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## "Pure" Science and "Impure" Influences: The DSM at a Scientific and Social Crossroads

Rebecca A. Johnson

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**“PURE” SCIENCE AND “IMPURE” INFLUENCES: THE DSM  
AT A SCIENTIFIC AND SOCIAL CROSSROADS**

*Rebecca A. Johnson\**

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**ABSTRACT**

The Diagnostic and Statistical Manual of Mental Disorders (DSM), the proverbial “bible” of mental illness, is at a unique point in its history and evolution. DSM diagnoses, designed with clinical uses in mind, have become ubiquitous across a broad range of settings, ranging from legislative statutes to civil commitment hearings for sexually violent predators to special education eligibility litigation. Despite the ubiquity of the manual’s categories, the American Psychiatric Association (“APA”), the professional organization in charge of the manual’s revisions and publication, has resisted the influence of these “impure aims,” arguing that revisions ought to be guided by scientific concerns about the validity and clinical utility of the constructs rather than concerns about social service eligibility, civil rights endangerment, and treatment reimbursement.

In this article, I challenge the APA’s resistance to pragmatic considerations. To do so, I offer a historical and sociological review of the way that these pragmatic considerations *did* and *do* influence the manual. Part I outlines the history and evolution of the DSM’s categories, showing how pragmatic concerns—pressure from third-party payers for a more standardized set of efficacy data; cultural critiques of psychiatry’s “pathologization” of deviance; the serendipitous discovery of antipsychotics—have influenced the DSM at various junctures. These pragmatic concerns led to a major shift between the first two editions of the DSM, manuals that were peripheral in both cultural discussions of mental illness and in clinical practice, and 1980s DSM-III, after which the DSM became a central locus of debate about mental illness and its social, legal, and economic impacts. The history of the DSM shows the way that these “impure” concerns inevitably pervade and shape the manual, despite the manual’s disclaimers about its narrow scope and narrow influence.

Part II surveys the interests at stake in DSM categories and how these interests can come into conflict. For example, patients may be interested in broad and inclusive diagnostic criteria that facilitate insurance reimbursement; clinicians may be interested in criteria that not only aid in treatment but are simple enough to not add large administrative burdens in time-pressed environments; basic science researchers may find the DSM categories too broad for investigations into the genetic bases of various mental illnesses, while epidemiological researchers may have a stronger interest in categories that are consistent between manuals to better track prevalence rates. This panoply of interests raises questions of which interests are legitimate versus illegitimate, which are important versus marginal, and how the APA can mediate between the manual’s uses across

these many contexts. Highlighting one clash between stakeholder interests, Part III focuses on proposed changes to the autism diagnostic categories in the DSM-5 and highlights how the DSM diagnoses stand at the nexus between diverse stakeholders with divergent aims. I highlight three clashes of stakeholders in the DSM autism category: parents and school districts, parents and insurers, and parents and children. Despite the undeniable presence of these clashes, the APA has attempted to distance itself from these “pragmatic” clashes and downplay concerns about the ramifications of the changes.

While the aim of this article is largely descriptive—outlining and articulating the many neglected interests with a stake in DSM categories—Part IV ventures into prescriptive territory. I make two suggestions about how the DSM can acknowledge the “impurity” of its categories. First is creating more heterogeneous Work Groups for revisions, especially for diagnoses such as developmental or sexual disorders where special education and legal proceedings greatly impact a sufferer’s life trajectory. Second is greater publicity about the DSM’s long-term aims; while it may be tempting from a social service standpoint to ensure that no one “loses” service eligibility, changes to diagnoses may have long-term benefits that must be publicized and acknowledged.

## INTRODUCTION

*There is nothing God-given or immutable about the [DSM] categories and definitions of their official nosology.<sup>1</sup>*

Debates rage between religious fundamentalists and theological liberals about how to view the Bible: is it handed down by a perfect God to a public who should not challenge its authority or “purity”? Or is the Bible a socially constructed document, written by various authors guided by specific intellectual orientations and social purposes? As many have noted, the American Psychiatric Association’s (APA) Diagnostic and Statistical Manual of Mental Disorders (DSM) has become the proverbial “bible” of mental illness. While most scholars of religious studies agree that the Christian Bible is a collection of writings shaped by an array of social, political, intellectual, and other considerations, these dimensions of the DSM, a modern metaphorical bible, remain underexplored. The manual is often conceived as a tool used purely for the purpose of clinical and scientific practice and guided by apolitical science alone. For example, Theodore Millon, a psychiatrist and member of the DSM-III task force, criticized interest groups such as gay rights activists or psychoanalytic theorists for attempting to thwart the courageous, scientific effort to significantly revise DSM diagnostic categories.<sup>2</sup> In this view, science engages in a battle with nefarious societal stakeholders—patient activists, legal professionals, third-party payers—whose stakes in the manual’s diagnostic categories exert an impure influence on the text.

The APA task force contends that its first priority in developing the DSM is “Clinical utility: make sure the manual is useful to those who diagnose and treat patients with mental illness, and to the patients being treated.”<sup>3</sup> In this article, I parse apart this broad and imprecise definition of “utility” to examine whether and how the DSM should take the social and legal uses of its categories into account. Patient utility may depend on whether a treatment is reimbursed by insurance, whether the diagnosis can help the patient gain social services, whether the DSM constructs are useful to researchers investigating the etiology of a given disorder, how the diagnosis affects one’s standing in a court of law, and a host of other

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1. Robert Kendell, *The Relationship Between DSM-IV and ICD-10*, 100 J. ABNORMAL PSYCHOL. 297, 300 (1991).

2. Theodore Millon, *The DSM-III: An Insider’s Perspective*, 38 AM. PSYCHOL. 804, 807 (1983).

3. *DSM-5 Development: Frequently Asked Questions*, AM. PSYCHIATRIC ASS’N (2012), available at <http://www.DSM5.org/about/Pages/faq.aspx>.

non-clinical factors. Should the developers of the DSM broaden their definition of the manual's utility and consider the way it is used in these "impure," non-clinical contexts? Should they incorporate sensitivity to these contexts in the manual's revisions? In this paper, I address these questions, a crucial task due to the manual's impact across these diverse settings, the recent May 2013 publication of the manual's 5th edition,<sup>4</sup> and the APA's commitment to more public transparency and involvement in subsequent revisions of the DSM.

