyzing the DSM. For example, one might argue that the development of a psychiatric nosology should strive to be an objective and scientific process; involvement by advocates or the public will taint the process with social or political values. Two other objections might be raised that, in contrast to political representatives and the legislation they produce, the DSM work groups are unelected and the manual carries no direct coercive power.

We reply that theories of representation, notwithstanding certain limitations, provides a useful lens for studying the legitimacy of the DSM revision process and by extension, the legitimacy of the DSM categories, for three interrelated reasons. First, we argue why we think psychiatric nosology is different—classifications draw on cultural norms about the boundaries of illness in addition to scientific knowledge. Second, we describe ways in which constituents can hold the APA accountable through means other than elections. Third, although clinicians and patients cannot be legally compelled to abide by DSM changes, changes to the DSM will have an impact on the liberties of individuals by providing the justification for decisions related to coercive treatments, assertive outpatient treatment, preventative commitment, or the termination of parental rights. Thus the DSM is a manual that carries indirect coercive authority.

In section 4, we offer a modest proposal for revising the revision process informed by the five sources of legitimacy outlined in section 2. We point to the ways professional diversity across work groups would enhance the legitimacy of the DSM revision process and argue for the formation of an interdisciplinary ethics and policy committee that would provide ongoing review and analysis of the process as it unfolds.

2. Theories of Representation and the DSM-5

2.1 The Constituents

In order to examine whether representation theory applies to the DSM, we must first ask, "Who exactly does the APA represent?" The APA self-identifies as representative of psychiatrists, serving as the "voice and conscience of modern psychiatry" and aiming to "advance and represent the profession of psychiatry."[17] The idea that the APA is an organization aimed at advancing the profession of psychiatry might lead us to conclude that it is an interest group for psychiatrists. And if the APA is merely an interest group for psychiatrists, then the question we address—How could the process of revising the DSM be made more legitimate by being more responsive to the constituencies impacted by the manual?—makes little sense, for psychiatrists would be the only constituent for the revisions that would matter and the only reform for the DSM revision process would be to ensure that it better reflects the interests of this narrow constituency. So is the APA simply an interest group?

We argue that while the APA does engage in some activities that resemble interest group politics—for instance, lobbying against legislation that would grant psychologists prescribing rights[18]—there are two reasons why the organization's scope has expanded beyond that of an interest group, and thus, two reasons for why our analysis of the DSM revision process's legitimacy is warranted. First is the DSM's success as a manual used not only by psychiatrists but also by virtually all mental health practitioners, insurance reimbursement guidelines, and medical researchers. Second is the APA's embrace of this broad use. The APA itself notes that the manual is "used by health care professionals in the United States and much of the world as the authoritative guide to the diagnosis of mental disorders."[19] Likewise, in the preface to the DSM-5, the APA frames the manual as providing a crucial common language for a diverse array of practitioners and researchers:

> DSM has been used by clinicians and researchers from different orientations (biological, psychodynamic, cognitive, behavioral, interpersonal, family/systems), all of whom strive for a common language to communicate the essential characteristics of mental disorders presented by their patients. The information is of value to all professionals associated with various aspects of mental health care, including psychiatrists, other physicians, psychologists, social workers, nurses, counselors, forensic and legal specialists, occupational and rehabilitation therapists, and other health professionals. . . . These diverse needs and interests were taken into consideration in planning DSM-5.[20]

These two factors—the DSM's actual use by a diverse array of practitioners and policy-makers and the APA's explicit embrace of that broad use—means that the DSM is the primary artifact instantiating the various representative roles served by APA. It is the diagnostic canon of allied behavioral health care, which includes but is not limited to psychiatry, clinical psychology, clinical social work, and addiction counseling. As a result, although some actions that the APA takes are narrow interest group actions, the process of revising and producing the DSM is an action in which the organization becomes more than an interest group and thus becomes accountable to constituencies beyond psychiatrists alone. Analogically, we might say laws or policies instantiate the representative roles of political representatives. They provide concrete evidence of delegates' positions on issues of public policy and affect their constituencies in any number of ways. Thus, it seems reasonable to apply theories of representation in an examination of the legitimacy of the DSM, much like such theories can be used to scrutinize the legitimacy of particular laws or policies.

A formal model of representation states that representative X is authorized by constituency Y to act with regard to good Z—there are procedures by which Y directs X with respect to Z.[21] Often, for political representation, we define a constituency by where they reside (e.g., a state, a house district) and by goods that may be provided to the constituency. In contrast to the relationship between citizens and policy-makers, the DSM constituents are dispersed across locations rather than concentrated in defined territories. Therefore, we will define the DSM constituencies by identifying groups affected by DSM revisions regardless of where these groups reside. Table 1 presents the four constituencies of the DSM and related goods.

When we think of a psychiatric diagnosis as a guide to treatment and research, the first constituency will be allied mental health professionals who use DSM diagnoses in practice: psychiatrists, psychologists, clinical social workers, counselors, primary care physicians, and others. Although these professionals have varied interests and treatment approaches, they implicitly authorize the DSM work groups to make decisions about categories that the professionals then implement in practice. Segments of this constituency publicly expressed dissatisfaction with

Table 1. Four constituencies affected by DSM revisions

Constituency	Goods Provided
Allied behavioral health and medical professionals	Diagnoses that aid in clinical decision making, treatment, and research
Mental health researchers*	Categories that provide a common lexicon for research into etiology and treatment of mental disorders
Current or future patients	Diagnoses that define a person's illness and influence his or her treatment across an array of institutions (e.g., medical care, legal system, social settings)
Payers	Diagnostic categories and codes used for reimbursement, formularies, and fee schedules

*This constituency is in flux as the Research Domain Criteria (RDoC) guide shifts researchers away from DSM.

the APA for not representing their theoretical orientation or epistemic vantage point, or for privileging some groups (e.g., psychiatrists) over others (e.g., social workers).

For example, a group of humanistic psychologists wrote an open letter critiquing the proposed manual. In it, they said that despite the fact that they are psychologists, they envision themselves as a core constituency affected by DSM changes. They described how "practicing psychologists in both private and public service utilize the DSM to conceptualize, communicate, and support their clinical work."[22] One of the group's grievances was that the manual's emphasis on "categories that keep pace with advances in neuroscience" overlooked the role that advances in other types of empirical knowledge (e.g. psychological, social, cultural, etc.) should have on classification.[23]

A second important constituency is formed by mental health researchers who rely on the DSM to conduct research on both the causes of mental illness and the efficacy of treatments. Recent editions of the DSM have provided a common lexicon for scientists working across the continuum of mental health research from the lab bench to the bedside to forums where health policies are created. There have been past and ongoing efforts to develop a unique glossary for researchers that would be both more reliable and etiologically precise than the DSM.[24] Indeed, the Research Domain Critieria (RDoC) in development by the National Institute of Mental Health (NIMH) is one such effort.[25] However, until the RDoC is ready for broader use, the DSM will continue to serve as the practical cornerstone of psychiatric research. Thus, researchers are heavily invested in the proceedings of the DSM revision process.