In Part I, I briefly review the history of the DSM, focusing on various social, economic, and intellectual forces that have shaped the inception and evolution of the manual over the past 60 years. This historical review is important in highlighting the way that "impure influences"—critiques of psychiatry's credibility, pressure from third party-payers to develop a more standardized system of clinical diagnosis, worries about the misinterpretation of DSM categories in legal sentencing—have influenced the manual at various junctures. Part II outlines the stakeholders in the DSM, discussing both explicit audiences of the manual—clinicians, researchers, patients and their families—and those who use the manual in contexts for which it is specifically not designed—school districts in determining special education benefits, the judicial system, insurance companies, and pharmaceutical manufacturers; the section outlines divergence and convergence between the interests of these diverse stakeholders. Part III is a case study of one specific debate between different stakeholders with divergent aims: proposed changes to the autism spectrum disorders diagnostic category in the DSM-5. In Part IV, I suggest two improvements for the DSM development process that can help the manual incorporate, or at least remain sensitive to, the array of stakeholder interests that operate across a multiplicity of clinical and non-clinical contexts.

The aim of this article is to show the way in which the DSM's official, "pure" aims of improving patient's clinical outcomes are dependent upon the many "impure," non-clinical factors that influence patient wellbeing: basic science research, the legal standing of the mentally ill, third party payers' trust that a given diagnosis warrants treatment reimbursement, and eligibility for federal and state-provided social services. Ultimately, I argue that although the task force's main priority should be the construction of useful clinical categories, a more

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4. This paper was submitted and revised in the months preceding the DSM-5's May 17<sup>th</sup>, 2013 publication date. Therefore, it does not directly address the final outcomes of the manual's revisions. However, the paper does address public responses to certain proposed revisions that occurred in the two years leading up to the DSM-5's May 2013 publication.

explicit sensitivity during the DSM development process to the different contexts in which the manual is used can be a natural extension of the APA's normative aims and goals.

## **I. THE EVOLUTION OF THE DSM AND ITS SOCIETAL STAKEHOLDERS**

The DSM's history illustrates that debates over how we ought to diagnose and classify mental illness have often been inextricably influenced by a broad array of societal stakeholders—insurance companies, cultural critics, philosophers of science, and the public at large—rather than psychiatrists and clinical psychologists alone. Furthermore, within the psychiatric community, intellectual and professional rivalries have profoundly shaped the prevailing psychiatric paradigm at the time. In the first section, I will explore the way in which two competing schools of thought—the Kraepelinians and the Freudians—battled for influence in early to mid-20th century psychiatry. The second section will explore the way in which World War II and the “normalization” of mental illness led to a need for a more comprehensive system of psychiatric classification. The crisis of legitimacy within psychiatry and consequent paradigm shift in the DSM III is the focus of the third section, as a confluence of social, scientific, and economic forces—scientific studies undermining the field's reliability, the serendipitous discovery of pharmacological therapies, cultural criticisms of psychiatry, the rise of third-party payers and insurance reimbursement—contributed to undermine public confidence in psychiatry as a profession. I argue that psychiatry then attempted to regain this confidence through a dramatic revision to psychiatric classification. The last section will explore influences on the manual since the DSM-III—the unprecedented success of the DSM as the “standard” manual across an array of contexts, the rise of managed care and other economic constraints on mental health treatment, challenges to the DSM's approach emerging from clinical care and neuroscience and genetics research, and the growing influence of disease-specific patient advocacy groups.

### **A. Before the DSM-I: Two European Schools of Thought**

Two European scientists, Emil Kraepelin (c. 1856 – 1923) and Sigmund Freud (c. 1856 – 1939), created theoretical paradigms of mental illness that greatly influenced later DSMs. Kraepelin, a German professor and researcher, was focused on the classification, categorization, and description of psychiatric disorders. He insisted that psychiatric



disturbances be treated as medical diseases and categorized as distinct entities with definable symptoms and prognosis.<sup>5</sup> Adolf Meyer, a leading intellectual figure in early 20<sup>th</sup> century American psychiatry, transmitted these ideas to the American psychiatric context as a way for psychiatry to establish the appearance of rigor with a more precise system of classification and to establish its place among other branches of medicine that were increasingly focused on characterizing more precise disease entities.<sup>6</sup>

However, this approach to systematic classification began to fall out of favor as the century proceeded. Meyer himself, for example, began to argue that Kraepelin's approach to diagnostic classification was less helpful for helping patients improve than a closer examination of the individual patient, his or her unique situation, and the patient's reaction to his or her unique life situation.<sup>7</sup> As one commentator summarizes this shift in thinking that led psychiatrists to question the need for psychiatric labels, "unique circumstances were not generalizable, hence diagnostic labels. . . yielded partial insights at best."<sup>8</sup> This de-emphasis on a precise classification scheme for mental illness in favor of a new emphasis on a patient's unique life history and reactions to life situations paved the way for the ascendance of psychoanalytic and psychodynamic approaches to psychiatry, approaches exemplified by two of Kraepelin's intellectual rivals—Sigmund Freud and Carl Jung—whose influence on American psychiatric diagnosis eclipsed that of Kraepelin by the 1930s and 1940s.<sup>9</sup>

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5. See generally RICHARD NOLL, *AMERICAN MADNESS: THE RISE AND FALL OF DEMENTIA PRAECOX* (2011) (discussing the ascendance of Kraepelin's ideas about discrete mental illness disease categories in America at the beginning of the 20<sup>th</sup> century).

6. *Id.* at 281 (describing how medicine in the late 19<sup>th</sup> century began to focus on standard and precise systems of disease classification that could be applied across patients regardless of a patient's unique life trajectory. Psychiatry, in order to maintain its standing as a branch of medicine, also needed to take the same approach to classification).

7. *Id.* at 167-168 (discussing how Meyer began to critique Kraepelin's approach to disease classification, viewing these methods as a form of "artificial abstraction" that "smothered the richness of the experiential details of an individual life." His case history approach to diagnosis "located the roots of insanity in the unique life circumstances of the individual.").

8. *Id.* at 175.