The third main constituency reflects the significant impact of DSM diagnoses on patients. The DSM categories essentially define the boundaries of the sick role; any contraction or expansion will affect those deemed as sick or not. Changes will have an impact on patient identity, access to services, and stigmatizing reactions a person may face. Also, despite a cautionary statement for forensic use, the DSM plays an important role in forensic decisions. Outside the courtroom, in everyday life, persons with mental illness are perceived to be more dangerous, unfit for demanding employment, and less desirable as friends or marriage prospects.[26] Because patients comprise another important constituency, they and their advocates should be able to hold the APA accountable for decisions that they think undermine rather than advance their interests.

A fourth possible constituency includes the payers of mental health services: the private insurers or governmental programs that require a DSM or ICD diagnosis and code to pay for treatment. For this constituency, the goods in question are diagnostic categories with corresponding treatments that the payer will cover. The role of third-party payers in affecting diagnostic decisions is well known. In fact, intentional misdiagnosis to secure insurance coverage for individual patients seems to be somewhat expected and tolerated in behavioral health care settings.[27] So-called "upcoding" and the avoidance of particular, albeit appropriate, diagnoses are common ways to achieve coverage for patients. Similarly, contested categories will result in conflict between clinicians and payers.

For example, a particular clinician may view a set of symptoms describing Internet addiction as a medical disorder worthy of treatment. Yet if payers view the category as illegitimate—as not a real disorder or a problem that should not be understood as medical in nature—the inclusion of the category in the DSM undermines the manual's status as a useful guide for reimbursable treatment. Although it is easy to envision this problem as plaguing contested diagnoses like Internet addiction, insurers have argued that even well accepted DSM categories capture problems that are not actually medical in nature and whose treatment should not be reimbursed. For example, insurers have argued that certain neurodevelopmental disorders such as autism produce problems in educational functioning rather than medical functioning.[28] They have argued that special education should pay for services for the disorder rather than medical insurance. These examples indicate third-party payers serve as a third important and influential constituency of the DSM.

It is also important to recognize that alongside the differing interests of these four constituencies is a steep epistemic grade that tracks the power of each group. Individual patients are by and large dependent on their mental health care providers for access to and translation of the knowledge embodied by the DSM. Patients are not only less empowered to influence the DSM revision process but also they are epistemically tethered to clinicians, researchers, and payers, for expertise and access to psychiatric knowledge and treatment. As we shall see, advocacy groups who aim to provide strength in numbers to individual patients recognize this disadvantage.

2.2 Legitimacy and Representation

Now that we have outlined constituencies affected by the DSM, we ask: How legitimate is the DSM revision process? We can distinguish between three different aspects of the DSM and its revision process that can be more or less legitimate.[29] First relates to whether the APA as an organization is the legitimate body to produce the authoritative guide to mental illness. Second is whether the DSM is legitimate as the authoritative guide to mental illness. For the purposes of this analysis, we accept the basic fact that the DSM is the authoritative guide to mental illness and that the APA is the organization that produces that guide; we do not try to propose a change to this situation—that is, we do not argue that a different means of classifying mental illness (e.g., the Psychodynamic Diagnostic Manual) or a different organization (e.g., the American Psychological Association) are more legitimate. Instead, we take the DSM and APA's preeminence as given, and focus on a third legitimacy-related question: How can the APA's process of revising DSM categories be made more legitimate by being made more responsive to the concerns and interests of the four main constituencies we outlined above?

Let us consider two sources of legitimacy: intrinsic and instrumental.[30] Features of intrinsic legitimacy include an organization's substantive and symbolic representation of constituents. In contrast, an organization's formal, descriptive, and participatory representations serve as instrumental means toward increasing legitimacy.[31] For example, consider the case of a nonprofit organization that aims to represent coal miners' interests. There will be features and actions of the organization that directly increase its legitimacy—for instance, they advocate for safer conditions that protect the miners rather than dangerous cost-cutting measures that benefit the mine owners. There may also be features of the organization that are means of increasing legitimacy—for example, having a few coal miners serve on the organization's board of directors, increasing the likelihood that the organization will advocate for correct positions related to mining safety.

Intrinsic and instrumental sources of representation thus work in tandem rather than in isolation. We turn now and outline several of these complementary sources of legitimacy that the APA might utilize for the DSM revision process.[32] Table 2 outlines these examples and proposals.

2.3 Intrinsic Sources of Legitimacy: Substantive and Symbolic Representation

2.3.1 Substantive Representation

Substantive representation refers to the congruence between the position a representative organization takes on an issue and the interests of its constituents. In the context of the DSM, substantive representation refers to the extent that the APA's revisions reflect the interests of its constituencies. Though this source of legitimacy seems straightforward, there remains debate about who should have the final say when there is disagreement between how constituents define what is in their best interests and how representatives define what is in the best interests of constituents.

The case of Asperger's syndrome illustrates conflicts about how DSM revisers should decide what changes are in constituents' interests. In the DSM-5, Asperger's has been folded into a single category called autism spectrum disorders, which also now includes classic autism and pervasive developmental disorder- not otherwise specified.[33] At the time of the proposal, many patients and advocates, including outspoken advocates like Temple Grandin, argued that despite evidence that Asperger's was a form of autism, it would be better for the disorder to remain separate to preserve the large community that has coalesced around Asperger's and to ensure that service provision remains uninterrupted.[34]

Table 2. Examples of sources of representation and proposals for future DSM revisions

Sources of Legitimate Representation	Examples from DSM-5 Revision Process	How Future DSM Revision Processes Could Increase This Source of Legitimacy
Intrinsic Sources of Legitimacy		
Substantive	Case of Asperger's syndrome suggests that the APA might operate with more of a trustee version of substantive representation, where they may deviate from constituents' expressed preferences if they believe that doing so is in the constituents' best interest	Try to identify guidelines for when work groups will heed constituents' expressed preferences about a manual revision, and when these expressed preferences should not influence the process
Symbolic	Some constituents expressed a diminished sense of trust in the revision process because they perceived it as being impacted by financial biases	Empirical research on what formal, descriptive, participatory procedures would increase trust in the revision process
Instrumental Sources of Legitimacy		
Formal	Conflict of interest (COI) guidelines for work group members, post draft revisions for comment	Citizen juries, more stringent COI guidelines, others?
Descriptive	Lack of descriptive correspondence between those who revise the DSM (research-focused psychiatrists and psychologists) and those impacted by the manual's content (patients and a broad array of mental health professionals)	Potentially include one or two practicing clinicians and patients on each work group
Participatory	Allow members of the public to submit comments in response to draft revisions	Enhance communication by not only disseminating draft revisions but also encouraging more active dialogue between work group members and DSM constituencies (patients and practicing mental health professionals—for example, online or in-person discussion forums)

Even leading researchers like Simon Baron-Cohen, while accepting the notion of a spectrum, initially expressed concern about the blurring of lines between those with Asperger's and those with classic autism, citing serious practical consequences.[35] Indeed, a study by the Volkmar group pointed to the possibility that a substantial percentage of individuals with Asperger's disorder would be excluded from the new category.[36] Advocates used these data in an effort to lobby the APA to maintain the current scheme. Interestingly, advocates for patients with classic autism also resisted the change, because they felt that the inclusion of high functioning so-called "Aspies" would diminish public understanding of the severity and seriousness of classic autism.

We should note that Consideration J of the proposed definition of mental disorders for DSM-5 stipulates that such pragmatic considerations should play a role in reshaping categories: "When considering whether to add a psychiatric condition to the nomenclature . . . potential benefits (for example, provide better patient care, stimulate new research) should outweigh potential harms (for example, hurt particular individuals, be subject to misuse)."[37] The spirit of this consideration resonates with the ideals of substantive representation, and it would seem the neurodevelopmental disorders work group must have considered the practical harms of re-categorization and diagnostic discontinuity on individuals with Asperger's. If so, they calculated the clinical and research benefits of re-categorization to be greater than advocates' interests in preserving the Aspergerian culture and access to services.

The case of Asperger's illustrates how two different models of substantive representation are in tension. On the one hand, a trustee model permits representatives to deviate from the expressed wishes of constituents if trustees believe that doing so is in the best interests of constituents. According to this model, the removal of Asperger's syndrome was a legitimate exercise of representation. In contrast, a delegate model of substantive representation places an emphasis on the self-expressed interests of particular constituents. This model would take seriously the interests of the Asperger's community and consider retaining Asperger's syndrome, despite scientific and clinical evidence supporting its removal.[38]

Both trustee and delegate models of representation focus on the representative's role in acting according to constituents' interests. However, the delegate model relies on constituents' ability to clearly articulate how certain DSM revisions might advance or set back their interests. In the Asperger's case, accurate delegation depends on the ability of persons with Asperger's or their caregivers to articulate why having a diagnosis distinct from autism was in their interest. This reliance on self-expressed interests is complicated by two main factors.

The first complication is a lack of clarity—constituents may be unclear about what their interests are or express inconsistent preferences. Representatives often must respond to issues that constituents have neither considered nor anticipated. The second complication is due to apathy. Although a delegate's decisions affect their interests, individual constituents may not care enough to actively convey their preferences about these decisions. Just as we can picture the apathetic citizen who rarely votes, does not monitor the positions of his elected representative, and seems content accepting the status quo, we can imagine mental health professionals who do not closely follow the revision process and who uncritically accept changes to the DSM.

2.3.2 Symbolic Representation

The second form of intrinsic legitimacy—symbolic representation—helps address this problem of how decision-makers like the DSM revisers should proceed when constituencies such as patients have difficulty clearly articulating their interests. Symbolic representation refers to the general sense of trust that constituents have in their representatives. To what extent do constituents accept the representative as someone who can be trusted to act according to their interests? For instance, a community mental health clinician might not closely follow or engage with the DSM revision process. But if she trusts the APA and its work groups, she might view the results of that process as acceptable.

How well has the APA succeeded in gaining the trust of constituents who rely on DSM categories? Trust in the APA and other medical institutions is a complex, multidimensional concept that includes dimensions like perceptions of the APA's competence in revising the manual and their honesty about the reasons for revisions.[39] It is clear that a crucial component of trust in the DSM is the belief that the APA will continue to refine categories primarily to serve patients and clinicians and not the financial interests of the organization or members of the revision groups. Trust in psychiatry in general and the APA specifically has waned significantly since the release of DSM-IV, in part due to worries about academic-industry relationships.[40] The critical attention to the present DSM revision process highlights this eroded sense of trust. Furthermore, diminished trust in the revision process can undermine efforts by practitioners to convince patients of the value of treatment—for instance, skepticism about the effect of financial interests on the ADHD criteria could inhibit help-seeking from children who could genuinely benefit from treatment. For now, more empirical research is needed to examine levels of trust in psychiatry, the APA, and the DSM revision process. These data can help us assess whether symbolic legitimacy operates as a form of representation in the DSM revision process.

2.4 Instrumental Sources of Legitimacy: Formal, Descriptive, and Participatory Representation

It seems reasonable to claim that representatives have an obligation to try to advance the interests of their constituents and also gain, maintain, and enhance constituents' trust and acceptance. The question that follows is how these goals can be achieved. Often organizations turn toward instrumental sources of legitimacy to help them act in ways that are more congruent with constituent interests and bolster trust among their constituencies. The first kind of instrumental legitimacy is found in procedures that provide formal authorization—these are explicit procedures defining *who* can make decisions that affect constituent interests and how these representatives will be held accountable.

2.4.1 Formal Representation

In the case of the DSM, two formal procedures were used: one focused on choosing work group members and the other on holding work group members accountable. The first created eligibility criteria for who could serve as a representative. The APA enacted rules related to the financial interests of work group members. These rules established limits on the amount of pharmaceutical funding work group members could receive. The aim was to increase legitimacy by minimizing the chance that work group members would represent—or be perceived to represent—a false constituency (pharmaceutical companies) rather than their real constituencies (practicing mental health professionals, researchers, and patients). Principles aimed at minimizing financial conflicts of interest were adopted in 2006 and included the prohibition of members from earning more than $10,000 annually from pharmaceutical industry sources or holding more than $50,000 in industry-based securities. It is unclear if this rule succeeded in minimizing financial conflict of interest.[41]

The second procedure affected how constituencies became informed about changes that the work group members considered making. The work groups published draft criteria to a public website for review and comment at three points during the revision process.[42] Over thirteen thousand comments were received. Some letters represented the views of individual clinicians concerned about the impact of category changes on everyday practice, others came from patients or advocates, and several well-publicized open letters were sent by professional groups.[43]

We should note that it remains unclear whether and how concerns expressed in the comments were addressed by the APA, which lessens the extent to which the procedure enhances legitimacy. If the work groups did a more thorough job of summarizing the comments and illustrating how the revisions made were either responsive to the concerns or reasons why the revisions were not responsive, this would help the public commenting process function better as a formal procedure to increase accountability. For instance, despite criticisms by patient advocates and other constituents,[44] the DSM task force decided to continue with its plans to remove a bereavement exclusion for major depressive disorder, which had excluded people from receiving the diagnosis if they experienced a major loss within the past two months. There was little explicit information about why the APA decided to proceed with the change amidst constituent criticism. This is an example where the APA's formal procedure of collecting public comments could be reformed simply by publishing responses to concerns expressed in comments.

2.4.2 Descriptive Representation

While formal representation focuses on processes for choosing decision makers and holding them accountable, descriptive representation looks at how closely representatives mirror certain relevant characteristics of their constituents. In the case of legislative policy-making, arguments advocating for greater descriptive representation question, for example, whether a legislature composed of affluent white men can legitimately represent racial minorities, women, or the poor.[45] In the case of the DSM, professional and public concerns were voiced about the composition of DSM work groups, which were composed of mostly psychiatrist researchers from highly ranked academic medical centers. Commentators argued that the groups should include members of the two key constituencies: practicing clinicians and patients/caregivers.[46]

Table 3, which highlights the makeup of DSM-5 revisions work groups, confirms these concerns and shows three ways that the makeup of work groups deviates from the makeup of those who use the manual. First, the APA's goals of creating work groups composed of research leaders means that the work groups were almost exclusively composed of persons working at academic medical centers or the National Institutes of Health (NIH), with work groups ranging from 84.6–100 percent of members drawn from these two sources. This makes sense given the goal of recruiting research leaders, but also highlights the absence of persons who spend the majority of their time in clinical practice. Second, the groups varied in terms of their professional diversity—some contained almost exclusively psychiatrists and clinical psychologists, but others, such as the substance-related disorders work groups, had disciplines like epidemiology represented. Given the diversity of professional disciplines that use the DSM categories for research and clinical purposes, it is worth asking whether other groups should aim for greater disciplinary diversity. Third, at this time, the work groups do not contain any patient or caregiver representatives.