9. See generally Dawn Bruijnzeel & Rajiv Tandon, *The Concept of Schizophrenia: From the 1850s to the DSM-5*, 41 *PSYCHIATRIC ANNALS* 289, 289 (2011) (arguing that from the end of World War II to the mid-1970s, American psychiatry adopted a model of mental disorders as conflicts of personality and intrapsychic conflict that was informed by Freud's "psychodynamic paradigms" of mental disorders and psychoanalytic thinking). See also JOHN BURNHAM, *AFTER FREUD LEFT: A CENTURY OF PSYCHOANALYSIS IN AMERICA* 4, 6 (2012) (arguing that the period from the 1940s to the 1960s was the "high point" of psychoanalytic thinking in American psychiatry and that evidence of Freud's legacy in American psychiatric thought at this time is overwhelming); NOLL, *supra* note 5, at 276 (describing the "monotheistic reign of the Freudians" within American psychiatry from the 1940s to the 1970s).

Freud and his protégé, Carl Jung, developed a very different approach to the study of psychiatric disturbance. Eschewing systems of sharp classification and the conceptualization of mental disorders as discrete entities, Freud focused on the etiology of mental disorders and the way in which stressful experiences, especially in childhood, influence one's psychological and emotional development.<sup>10</sup> The psychoanalysts and psychodynamic theories of psychiatric disturbance came to dominate American psychiatry from the 1930s to the 1960s-1970s.<sup>11</sup>

### **B. DSM-I and DSM-II: World War II and Psychodynamic Continuity**

World Wars I and II reinforced the ascendance of these psychodynamic theories by reinforcing their depiction of inner turmoil interacting with external stress to produce psychiatric disturbance. World War I introduced the concept of "shell shock" into common parlance and highlighted a large number of soldiers suffering from both mild and severe psychiatric distress after their wartime experience.<sup>12</sup> The war underscored that environmental stressors could have a profound impact on psychological functioning, and led to the conceptualization of a spectrum between mental illness and mental health rather than a sharp dichotomy between the two.<sup>13</sup> World War II further blurred these boundaries, and was accompanied by a proliferation of mental health service settings: the Veterans Health administration provided care to returning soldiers and the newly-created National Institutes of Mental Health ("NIMH") provided government support to more practitioners.<sup>14</sup>

Unsurprisingly given American psychiatry's explicit marginalization of psychiatric classification, the two existing systems of psychiatric classification at the time—the APA's Standard Classified Nomenclature of Disease and the most recent version of the International Classification of Diseases (ICD), the ICD-6—were inadequate for describing the broad

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10. Rick Mayes & Allen V. Horwitz, *DSM-III and the Revolution in the Classification of Mental Illness*, 41 J. HIST. BEHAV. SCI. 249, 260 (2005).

11. *Id.* at 260.

12. See IAN DOWBIGGIN, *THE QUEST FOR MENTAL HEALTH: A TALE OF SCIENCE, MEDICINE, SCANDAL, SORROW, AND MASS SOCIETY* 96-97 (2011) (describing how "shell shock" was embedded in popular usage following World War II for the trauma experienced by soldiers).

13. *Id.* at 98-99. See also Gerald N. Grob, *Origins of the DSM-I: A Study in Appearance and Reality*, 148 AM. J. PSYCHIATRY, 427 (1991) (discussing how the war contributed to the idea that the stress associated with combat contributed to mental maladjustment).

14. RICHARD G. FRANK & SHERRY A. GLIED, *BETTER BUT NOT WELL: MENTAL HEALTH POLICY IN THE UNITED STATES SINCE 1950*, 80 (2006).

range of psychiatric disturbance that veterans exhibited.<sup>15</sup> Psychiatrists and clinical psychologists rushed to develop more comprehensive descriptions of the broad array of post-war psychopathology.<sup>16</sup> In this sense, the first edition of the DSM was not prompted by a purely scientific need for a more standardized system of classification but by a social and clinical concern in the influx of veterans with psychiatric distress whose disturbances were not fully described in existing psychiatric nomenclature.

These concerns resulted in the quick development and publication of the American Psychiatric Association's (APA's) DSM-I, published in 1952 after a one-year development process by an appointed Work Group.<sup>17</sup> The APA's Work Group—the Committee on Nomenclature and Statistics—solicited *some* feedback on the manual upon sending a draft of the manual to 10% of practicing psychiatrists, with 241 of those psychiatrists returning questionnaires to provide comments on the categories.<sup>18</sup> Yet as I will discuss later, this closed-doors process, conducted by psychiatric experts with little to no input from patients and their families, stands in stark contrast to the DSM-5's process of public input and engagement.<sup>19</sup>

The first edition of the DSM was heavily influenced by the psychodynamic theories that described disorders not in terms of observable symptoms but in terms of conflicts between biological drives and external pressures.<sup>20</sup> The DSM-II, published in 1968, both took longer

15. See Mitchell Wilson, *DSM-III and the Transformation of American Psychiatry: A History*, 150 *AM. J. PSYCHIATRY*, 399, 401 (1993); Thomas A. Widiger et al., *Toward an Empirical Classification for the DSM-IV*, 100 *J. ABNORMAL PSYCHOL.* 280, 281 (1991); See also Atwood Gaines, *From DSM-I to III-R: Voices of Self, Mastery, and the Other: A Cultural Constructivist Reading of U.S. Psychiatric Classification*, 35 *SOC., SCI. & MED.*, 3, 7 (1992).

16. See Gaines, *supra* note 15, at 7-8.

17. STUART A. KIRK & HERB KUTCHINS, *THE SELLING OF THE DSM: THE RHETORIC OF SCIENCE IN PSYCHIATRY* 27 (1992).

18. Widiger, *supra* note 15, at 281.

19. The APA has posted all potential revisions to a public website and proposed changes to diagnostic criteria have been debated and parsed apart in the popular media. For the public website at which DSM revisions were posted, see American Psychiatric Association, *DSM-5 Development*, at <http://www.dsm5.org/Pages/Default.aspx>. For a brief sample of the media debate about DSM changes, see, e.g., Paula Span, *Grief After New Depression Diagnosis*, *N.Y. TIMES* (Jan. 24, 2013), at <http://newoldage.blogs.nytimes.com/2013/01/24/grief-over-new-depression-diagnosis/>; Greg Jaffe, *New Name for PTSD Could Mean Less Stigma*, *WASH. POST* (May 5, 2012) at [http://www.washingtonpost.com/world/national-security/new-name-for-ptsd-could-mean-less-stigma/2012/05/05/gIQA1V8M4T\\_story.html](http://www.washingtonpost.com/world/national-security/new-name-for-ptsd-could-mean-less-stigma/2012/05/05/gIQA1V8M4T_story.html); John Cloud, *Redefining Crazy: Researchers Revise the DSM*, *TIME* (Mar. 11, 2009), available at <http://www.time.com/time/health/article/0,8599,1884092,00.html>; Erin Allday, *Revision of Psychiatric Manual Under Fire*, *S.F. CHRONICLE* (Nov. 26, 2011), available at <http://www.sfchronicle.com/news/article/Revision-of-psychiatric-manual-under-fire-2295555.php>.