Why does it matter how closely the DSM work groups resemble the constituents whom they represent? First, resemblance may enhance the quantity and quality of communication between constituents and representatives. For example, a person diagnosed with schizophrenia may receive better uptake about his concerns with a peer representative on a work group. Similarly, a practicing clinician may be better able to express a concern—for example, that the addition of a severity rating scale for a disorder will not be clinically valuable and will overwhelm her already busy practice—to another practicing clinician than to a work group member who spends much of her time focused on research rather than treating patients. Enhanced communication resulting from descriptive congruity of work group members and constituents may further the legitimacy and clinical effectiveness of the manual.

Second, greater descriptive representation may reassure persons long-excluded from positions of power that "persons like them" are welcome into key decision-making bodies. Historically, mentally ill persons have been excluded from positions of decision-making power due to judgments of incompetency. Including patients on work groups thus might reassure a key constituency of the DSM that their views matter and that they are no longer excluded from important processes

Table 3. Descriptive features of DSM work groups

	Training*							Type of Employment			Other Characteristics	
DSM Work Group	MD, psychiatry	MD, other specialty (type on the work group)	PhD, clinical psych.	PhD, basic science (non-clin. psych., biology, genetics, neuroscience)	PhD, other (type on the work group)	JD	MSW	Academic medical center or dept. (of those, percent ranked in top 25 US research hospitals or institutions)**	NIH	Site not affiliated with university or NIH	Primary employment in country other than United States, UK, or Canada	Female
ADHD and Disruptive Behavior Disorders (N = 10)	50%	0%	40%	10%	10% (special education)	0.0%	10%	100% (40% are top 25)	0%	0%	10%	30%
Anxiety, Obsessive-Compulsive Spectrum, Post-Traumatic, and Dissociative Disorders (N = 14)	71.4%	7.1% (pediatrics)	14.3%	14.3%	14.3% (educ. development, psychopharmacology)	0.0%	0.0%	100.0% (69.2% in top 25)	0.0%	0.0%	28.6%	28.6%
Childhood and Adolescent Disorders (N = 8)	75.0%	12.5% (pediatrics)	12.5%	0.0%	0.0%	0.0%	0.0%	50.0% (75% in top 25)	50.0%	0.0%	0.0%	50.0%
Eating Disorders (N = 12)	41.7%	8.3% (pediatrics)	33.3%	8.3%	25.0% (anthropology, nursing)	0.0%	8.3%	91.7% (36.4% in top 25)	8.3%	8.3%	0.0%	50.0%
Mood Disorders (N = 11)	81.8%	9.1%	9.1%	9.1%	9.1% (anatomy/ physiology)	0.0%	0.0%	81.8% (22.22% in top 25)	9.1%	9.1%	18.2%	27.3%
Neurocognitive Disorders (N = 9)	77.8%	22.2%	0.0%	11.1%	55.6% (epi. [2], counseling psychology, psychiatry)	0.0%	0.0%	100.0% (33.3% in top 25)	0.0%	0.0%	11.1%	33.3%

	Training*							Type of Employment			Other Characteristics	
DSM Work Group	MD, psychiatry	MD, other specialty (type on the work group)	PhD, clinical psych.	PhD, basic science (non-clin. psych., biology, genetics, neuroscience)	PhD, other (type on the work group)	JD	MSW	Academic medical center or dept. (of those, percent ranked in top 25 US research hospitals or institutions)**	NIH	Site not affiliated with university or NIH	Primary employment in country other than United States, UK, or Canada	Female
Neurodev. Disorders (N = 13)	46.2%	46.2%	7.7%	23.1%	7.7% (speech and hearing sciences)	0.0%	0.0%	84.6% (54.5% in top 25)	7.7%	0.0%	0.0%	53.8%
Personality Disorders (N = 10)	50.0%	0.0%	50.0%	0.0%	0.0%	0.0%	0.0%	90.0% (33.3% in top 25)	0.0%	10.0%	10.0%	20.0%
Psychotic Disorders (N = 12)	91.7%	16.7%	16.7%	16.7%	8.3% (genetic epi.)	0.0%	0.0%	100.0% (33.3% in top 25)	0.0%	0.0%	16.7%	33.3%
Sexual and Gender Identity Disorders (N = 13)	46.2%	7.7%	30.8%	30.8%	15.4% (epi.)	0.0%	0.0%	84.6% (36.4% in top 25)	0.0%	15.4%	23.1%	23.1%
Sleep-Wake Disorders (N = 7)	14.3%	28.6%	28.6%	28.6%	14.3% (nursing)	0.0%	0.0%	100.0% (42.9% in top 25)	0.0%	0.0%	14.3%	42.9%
Somatic Symptoms Disorders (N = 9)	88.9%	0.0%	11.1%	0.0%	0.0%	0.0%	0.0%	100.0% (66.7% in top 25)	0.0%	0.0%	11.1%	0.0%
Substance-Related Disorders (N = 14)	50.0%	21.4%	14.3%	7.1%	50.0% (epi. [4], neurophys., anthropology, psychiatry)	0.0%	7.1%	71.4% (100% in top 25)	14.3%	7.1%	14.3%	21.4%

*May add up to >100% because of dual degrees such as MD, PhD.

** United States academic medical center rankings were ascertained from the *U.S. News & World Report* rankings of research-focused medical schools. United States academic department rankings were ascertained from the *U.S. News & World Report* ranking of research universities.

that affect their interests. In turn, this can increase patients' trust in the overall revision process via symbolic representation.

2.4.3 Participatory Representation

Lastly, theories of participatory representation highlight why it is not sufficient to merely include persons who descriptively resemble the important DSM constituents of practicing mental health professionals and patients. Instead, there is a ladder of participation that constituents can engage in to help increase the legitimacy of organizations that represent them. The lower rung is being placed on "rubber stamp advisory committees"; the middle rung is where constituents are included as token members without sufficient support to have an influence; the highest rung is "partnership and delegated power," which refers to including a "critical mass" of constituents so that they are no longer tokens or persons whose voice is overwhelmed by the presence of forceful majority opinions.[47] Instead, they are important decision-making partners. As constituents ascend this ladder of participation, they may increase the body's quality of decision making, as they are able to add an additional epistemic perspective to each level. They may also become more educated about the issues at stake as a result of engaging in this deliberative role.

So, for example, suppose a practicing community mental health clinician serves as a member of a DSM psychotic disorders work group that is debating whether to include a disorder that captures clinically distressing sub-threshold psychotic symptoms, but that should not be treated with antipsychotics. For the community clinician, the process of serving on the decision-making body can help increase his understanding of why antipsychotics may be ill-advised, since he had a stake in formulating the decision rather than receiving it from above.

At present, the participation of stakeholders like patients and practice-focused clinicians falls on the lower rungs of the participatory ladder. They were offered the opportunity to provide input on the revisions, but were not informed about how this input specifically influenced final DSM-5 revisions. A fuller actualization of participatory representation would allow constituents to move up the participatory ladder. For example, work groups might begin by granting individual patients observer status in work group deliberations. As patient representatives begin to understand and participate more fully, moving up the ladder, they could eventually be allowed to vote on draft proposals.

3. LIMITATIONS IN APPLYING REPRESENTATION THEORY TO THE DSM

In section 2, we sketched the constituencies of the DSM and surveyed the landscape of representation theory vis-à-vis the DSM revision, offering examples to illustrate how the various models of representative legitimacy have been either utilized in the revision process or could be utilized more fully in future revisions.

One might argue, however, that dissimilarities between the DSM and typical cases of representation make it inappropriate to use theories of representative legitimacy to analyze the DSM revision process. First is that although the DSM serves many purposes, the manual is primarily intended to serve as a valid and reliable compendium based on the latest scientific and clinical evidence.[48] Therefore, it seems strange to subject its revision to the whims of constituents such as practice-focused clinicians or patients, who may neither understand nor care to understand the science upon which the document is built. Thus, it might be argued, our starting premise that the DSM revision process is or should be viewed as an exercise where work group members represent constituents is false.

Second, it is clearly the case that basic differences exist between what APA work group members do and what legislators do in policy-making. When an Illinois resident elects a senator to represent his interests in Congress, he may hold that senator accountable by withholding future votes and campaign support. The DSM revision process differs from this simple case in two obvious ways. First, and simply, government policy-makers are elected while DSM revisers are not. Second, the actions of DSM revisers do not directly lead to coercive policies backed by the weight of the government. Do these key differences alter or undermine the prism of representation theory as a prism to examine the DSM revision process?

3.1 Is Psychiatric Nosology Different?

Oncologists studying variations of cancer cells, molecular markers, histological samples, or tumor types to more precisely define cancers do not subject their proposed new categories to a popular vote or provide open commenting periods on public websites. Why should psychiatrists? Is psychiatric nosology development so different from other areas of science and medicine that it requires an inclusive and deliberative process? Or is the move toward broader representation in psychiatric nosology development unwarranted and possibly counterproductive?

The argument that representation theory is inapt because nosology development ought not be a political process ignores some basic, widely accepted features of both science and medicine as well as the unique socio-cultural and historical position of American psychiatry. First, as is now well accepted, basic science—even at is most "objective"—is a distinctly social enterprise, steeped in professional, cultural, and political values.[49] We see this value-ladenness in both subtle and obvious ways. From research funding priorities to categories of planetary objects, cultural values, emotional appeals, and politics will play a role. In the case of psychiatry, the concept of mental disorder reflects particular values that are often culturally bound. That an ideal of psychosocial function is considered to be that of the autonomous, self-directed, and rational individual reflects particular norms of American culture that are considered less important in other parts of the world. These variations need not entail mental illness as an artifact of cultural relativism, but it does mean that those developing categories of disorders should be sensitive and responsive to cultural norms as they do their work.[50]

Second, and perhaps more importantly, the history of American psychiatry is punctuated by questionable categories and institutional abuses. In diagnosing slaves that ran away as having "drapetomania," or including homosexuality as it was in the original DSM, psychiatric nosology has gotten things very wrong on a number of occasions.[51] These cases were not errors of basic science with difficult-to-trace downstream effects. Rather, they were mistakes that were often guided by extramedical values such as race, gender, religious tradition, or money. They profoundly affected individuals on a daily basis, eventually fueling a psychiatric rehabilitation movement aimed at correcting the abuses and securing civil rights for so-called "psychiatric survivors." Although these categories were but a sliver of the many valid and reliable diagnostic categories developed over the years, their legacy lingers.

Psychiatry's unique social embeddedness and its history provide two interrelated reasons to distinguish psychiatric nosology from other taxonomic efforts, thereby making representation theory apt in examining the DSM process.

3.2 Representation without Elections

Traditionally, we might think that free and fair elections are necessary for a representative to be legitimate. The representative gains legitimacy because affected parties can give or withhold votes based on how well the representative advances their interests. The DSM task force members are appointed by an APA committee rather than elected.[52] But are elections the only way to confer legitimacy upon a decision-making body like the DSM revisers? A similar question comes up, for example, when examining the legitimacy of advocates who claim to represent vulnerable and disenfranchised persons such as those living in poverty in developing nations or stigmatized persons such as individuals with HIV/AIDS.[53]

In these cases, political theorists have argued that it may be appropriate to expand the concept of representative legitimacy to include both persons who are elected as representatives and nonelected or self-appointed representatives who meet particular criteria and have the special expertise to advance the interests of a constituency united by common needs rather than a defined geographic territory.[54] Such a category would include the APA work group members who make decisions about DSM categories. In defense of this expansion, these commentators point out that constituents can use mechanisms other than voting to hold decision makers accountable for their decisions. Applied to the DSM and the four main constituencies we discussed earlier—mental health clinicians, researchers, patients, and third-party payers—we see that the constituencies have expressed their dissatisfaction with DSM decisions in different ways, triggering a potential redirection of the proposed revisions.

3.2.1 Clinicians and Researchers

Clinicians and psychiatric researchers join and pay membership dues to the American Psychiatric Association presumably because they agree with the way the organization advances the profession's and their own individual interests. They can dissent or deem the professional association illegitimate and leave the group. They might organize an alternative organization to more effectively advance their interests. Or, these constituencies might attempt to abandon the manual entirely by constructing rival systems of psychiatric classification that better represent the interests of affected parties, such as the *Psychodynamic Diagnostic Manual* (PDM) and the Research Domain Criteria (RDoC) project.

3.2.2 Patients

Patients, though they are not given the opportunity to directly elect work group members or to join the APA, have expressed dissatisfaction through public protest or through forming alliances with research leaders supportive of their cause. For instance, after the Vietnam War, veterans and allied psychiatrists lobbied for the DSM-III inclusion of a disorder that would capture postwar stress, a "post-Vietnam syndrome."[55] These patients were dissatisfied that under the purview of the existing DSM, psychiatry traced their problems to an underlying predisposition to mental illness that the war merely exacerbated, rather than to problems caused by the war itself.[56] Likewise, as Bayer has chronicled, gay rights advocates, through sustained political action both within and outside the APA, saw homosexuality redacted from DSM-III.[57]

3.2.3 Third-Party Payers

Third-party payers are also able to express dissatisfaction through non-electoral means. Rather than "voting with their feet," as psychiatrists who leave the APA or resign from the work groups might do, or "voting with their voices," as patients might do, payers "vote with their dollars" by deciding whether treatment for a certain problem is a "medical necessity" or not.[58] These decisions can then influence DSM revisions. For example, many have noted insurers' greater degree of reluctance to cover Axis II personality disorders than Axis I clinical disorders, sometimes under the premise that the former lack evidence-based treatments.[59] The DSM-5 decision to eliminate the formal distinction between Axis I clinical disorders and Axis II personality disorders did not explicitly reference insurance non-parity between the two as a reason behind the decision.[60] But the decision's emphasis on ending "arbitrary boundaries" and "artificial distinctions" between the two types of disorders could have the secondary consequence of increasing the chance that payers de-emphasize these distinctions and give more equal funding support to personality disorders.