20. Grob, *supra* note 13, at 429; See also Wilson M. Compton & Samuel B. Guze, *The Neo-Kraepelinian Revolution in Psychiatric Diagnosis*, 245 *EUR. ARCHIVES PSYCHIATRY & CLINICAL NEUROSCIENCE*, 196, 198 (1995) (describing how the disorders were called “reactions” which may have been largely shaped by psychiatrists’ experiences with stress-related cases after World War II).

to create—three years compared to one—and featured an expanded number of diagnoses: 182 compared to the DSM-I's 106.<sup>21</sup> Despite this expanded gestation and expanded list of diagnoses, the DSM-II reflected the same theoretical spirit as the first edition, casting symptoms as reflections of underlying intra-psychic conflicts or stressful life conditions. Both the DSM-I and DSM-II eschewed elaborate, symptom-based classification schemes, arguing that symptoms “did not reveal disease entities but disguised underlying conflicts.”<sup>22</sup> As a result of the theoretical orientation of psychodynamic theory—symptoms and diagnoses mattered much less than an in-depth exploration of a patient's unique life history—the first two editions of the DSM, by many accounts, were seldom used.<sup>23</sup> The manual itself remained somewhat peripheral to both discussions within the psychiatric community and to discussions in broader culture about the nature of mental illness.<sup>24</sup> When the psychiatric profession became engulfed in a crisis of legitimacy, however, the manual and the diagnoses it had constructed came under increased scrutiny. In turn, this social, political, and intellectual scrutiny led to a dramatic shift in the way mental illness was classified.

### C. DSM-III: The Copernican Revolution of Classification

The scrutiny that contributed to psychiatry's crisis of legitimacy can be traced to five sources discussed below and that spanned from the early 1950s to the early 1970s: (1) research studies that undermined the perceived effectiveness of the professions of psychiatry and psychology, (2) the rise of effective pharmacological interventions whose development had little connection to theories of psychiatric disturbance, (3) cultural critiques of psychiatry's standing as a medical profession, (4) the rise of third-party insurance coverage of psychotherapy, and (5) the inhumane conditions of certain inpatient institutions. The diversity of these critiques illustrates the way in which the DSM's concerns permeate beyond the clinical context, engaging a variety of stakeholders who exerted an “impure” influence upon the DSM categories leading up to the major 1980 revision of the manual.

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21. DOWBIGGIN, *supra* note 12, at 175.

22. Mayes & Horwitz, *supra* note 10, at 250.

23. *Id.* at 250.

24. Wilson, *supra* note 15, at 401.

## 1. Critique One: Are Psychiatrists and Clinical Psychologists Superfluous?

Two studies were particularly damaging to the reputation of psychiatry and clinical psychology in the period from the 1950s to the 1970s. In 1952, Hans Eysenck reviewed twenty-four studies of psychodynamic and eclectic psychotherapy and found that psychotherapy was no more effective than no treatment at all.<sup>25</sup> Even if psychotherapy's *effectiveness* was challenged by Eysenck, perhaps clinicians still possessed better than average skill of discerning a patient's prognosis and best course of treatment? Paul Meehl challenged psychiatrists and clinical psychologists' claims to the legitimacy of their clinical judgment with a "disturbing little book" published in 1954.<sup>26</sup> Meehl's book claimed that statistical prediction—the use of an actuarial formula based on inputted information—outperformed clinical prediction, which involves the use of clinical skill, intuition, and flexibility, in predicting outcomes such as which treatment best benefits a mentally ill person.<sup>27</sup>

## 2. Critique Two: Pharmacology Developed by Serendipity Rather Than Theory

The rise of effective anti-psychotics augmented these critiques of clinical judgment. The anti-psychotic Thorazine (chlorpromazine) was first introduced in 1955; in 1960, the first large-scale, double-blinded, placebo-controlled clinical trial showing the antipsychotic's efficacy was published.<sup>28</sup> Thorazine began to replace ineffective (and often inhumane) treatments such as lobotomies, insulin therapy, and electric shock treatment.<sup>29</sup> The medication's use was also eventually codified into manuals shaping clinical practice: while the 1959 *Handbook of American*

25. Hans J. Eysenck, *The Effects of Psychotherapy: An Evaluation*, 16 J. CONSULTING & CLINICAL PSYCHOL. 319-24 (1952). See also BRUCE E. WAMPOLD, *THE GREAT PSYCHOTHERAPY DEBATE: MODELS, METHODS, AND FINDINGS* 62 (2010) (discussing the questionable reliability of Eysenck's literature review, such as the data being culled from two separate patient pools and the lack of a control group).

26. PAUL E. MEEHL, *CLINICAL VERSUS STATISTICAL PREDICTION: A THEORETICAL ANALYSIS AND REVIEW OF THE EVIDENCE* (1954). See also Drew Westen & Joel Weinberger, *When Clinical Description becomes Statistical Prediction*, 59 AM. PSYCHOLOGIST 595, 595 (2004); Drew Westen & Joel Weinberger, *In Praise of Clinical Judgment: Meehl's Forgotten Legacy*, 61 J. CLINICAL PSYCHOL. 1257, 1266 (2005).

27. MEEHL, *supra* note 26, at 22.

28. FRANK & GLIED, *supra* note 14, at 29 (discussing the success of Thorazine and how that success spawned other neuroleptics in the 1960s and 1970s).

29. See Benjamin Pollack, *Preliminary Report on 500 Patients Treated with Thorazine at Rochester State Hospital*, 29 PSYCHIATRIC QUARTERLY, 439, 439, 444 (1955) (describing Thorazine use in patients with "mental deficiency," "psychoneurosis," and "manic depressive psychosis." As Pollack describes, "lobotomies have been indefinitely deferred for some patients because of the marked improvement in them following treatment with Thorazine . . . these patients had previously been treated with insulin, electric shock, or other types of therapy—with temporary, slight, or no results.").