3.3 Direct versus Indirect Coercive Power

Another potentially significant difference between the DSM and legislatures with respect to representation theory exists: legislatures by way of the state and judicial systems possess coercive power to enforce the decisions they make. The APA, of course, possesses no power to coerce clinicians to abide by the DSM. Since the DSM has the non-binding power of a clinical guideline rather than the binding power of the law, perhaps it does not matter whether the APA's decisions about psychiatric classification are legitimate or not. Put differently, the APA does not legislate directly but relies on other bodies—courts and insurers—to use its categories and to enforce its power.

The DSM itself does not have a direct binding force of law—that is, US mental health professionals are certainly not sanctioned if they deviate from DSM criteria when making a diagnosis; patients are not legally compelled to agree that a given diagnosis describes their symptoms well. Nonetheless, the DSM does indirectly serve as a tool of coercion. Despite the fact that the editors of DSM warn against using the manual for forensic purposes, it is the case that DSM-based disorders are pivotal to policies significantly impacting individual liberty. The examples are many, but we present two: (1) the coercive power of DSM diagnoses on persons with paraphilia disorders who are actively monitored in the community, and (2) individuals with DSM-based disorders whose parental rights are terminated.

The first example is DSM paraphilia diagnoses and decisions about confining sexually violent predators to indefinite civil commitment upon completion of their prison sentences. The three criteria for this commitment are (1) being convicted of a violent sexual crime; (2) having a diagnosed mental disorder; and (3) as a *result* of that diagnosed mental disorder, being likely to engage in sexually violent offenses if not subject to preventive civil commitment.[61] Diagnoses like pedophilia and other paraphilias can appear to satisfy both the second and third criteria—they are diagnosed mental disorders and the disorders might increase a person's risk for future sexual violence. Despite warnings contained in the DSM and Supreme Court cases that emphasize evaluating each person's risk of future sexual violence on a case-by-case basis, certain evaluators and courts seem to interpret these DSM diagnoses as sufficient to justify indefinite civil commitment when combined with an offender's conviction of sexual violence.[62] Therefore, decisions about the scope and shape of DSM criteria have implications for coercive civil commitment—for instance, if pedophilia's criteria are expanded to include attraction to a broader range of ages, this could increase the number of offenders committed following completion of their sentence. So the legitimacy of how these changes are made matters a great deal.

Likewise, DSM diagnoses play a role in decisions about parental rights. Determining when to remove a child from a parent's custody is a complex decision that involves determinations of risk. State legislation allows mental illness to influence these judgments. As of 2005, thirty-six states specifically state that the presence of a mental illness may be grounds for termination of parental rights.[63] As one commentator summarizes, "while the laws do not authorize termination of parental rights based solely on a parent having a mental illness, *they invite a focus* on the disability [the mental illness] itself rather than on specific behavior that puts a child at risk."[64] Caseworkers aware of the person's diagnosis become predisposed to view behaviors that many parents might display—a messy house, or expressions of stress—through the lens of the illness, leading to more pessimistic evaluations of the parent's fitness for reunification and an increased risk that they will remove the child from the home.[65]

These two cases illustrate that the manual is not merely a non-binding clinical document that clinicians or patients can easily ignore. The DSM diagnoses have a bearing on significant and legally coercive decisions such as preventive civil commitment following prison or loss of parental rights. Proposals by elected officials are often closely scrutinized when they affect personal liberty, privacy, and security. Similarly, insofar as the decisions of the APA will have legally binding implications, their actions should also be carefully examined.

4. Revising the Revision Process

We have tried to show that the DSM is the product of representation for four well-defined constituencies: practicing mental health clinicians and researchers (which includes more than just psychiatrists who make up the APA's membership), patients who are recipients of DSM diagnoses, and payers who make treatment reimbursement decisions based on DSM categories. The DSM faces many of the same challenges regarding its legitimacy that both elected legislatures and nonelected organizations like Non-Governmental Organizations (NGOs) face. The revision process includes mechanisms that constituents can use to express dissatisfaction, the manual has an impact on legally coercive decisions, and the manual's revisions greatly affect those given a psychiatric label.

As a result, the theories of representation we outlined in section 2—which focus on how to increase the legitimacy of the DSM revision process—seem useful for charting ways to improve the revision process. In this section, we focus on three means by which the APA may increase their legitimacy through strategies grounded in formal representation, descriptive representation, and participatory representation. We propose examples of ways to revise the DSM revision process heeding each source of legitimacy.

4.1 Broadening the APA Membership Criteria

Currently only physicians may become members of APA, excluding tens of thousands of behavioral health care providers whose clinical work and research findings both inform and, in some cases, ground the work of practicing psychiatrists.[66] This membership condition seems to be an anachronism, harkening to a time before the DSM was widely utilized as the basis for mental health practice and when the organization's tasks were confined to issues of more specific interest to psychiatrists alone. It is true that in times past, the APA served as a professional guild that provided a form of collective professional advancement as well as a mechanism for self-policing. Today, given the wide medical, social, and economic influence of the DSM, the role of the APA has changed, requiring a rethinking of which constituents should be allowed to join the organization.

Through the DSM's success, contemporary psychiatry has come to occupy a unique professional niche: while they are only one mental illness profession among many, they produce the guide to treatment and research that the other mental health professions use. Given these changes, the APA should reconsider its membership rules and allow other mental health care professionals to become members of the organization. This move would increase two sources of legitimacy. First, in terms of descriptive representation, the APA's leadership would be composed of persons who resemble the diversity of the mental health profession rather than a small swath of it. Second, while non-psychiatrists already do serve on DSM revision work groups, having more non-psychiatrist professionals as APA members can help increase participatory representation by having these professionals at forums like professional meetings where they can broadcast their perspectives on DSM categories. As Sadler and Fulford argue: "No other medical specialty has the same responsibility to ensure that its diagnostic categories are as valid from the perspectives of patients as well as its professionals. Who then is better able to help with developing the DSMs than patients and families themselves?"[67]

While this proposal involves broadening the APA membership to incorporate non-psychiatrists with important perspectives on the DSM, others, like Frances and Widiger, have proposed a more dramatic change: the task of formulating and reformulating the psychiatric nosology should be taken from the APA and be done under the auspices of NIMH or the Institute of Medicine (IOM). They argue: "[P]aradoxically, we mount a fairly careful process of regulatory approval for new drugs through the Food and Drug Administration, but simultaneously we perform a perfunctory vetting of new diagnoses and allow the primary reviews to be done by small and parochial panels of experts who have a narrow experience, a vested interest, and a lack of appropriate skills."[68]

As we stated earlier, the present paper is focused on how to make the process of the APA-led DSM revisions more legitimate, and not on whether the process should be completely removed from the APA's control or whether a new manual should take over the DSM's functions. Furthermore, shifting control over the manual to the NIMH or Institute of Medicine (IOM) would not automatically make the revision process more responsive to the needs of constituents, nor would a shift automatically result in a more diverse group of representatives deciding on revisions. For instance, an NIMH-led manual might privilege the interests of research-psychiatrists to an even greater extent than the APA-led DSM. Likewise, although the IOM holds public hearings to collect feedback on a committee's task, it also relies on private deliberations that raise similar questions as the APA-led revisions about how committee members are held accountable for their decisions. Therefore, the issues discussed in this paper about increased procedural legitimacy are applicable to both the current APA-led revision process and future processes where decision making about mental illness categories may shift to a different body. Meanwhile, while the APA retains control over the DSM revision process, broadening the membership organization's inclusion criteria to include a more diverse set of mental health professionals could allay these commentators' concerns about the narrowness of who controls the manual's changes.