*Psychiatry* argued that psychotherapy ought to be the “treatment of choice” for practicing psychiatrists, the 1967 *Comprehensive Textbook of Psychiatry* described antipsychotic therapies as breakthrough treatments.<sup>30</sup>

Thorazine did not undermine the first two editions of DSM and its categories by itself, but the success of the medication contributed to a growing critique of psychoanalytic methods of treatment and the psychoanalytic influence on DSM categories.<sup>31</sup> Thorazine had been an anti-histamine treatment until French psychiatrists repurposed it; meanwhile, Indian physicians had used the tranquilizer reserpine for hundreds of years.<sup>32</sup> What credibility did the profession and its categories have when other disciplines and researchers, divorced from psychoanalytic theory, had “invented” effective therapies for its conditions? Though pharmacologic interventions did not fully supplant psychotherapeutic ones, these medications were weapons added to the arsenal directed against the profession’s legitimacy.

### 3. Critique Three: Psychiatry as a “Coercive” Labeler of Societal Deviance

While one could call the ascendance of antipsychotics a “pure” influence on the DSM—a “revolution” in psychiatric treatment that had the backing of some of psychiatry’s leading proponents<sup>33</sup>—many “impure” voices of either non-psychiatrists or former psychiatrists who explicitly disavowed their affiliation with the profession also challenged the manual at the time. A wave of cultural criticism engulfed the field of psychiatry in the 1960s and 70s. French philosopher Michel Foucault critiqued mental institutions as perpetuating power arrangements and pathologizing nonconformity; the book and film *One Flew Over the Cuckoo’s Nest* depicted psychiatrists as “mental police” and inpatient treatment as a horrific prison;<sup>34</sup> a former psychiatrist and psychoanalyst, Thomas Szasz, published *The Myth of Mental Illness*, which argued that mental illness is

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30. FRANK & GLIED, *supra* note 14, at 30.

31. A survey of medical residents in psychiatry points to the growing dissatisfaction with psychoanalytic theories and methods in the 1960s and 70s. Few in the 1950s doubted the importance of psychoanalysis and by 1975, only 45% of psychiatric residents rated psychoanalysis as an important tool. Many valued experience in pharmacotherapy more highly than training in psychoanalysis. See Robin M. Murray, *A Reappraisal of American Psychiatry*, 313 LANCET 255, 255 (1979).

32. Linford Rees, *Indications for the Use of Drugs in the Treatment of Psychiatric Disorders*, 39 POSTGRAD. MED. J. 48, 48 (1963).

33. As one psychiatrist describes, “during the past decade [1950-1960], the drug treatment of psychiatric illness has advanced with remarkable rapidity...the discovery of new drugs has revolutionized psychiatric treatment.” *Id.* at 48-52.

34. Mayes & Horwitz, *supra* note 10, at 252.

determined by social and ethical, rather than medical, criteria.<sup>35</sup> Whether or not these cultural critiques were legitimate, they were a highly public assault on the credibility of the psychiatric profession. David Rosenhan's 1973 study "On Being Sane in Insane Places," in which actors posing as patients had difficulty convincing professionals at a psychiatric hospital that they were "normal" and should be released, further buttressed the cultural critique of psychiatry.<sup>36</sup> Psychiatrists, in this view, were not only useless at identifying mental illness and improving patient outcomes, but also caused harm by conflating deviation from prevailing social norms with psychiatric disturbance.

#### 4. Critique Four: The Bottomless Pit of Ineffective Treatment

Perhaps more influential than these cultural and within-discipline critiques was the change in insurance coverage of psychiatric treatment in the 1960s and 70s. While many patients in the 1950s paid for psychotherapy completely out of pocket, by the 1960s, private insurance began to partially reimburse psychotherapy.<sup>37</sup> The creation of Medicaid under the 1965 Social Security Amendments led to another means of paying for psychotherapy and accompanying demand for efficacy data to justify those payments. In the 1970s, more than a dozen states, exasperated by the tight restrictions that many private insurers placed on mental health treatment coverage and the burden these restrictions placed on the public mental health system, created laws requiring certain insurers to cover mental health services.<sup>38</sup> Psychotherapy, judged against treatments for other diseases, faced increased scrutiny about the diagnostic criteria guiding its treatments, the lack of uniformity across different therapists, and whether therapy led to cost-worthy outcomes for patients.<sup>39</sup> The Medical Director of the APA at the time, Melvin Sabshin, recalls that private insurance companies and the federal government began to view

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35. THOMAS SZASZ, *THE MYTH OF MENTAL ILLNESS* (1974); See also Jonathan Y. Tsou, *The Importance of History for Philosophy of Psychiatry: The Case of the DSM and Psychiatric Classification*, 5 J. PHIL. HIST. 445, 445-69 (2011).

36. David Rosenhan, *On Being Sane in Insane Places*, 179 SCI. 250, 250-258 (1973).

37. Nancy Tomes, *The Development of Clinical Psychology, Social Work, and Psychiatric Nursing: 1900s - 1980s*, in *HISTORY OF PSYCHIATRY AND MEDICAL PSYCHOLOGY* 657, 673 (Edwin R. Wallace & John Gach eds., 2008); See also Cynthia Smith, *Retail Prescription Drug Spending in the National Health Accounts*, 23 HEALTH AFF. 160, 163 (2004).

38. Richard Frank, Chris Koyanagi, & Thomas G. McGuire, *The Politics and Economics of Mental Health 'Parity' Laws*, 16 HEALTH AFF. 108, 112 (1997).

39. See ALLAN HORWITZ, *CREATING MENTAL ILLNESS* 185 (2002) (discussing how the "the rise of third-party payers contributed to pressures to change the dynamic model: the continua and symbolic mechanisms of dynamic psychiatry did not fit an insurance logic that would only pay for the treatment of discrete diseases.").

psychiatry as a “bottomless pit—a voracious consumer of resources and insurance dollars—because its methods of assessment and treatment were too fluid and unstandardized.”<sup>40</sup>

### 5. Critique Five: The Inhumane Conditions of Inpatient Institutions

While insurers place pressure upon psychiatrists as a profession to justify the effectiveness and reimbursement-worthiness of the treatments they provided, other stakeholders at the time had a very different critique of psychiatry's methods of treatment. Sociologist Erving Goffman's *Asylums: Essays on the Social Situation of Mental Patients and Other Inmates*, published in 1961, presented a critique of inpatient mental hospitals as “total institutions” that deprived their patients not only of their freedom but also of their sense of self; the book asserted that the mental patient is “led into a series of abasements, degradations, humiliations” that cuts off his or her family, occupational, and educational interests.<sup>41</sup> In line with the anti-psychiatry tenor of the time, not only cast the psychiatric profession as ineffective at treating mental illness, but also implied that psychiatry's treatment methods, especially ones involving inpatient treatment, were inhumane and degrading towards patients. Goffman's critique of inpatient mental institutions had a more far-reaching impact on perceptions of psychiatry than critiques such as those of Szasz.<sup>42</sup> The impact of Goffman's critique was bolstered by newspaper exposes and public commissions argued that the conditions of these institutions were inhumane and deplorable; mental hospitals were “dehumanizing ‘warehouses’—‘snake pits’” where persons were “neglected or abused.”<sup>43</sup> These critical appraisals of inpatient psychiatric institutions contributed to a shift in the provision of mental illness services of deinstitutionalization,<sup>44</sup> where persons from mental health institutions were released into the

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40. Wilson, *supra* note 15, at 403.