4.2 Transparent and Inclusive Procedures for Work Group Selection

At present, scrutiny applied to the DSM work group selection process overwhelmingly focuses on financial conflicts of interest. Qualifying criteria should focus less on the detection and rooting out of financial conflicts of interest. We recognize that strict policies around conflict of interest are necessary to convey politically correct optics, but are such policies effective and do they lead to a better product? As we have seen, policies that aim to restrict financial ties and provide transparent reporting do not necessarily work to "purify" DSM work groups.[69] Moreover, when these policies do work, they disqualify leading researchers and subject matter experts from participation. Instead, the APA should develop and convey a more sophisticated understanding of conflicts of interest to the public that provides a clear rationale for why particular experts have been chosen (or are eligible for election) to a particular work group. In other words, instead of trying to appeal to those who possess the more radical view that work group members should have no ties to pharmaceutical companies, the organization should aim to educate the vast majority of providers and consumers who will use the DSM about the potential issues raised by industry-academic relationships, consulting relationships, speaker's bureaus, and other fraught financial arrangements. This would come in the form of requiring disclosure of certain conflicts and elimination of other financial relationships. Less attention is paid to who is eligible for work group selection and how work group members are selected, a broader and more important issue than work group members' relationships with for-profit and nonprofit funding sources.

To broaden its focus beyond financial conflicts of interest, the APA could consider a more expansive and transparent election process for selecting committee members. An electorate would include members of the APA, and possibly extend to members of other professional organizations such as the American Psychological Association, the National Association of Social Workers, and the American Academy of Neurology. Similarly, candidates for slots on committees might come from allied professional societies.

Relatedly, it seems that participation by insurance representatives is also appropriate. To exclude payers from the discussion is to ignore the important fact that the DSM serves as both a clinical handbook and as an insurance schedule. Key executives from private insurance firms as well as representatives from federal- and state-based insurance programs should have a place at the revision table. It is this latter group, in fact, that manages the largest budgets devoted to providing mental health services. While the financial conflict of interest policy is one important formal procedure for increasing the chance that work group members will serve the correct set of constituent interests, these other formal procedures can increase congruence between constituent interests and work group member decisions.

4.3 Greater Participatory Representation

No matter how diverse the DSM revision work groups become, the reality is that a small group of experts will have an outsized impact on the shape of DSM revisions. In spite of this, improving the way that patients, caregivers, and community practitioners are engaged in the revision process can increase the chance that persons both trust the way the process is conducted and believe the DSM changes are in their best interest. The DSM-5 made important advances in public engagement, but the process of soliciting public feedback can be made more transparent. It is not enough to call for public comments without promulgating how or if those comments were integrated into the revision process. We ourselves have called upon the APA to release the thirteen thousand comments so that we and other researchers may be able to examine the content of the comments and begin to piece together whether and how patient/practitioner concerns about proposed changes had any real impact on the DSM-5. This can help increase the role of patients and practitioners in the revision process from one-sided feedback on categories in progress to a more active dialogue about how changes can best serve these constituencies.

4.4 Globalizing the DSM

As the DSM continues toward harmony with the ICD and the ICF, increased participation from non-US stakeholders will become more important. To their credit, the DSM-5 task force leaders recognized the manual's global influence and between 2003 and 2008 convened thirteen international conferences. Participants hailed from thirty-nine countries; half of the participants were from outside North America.[70] This was a start. Sustained international engagement in future revisions should be ongoing.

There remain serious shortcomings in the way the DSM is utilized in nations outside the United States. In part, DSM categories are geared for interpretation and use by trained mental health professionals. Developing nations often lack such specialists, so categories must be utilized by primary care providers who both lack the experience to appropriately diagnose more complicated mental disorders and who shy away from labeling distress in terms of DSM categories.[71] If the DSM is to remain relevant outside the United States, it must go beyond lists of "culture-bound" disorders and cultural formation instruments and evolve with the input of stakeholders who endorse very different paradigms for mental disorder. The question of how to more fully and legitimately globalize psychiatric nosology remains an area for further research.

CONCLUSION

Since DSM-III, the manuals have had an unexpected degree of success that has resulted in their broad reach across the allied behavioral health care professions and institutional settings (e.g., clinical treatment, special education categories, legal proceedings).[72] But the DSM's success has created new social responsibilities for the APA to ensure that revisions proceed in a way that is legitimate in the eyes of the constituents affected by the DSM's categories. The present paper highlights ways in which the DSM revision process is more or less legitimate: first, the extent to which the changes are congruent with the interests of constituents (substantive representation), and second, the extent to which constituents trust that the DSM revisions were made in a way that advances their interests even if they do not have the time or energy to closely watch how the process unfolds. We also highlight *means* of increasing those forms of legitimacy.

In some ways, the APA has become a victim of its own success and power—much of which can be traced to the monopoly it holds over the writing and publication of the psychiatry nosology. In wielding this power, the APA also takes on important social and political responsibilities that, without reform of the way it represents constituents, it may lack the legitimacy to adequately meet.

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NOTES

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1. APA, *DSM-5.*
2. Sadler, "Considering the Economy."

3. Research psychiatrists were selected by a revision Task Force and formed ten-to-twelve-member work groups organized around topical areas.

4. Kuhl, Kupfer, and Regier, "Patient-Centered Revisions"; Spitzer, "DSM-V Transparency."

5. Hansen et al., "Independent Review."

6. APA notes the following diversity of professional backgrounds: "These members, recruited based on their expertise and leadership in their respective fields, included more than 160 world-renowned scientific researchers and clinicians with expertise in mental disorders, neuroscience, biology, genetics, statistics, epidemiology, and public health—and not only psychiatrists but psychologists, social workers, psychiatric nurses, pediatricians and neurologists." APA, "From Planning to Publication."

7. Frances, "Diagnosing the DSM."

8. Quoted in Brauser, "APA Answers DSM-5 Critics," 5.

9. Hansen et al., "Independent Review," 5.

10. Sadler, "Considering the Economy"; APA, "DSM: History of the Manual."

11. Rounsaville et al., "Basic Nomenclature issues for DSM-V." See also First, "Harmonisation of ICD-11."

12. Sadler, "Considering the Economy."

13. Benhabib, *Democracy and Difference*, chap. 4.

14. For instance, and as we discuss in greater detail later, there may be irreconcilable differences between the interests that practicing clinicians have in a DSM category and the interests that basic science researchers might have. As a result, even a highly legitimate process will not produce outcomes that fully satisfy each constituent's interests. What matters is that the constituents felt that their interests were heard and responded to in the deliberative processes that produce the new categories and that they received a clear reason for why the final category might deviate from their interests.

15. See Boorse, "What a Theory of Mental Health Should Be"; Wakefield, "Concept of Mental Disorder"; Conrad, "Discovery of Hyperkinesis"; Gernsbacher, Dawson, and Goldsmith, "Three Reasons Not to Believe"; Moreno et al., "National Trends in the Outpatient Diagnosis."

16. Spitzer, "DSM-V: Open and Transparent?"; Frances, "Diagnosing the DSM"; Cosgrove and Krimsky, "Comparison of DSM-IV and DSM-5."

17. APA, "About APA."

18. Melville, "Physicians Fight."

19. APA, "Frequently Asked Questions."

20. APA, DSM-5, xli.

21. Urbaniti and Warren, "Concept of Representation."

22. "Open Letter to the DSM-5 Task Force and the American Psychiatric Association."

23. Ibid. Indeed, the APA acknowledged this broad constituency during the well-regarded DSM-III revision process. These revisions, and their focus on symptom-based

criteria represented a sort of détente between competing theoretical factions within psychiatry and mental health practice in general. The "a-theoretical" nature of the DSM thus positioned the manual as appealing to a broad constituency rather than to psychiatrists espousing a single theoretical orientation. For a discussion of the move to a-theoretical manual, see Bayer and Spitzer, "Neurosis, Psychodynamics, and DSM-III"; Johnson, "Pure Science and Impure Influences."

24. Spitzer, Endicott, and Robins, "Research Diagnostic Criteria."

25. Insel et al., "Research Domain Criteria."

26. Pescosolido, "Public Stigma of Mental Illness."

27. Kress, Hoffman, and Eriksen, "Ethical Dimensions of Diagnosing."

28. Stuart, "Autism Insurance Reform." For an example of an insurance plan specifying that certain one-on-one behavioral interventions should be considered "educational" and not covered by the plan, see Anthem Clinical UM Guideline, "Applied Behavior Analysis for Autism Spectrum Disorder."

29. We thank an anonymous reviewer for pointing us to these three senses of legitimacy.

30. Guo and Musso, "Representation in Nonprofit and Voluntary Organizations."

31. The first four forms of representation were outlined in Pitkin, *Concept of Representation*. The last (participatory representation) was added by Guo and Musso, "Representation in Nonprofit and Voluntary Organizations." They argued that representation was especially useful for analyzing nonprofit organizations.

32. Guo and Musso, in "Representation in Nonprofit and Voluntary Organizations,"call this the "representative mix" that an organization pursues. Pitkin, in *Concept of Representation*, argues that different forms of representation are parts of a coherent whole.

33. APA, *DSM-5*, xlii.

34. Wallis, "Powerful Identity."

35. Baron-Cohen, "Short Life of a Diagnosis."

36. See McPartland, Reichow, and Volkmar, "Sensitivity and Specificity." We should note that this study was rejected by members of the DSM Task Force and others on the grounds that its methodology—a retrospective chart review of participants in a DSM-IV field trial—was flawed. The DSM-5 ASD symptoms could not be captured because, obviously, DSM-5 criteria were unavailable at the time. See Carey, "New Definition of Autism."

37. Stein et al., "What Is a Mental/Psychiatric Disorder?," 1761.

38. The trustee/delegate models are more complex than a binary distinction. See Rehfeld, "Representation Rethought."

39. Hall et al., "Trust in Physicians and Medical Institutions."

40. Insel, "Psychiatrists' Relationships with Pharmaceutical Companies."

41. Cosgrove, and Krimsky, "Comparison of DSM-IV and DSM-5."

42. APA, *DSM-5*, 8.

43. APA, "Division 32's Project."; International DSM-5 Response Committee, "Statement of Concern"; Locke, Letter to John Oldham.

44. Cacciatore, "Open Letter to the APA."

45. Mansbridge, "Should Blacks Represent Blacks?"

46. Sadler and Fulford, "Should Patients and Their Families Contribute?"

47. Guo and Musso, "Representation in Nonprofit and Voluntary Organizations."

48. Regier, Kuhl, and Kupfer, "DSM-5."

49. Kuhn, *Structure of Scientific Revolutions*; Longino, *Science as Social Knowledge*.

50. Sisti, Young, and Caplan, "Defining Mental Illnesses."

51. See Cartwright, "Report on the Diseases"; Bayer, *Homosexuality and American Psychiatry*; Bayer and Spitzer, "Neurosis, Psychodynamics, and DSM-III."

52. Though the APA has its member psychiatrists vote for an elected board of trustees, the DSM process is headed by an APA Task Force whose members are appointed by the elected APA president rather than elected straight by APA members. In turn, the task force appoints DSM work groups across several major areas (e.g., psychotic disorders; neurodevelopmental disorders). In sum, the persons who make decisions about DSM categories (DSM work group members) are two steps removed from any electoral process: they are appointed by a group (the Task Force) that is in turn appointed by the APA's elected leaders.

53. Saward, "Authorisation and Authenticity."

54. Guo and Musso, "Representation in Nonprofit and Voluntary Organizations"; Saward, "Authorisation and Authenticity"; Urbinati and Warren, "Concept of Representation"; Montanaro, "Democratic Legitimacy."

55. Young, *Harmony of Illusions*; McNally, "Progress and Controversy."

56. Jones, Fear, and Wessely, "Shell Shock."

57. Bayer, *Homosexuality and American Psychiatry*.

58. Sabin and Daniels, "Determining 'Medical Necessity.'"

59. Kersting, "Axis II Gets Short Shrift."

60. APA, "Personality Disorders Fact Sheet."

61. Frances, Sreenivasan, and Weinberger, "Defining Mental Disorder."

62. Ibid.

63. Lightfoot, Hill, and and LaLiberte, "Inclusion of Disability."

64. Mathis, "Keeping Families Together," 521.

65. In a Medicaid sample, mothers with a psychiatric diagnosis (schizophrenia, major affective disorder) are over three times more likely to have a child placed in out-of-home care (e.g., foster care, a group home) compared to demographically similar mothers without a diagnosis who face similarly difficult economic circumstances. See Park, Solomon, and Mandell, "Involvement in the Child Welfare System."

66. APA, "Becoming a Member."

67. Sadler and Fulford, “Should Patients and Their Families Contribute?,” 136.

68. Frances and Widiger, “Psychiatric Diagnosis,” 125.

69. Cosgrove and Krimsky, “Comparison of DSM-IV and DSM-5.”

70. Kupfer, “DSM-5: An Interview.”

71. Jacob and Patel, “Classification of Mental Disorders.”

72. Sabshin, “Turning Points”; Maser, Kaelber, and Weise, “International Use and Attitudes.”

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