41. ERVING GOFFMAN, *ASYLUMS: ESSAYS ON THE SOCIAL SITUATION OF MENTAL PATIENTS AND OTHER INMATES* 14 (1961).

42. See Marcelo T. Berlim, Marcelo P.A. Fleck, and Edward Shorter, *Notes on Antipsychiatry*, 253 EUR. ARCH. PSYCHIATRY CLIN. NEUROSCI. 61, 65 (2003) (arguing that although figures such as Thomas Szasz, the author of the *Myth of Mental Illness*, became “cult figures for the radical left in the late 1960s,” he did not have much influence on “psychiatrists or on Health Department policies.” In contrast, the authors argue that Goffman “provided convincing arguments that mental hospitals were not merely profoundly anti-therapeutic institutions in practice but were almost bound to be so because of the profound power gulf between patients and staff, and the latter's total control over the lives of the former. He therefore provided Health Departments and taxpayers with a justification for closing large numbers of expensive hospitals.”)

43. Howard H. Goldman and Joseph P. Morrissey, *The Alchemy of Mental Health Policy: Homelessness and the Fourth Cycle of Reform*, 75 AM. J. PUBLIC HEALTH 727, 728 (1985).

44. See Rajendra Persaud, *Home Street Home*, 306 BMJ 726, 726 (arguing that Goffman's *Asylums* was a “major impetus” behind the deinstitutionalization movement).



community to seek our care from other sources.<sup>45</sup> But I argue that the critique also contributed to the growing tide of cultural criticism of psychiatry, its means of diagnosis, and its methods of treatment for those labeled with a mental illness.

## 6. The result: a renewed attention to “objective” psychiatric classification

These mounting pressures—medical, cultural, and economic—incrementally accumulated over the period of time spanning from the 1950s to 1970s to strongly undermine the scientific and professional legitimacy of the profession of psychiatry. I contend that the profession of psychiatry then focused on the DSM revision process as a tool for regaining its legitimacy among heretic psychiatrists, the critical sociologists, the skeptical third-party payers, and the concerned public at large who launched these critiques. The means by which psychiatry tried to regain its legitimacy was a paradigm shift in the creation of 1980s DSM-III.

With pharmacological interventions that required little psychoanalytic training becoming popular, Freudian theories falling out of favor, and an insurance industry seeking treatment methods with a broader corpus of scientific backing, psychiatry needed to prove that its diagnoses were legitimate and establish clearer standards for the classification of mental illness. A group of researchers at Washington University in St. Louis, whom some called the “neo-Kraepelinians,” published a manifesto describing psychiatry as a science that should study discrete mental illnesses uncovered through research utilizing statistical methodologies.<sup>46</sup> In 1972, these researchers published what came to be known as the Feighner criteria, which outlined specific diagnostic criteria for fourteen psychiatric illnesses.<sup>47</sup> The criteria were well-liked by the leader of the APA task force for the DSM-III, Robert Spitzer, who I argue was attracted to the criteria for reasons that were arguably political as much as intellectual.<sup>48</sup> Spitzer, having been intimately involved in the APA’s

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45. *Id.* at 728-729.

46. Hannah S. Decker, *How Kraepelinian was Kraepelin? How Kraepelinian are the neo-Kraepelinians? From Emil Kraepelin to DSM-III*, 18 *HIST. PSYCHIATRY* 337, 345-348 (2007).

47. See generally Kenneth S. Kendler, Rodrigo A. Munoz, & George E. Murphy, *The Development of the Feighner Criteria: A Historical Perspective*, 167 *AM. J. PSYCHIATRY* (2010).

48. *Id.* at 138-139, 141. Kendler et al. describe how Robert Spitzer made six visits to meet with the researchers at Wash U. who developed the Feighner criteria and that he learned lessons that then “deeply” shaped his efforts with the DSM-III such as the need to operationalize criteria through using a checklist-based set of symptoms to diagnose patients and the need to base the inclusion of diagnoses within the manual on evidence in addition to “clinical wisdom.” The same authors quote Spitzer, who argues that if

negotiations with gay rights activists in the 1970s who wanted “homosexuality” removed from the DSM, recognized the social importance of diagnostic criteria that were more closely allied with scientific backing.<sup>49</sup> The search for rigorously defined, symptom-based criteria took on an added political and social urgency as the scientists sought to defend the conceptual and theoretical grounding of the DSM’s diagnostic criteria against accusations that diagnoses were merely arbitrary condemnations of socially deviant behavior or vague categories whose treatments insurers were required to partially cover with minimal justification.<sup>50</sup>

The finished form of the DSM-III no longer described diagnoses as reactions to intra-psychoic disturbances but instead included detailed outlines of the necessary features of an illness, the associated/frequent features, and data on the age of onset, course, impairment, and predisposing factors.<sup>51</sup> Though the manual was aimed at use by clinicians, biomedical investigators who were interested in categories amenable to empirical research were the ones in charge of the manual’s revision.<sup>52</sup> Belying this focus, many changes to the manual facilitated empirical research in addition to clinical practice. As Theodore Millon, one of the DSM-III task force members describes “The schema . . . establishes a coherent framework within which the data of future studies can be systematically introduced.”<sup>53</sup> The DSM-III seemed to successfully accomplish this aim of creating standardized diagnoses for systematic investigations into mental illness: as one commentator has noted, “both referees and journal editors expected manuscripts submitted to scholarly journals to be written in its [the DSM’s] language,” and a proliferation of

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the Feighner criteria had never emerged, the “DSM-III . . . would likely have looked quite different.”

49. See Ronald Bayer, *Politics, Science, and the Problem of Psychiatric Nomenclature: A Case Study of the American Psychiatric Association Referendum on Homosexuality*, in *SCIENTIFIC CONTROVERSIES: CASE STUDIES IN THE RESOLUTION AND CLOSURE OF DISPUTES IN SCIENCE AND TECHNOLOGY* 381, 387-391 (Arthur L. Caplan ed., 1987). Homosexuality was removed during the seventh printing of the *DSM-II* in July 1974 after a vote by the trustees of the American Psychiatric Association in December of 1973.

50. For an example from that time period of the critique of DSM diagnoses as condemnations of socially deviant behavior, see, e.g. SZAZ, *supra* note 35. For a discussion of insurance companies’ worries that the treatments corresponding with DSM diagnoses had minimal evidence of efficacy, see Mayes and Horwitz, *supra* note 10, at 253-254.

51. See generally AM. PSYCHIATRIC ASS’N, *DIAGNOSTIC AND STATISTICAL MANUAL OF MENTAL DISORDERS: THIRD EDITION* (Am. Psychiatric Ass’n eds., Am. Psychiatric Publ’g 1980). For a discussion of the major features of the shift, see Gerald L. Klerman, *The Advantages of the DSM-III*, 14 *AM J. PSYCHIATRY* 539, 540-541 (1984) (describing how some of the advantages of the DSM-III over previous manuals are the fact that it contains “operational criteria” describing the observable symptoms of a disorder rather than its presumed etiology and the fact that the psychiatric nomenclature would now be determined by “the state of evidence rather than the assertions of competing ideological camps”).

52. Millon, *supra* note 2, at 812.

53. Millon, *supra* note 2, at 808.

journal articles citing DSM terminology bears witness to this standardization.<sup>54</sup>

As Figures 1 and 2—a comparison of the DSM II criteria for anxiety neurosis and the DSM-III generalized anxiety disorder—illustrate, the DSM-III incorporated specific rules for the diagnosis of each disorder. These rules, called “operational criteria,” helped standardize research across different sites and settings.<sup>55</sup> They specified what features could and could not be associated with a given disorder, and what minimal criteria—age, a set number of symptoms—must be met in diagnosis.<sup>56</sup> The purpose of these major changes illustrates the way that reputational and economic concerns influenced the manual. As Millon, the task force member, writes: “uniform DSM-III criteria should help stem the tide of insubstantial, unreliable, or at best minimally generalizable data that has come to characterize publications in the field.”<sup>57</sup> Though these clearer and more precise criteria were presumably of aid to clinicians in diagnosis, Millon emphasizes the way in which the manual’s added clarity and coherency will help generate “verifiable empirical knowledge” that the field sorely needs.<sup>58</sup>

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54. Mayes & Horwitz, *supra* note 10, at 264.

55. Millon, *supra* note 2, at 808 (describing how operational criteria, by specifying criteria through which a person could be included in or excluded from a diagnosis, would help different researchers include more homogeneous patient populations in their studies by all applying the same rules to the diagnosis of the patients).

56. *Id.* at 808.

57. Millon, *supra* note 2, at 808.

58. *Id.* at 808.

## Figure 1. DSM-II Anxiety Neurosis

### 300 Neuroses

Anxiety is the chief characteristic of the neuroses. It may be felt and expressed directly, or it may be controlled unconsciously and automatically by conversion, displacement and various other psychological mechanisms. Generally, these mechanisms produce symptoms experienced as subjective distress from which the patient desires relief.

The neuroses, as contrasted to the psychoses, manifest neither gross distortion or misinterpretation of external reality, nor gross personality disorganization. A possible exception to this is hysterical neurosis, which some believe may occasionally be accompanied by hallucinations and other symptoms encountered in psychoses.

Traditionally, neurotic patients, however severely handicapped by their symptoms, are not classified as psychotic because they are aware that their mental functioning is disturbed.

### 300.0 Anxiety neurosis

This neurosis is characterized by anxious over-concern extending to panic and frequently associated with somatic symptoms. Unlike *Phobic neurosis* (q.v.), anxiety may occur under any circumstances and is not restricted to specific situations or objects. This disorder must be distinguished from normal apprehension or fear, which occurs in realistically dangerous situations.

## Figure 2. DSM-III Generalized Anxiety Disorder

### Diagnostic criteria for Generalized Anxiety Disorder

A. Generalized, persistent anxiety is manifested by symptoms from three of the following four categories:

- (1) *motor tension*: shakiness, jitteriness, jumpiness, trembling, tension, muscle aches, fatigability, inability to relax, eyelid twitch, furrowed brow, strained face, fidgeting, restlessness, easy startle
- (2) *autonomic hyperactivity*: sweating, heart pounding or racing, cold, clammy hands, dry mouth, dizziness, light-headedness, paresthesias (tingling in hands or feet), upset stomach, hot or cold spells, frequent urination, diarrhea, discomfort in the pit of the stomach, lump in the throat, flushing, pallor, high resting pulse and respiration rate
- (3) *apprehensive expectation*: anxiety, worry, fear, rumination, and anticipation of misfortune to self or others
- (4) *vigilance and scanning*: hyperattentiveness resulting in distractibility, difficulty in concentrating, insomnia, feeling "on edge," irritability, impatience

B. The anxious mood has been continuous for at least one month.

C. Not due to another mental disorder, such as a Depressive Disorder or Schizophrenia.

D. At least 18 years of age.

Notably, the manual also claimed to be “atheoretical”—it sought to describe symptom-based disorders without positing an underlying theoretical construct for *why* these disorders may emerge or what contributed to causing these psychiatric disturbances.<sup>59</sup> The rationale behind not incorporated supposed causes of mental illness was that not enough was known about these causes to hypothesize about them in the manual.<sup>60</sup> Yet psychoanalysts questioned the manual’s declared agnosticism toward competing theoretical orientations. These psychiatrists pointed to the exclusion of “neuroses” and other psychodynamic terms as a “wholesale expurgation of psychodynamics from the psychiatric knowledge base.”<sup>61</sup>

Rebutting these critiques, the psychiatrists in charge of the final manual argued that the protests against the changes did not represent legitimate differences in scientific opinion about the nature of mental illness but instead, viewed the psychoanalysts’ (failed) protests as ideologically motivated and as an attack on “courageous” and non-ideological science.<sup>62</sup> Millon laments, “The furor and threats that ensued deserve public censure for they were not mere idle posturings. A review of the agonizing events that followed will be instructive in that they illuminate the awesome power of unremitting ‘political’ pressure designed to thwart a courageous and ‘scientific’ effort to undo questionable tenets and conceptual presumptions that are unsupportable.”<sup>63</sup> The DSM-III framers, despite the many social pressures and intellectual contingencies that had shaped the manual’s development, framed the text as a victory of “science over ideology.”<sup>64</sup>

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59. Ronald Bayer & Robert L. Spitzer, *Neurosis, Psychodynamics, and DSM-III: A History of the Controversy*, 42 ARCHIVES GEN. PSYCHIATRY 187, 187-9 (1985).

60. AM. PSYCHIATRIC ASS’N, DIAGNOSTIC AND STATISTICAL MANUAL OF MENTAL DISORDERS: THIRD EDITION: 7 (Am. Psychiatric Ass’n eds., Am. Psychiatric Publ’g 1980) (describing how the DSM-III took the approach of being “atheoretical” about the etiology of a disorder, except for the disorders for which the cause was well-established). For a critique of the manual’s claim to an “atheoretical” approach published six years after the manual’s publication, see David Faust & Richard A. Miner, *The Empiricist in His New Clothes: DSM-III in Perspective* 143 AM. J. PSYCHIATRY 962, 963 (1986) (arguing that features of the DSM-III such as specifying a disorder’s necessary age of onset make some assumptions about the types of factors that can cause the disorder—for example, autism’s necessary early onset compared to schizophrenia’s later onset implies the two disorders likely have different causes).

61. Wilson, *supra* note 19, at 407.

62. Millon, *supra* note 2, at 807 (describing how critiques of the DSM-III were designed to thwart a “courageous” effort to create diagnostic categories that were empirically supported).

63. *Id.* at 807.

64. Melvin Sabshin, *Turning Points in Twentieth-Century American Psychiatry*, 147 AM. J. PSYCHIATRY 1267, 1272 (1990).

#### D. DSM-III-R (1987), DSM-IV (1994), DSM-IV-TR (2000) and the ICD

The DSM-III represented a paradigm shift in the field of psychiatry: the eclipse of psychodynamic theory by a biomedical model that remained agnostic on the underlying forces behind or etiology of psychiatric disorders. The manuals and their revisions thereafter have done little to tangibly alter the new paradigm. Yet the presence of “impure” influences remains. In this section, I discuss the presence of these impure influences during each of the manual’s subsequent revisions. I then discuss four broad themes that cut across these changes to the manual—(1) the text’s transformation into a widely-used psychiatric “bible,” (2) the rise of managed care and other cost-containment measures, (3) skepticism about the categories’ usefulness raised by neuroscience and genetics research, and (4) the rise of disease-specific advocacy groups that attempt to exert influence on the manual. Each force illustrates the way in which a diverse array of stakeholders—research psychologists, the insurance industry, clinical practitioners, patient and family advocates—often experience tension between the divergent ways in which the manual can be used.

##### 1. DSM-III-R through DSM-IV-TR

The DSM-III-R, published in 1987, contained far less dramatic changes than the monumental shift that occurred from the DSM-II to the DSM-III. Some new disorders were proposed—body dysmorphic disorder, trichotillomania (compulsive hair pulling), and others—and the revisers made various changes to the manual’s wording, names for disorders, and criteria sets.<sup>65</sup>

Did newly emergent evidence in the field of psychiatry drive these changes or did other drivers and forces play the predominant role? One commentator, ruling out the idea that the changes were prompted by new and compelling evidence for disorders, argues that the timeline for the manual’s updates undermines the idea that the changes were prompted by empirically supported scientific concerns.<sup>66</sup> The DSM-III was published in 1980. The process of revising the manual began three years later in 1983—too short a time, the commentator argues, for scientists to conduct and replicate empirical studies that would support changes to the manual’s categories.<sup>67</sup> Indeed, as the introduction to the DSM-III-R admits, “data

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65. See Joseph M. Rey, *DSM-III-R: Too Much too Soon?* 22 *AUSTL. & N.Z. J. Psychiatry* 173, 174 (1988) (Table 1 gives examples of new disorders).

66. *Id.* at 180.

67. *Id.* at 180.

from empirical studies were lacking” at the time of revision, and primary importance was therefore given to “some other consideration.”<sup>68</sup> One consideration was clinician dissatisfaction with ambiguity in the manual; another consideration was the fact that the APA was invited to contribute to the upcoming 10th edition of the World Health Organization’s (“WHO”) International Classification of Diseases edition and needed to begin scrutinizing the DSM-III for updates to make contributions to the international manual.<sup>69</sup> The need for American psychiatry to present a unified and credible face to the WHO was one “impure” concern influencing the DSM-III-R.

Despite the modesty of the DSM-III-R’s proposed changes, certain categories provoked feminist outcry. Critics objected to three disorders proposed for the DSM-III-R that appeared in its first draft in 1985: self-defeating personality disorder, paraphilic coercive disorder, and premenstrual dysphoric disorder.<sup>70</sup>

The criteria for self-defeating personality disorder—individuals who make no demands on others, are self-sacrificing, and often neglect their own goals and pleasures for those of others—“smacked of traditional female role socialization” for feminists, who worried that the disorder would be used to “blame” female victims of abuse or domestic oppression by labeling those victims with a psychiatric disorder.<sup>71</sup> Feminists critiqued premenstrual dysphoric disorder (later renamed late luteal phase dysphoric disorder) on similar grounds.<sup>72</sup> By definition, it only applied to one gender and its inclusion could lead to the stigmatization of “normal women.”<sup>73</sup> These two critiques highlight the manual’s influence on popular notions of mental illness and the fear accompanying that influence. The DSM and psychiatric diagnoses were no longer esoteric constructs, marginalized even by psychiatrists within clinical practice. The DSM had achieved a degree of prominence such that commentators critiqued its constructs from the lens of how those constructs would interact with societal gender roles

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68. *Id.* at 180.

69. Robert L. Spitzer & Janet B.W. Williams, *Introduction* to AM. PSYCHIATRIC ASS’N, DIAGNOSTIC AND STATISTICAL MANUAL OF MENTAL DISORDERS xvii, xxi (Am. Psychiatric Ass’n eds., Am. Psychiatric Publ’g 1987).

70. See Constance Holden, *Proposed new Psychiatric Diagnoses Raise Charges of Gender Bias*, 231 SCI. 327, 327-8 (1986) (describing the three disorders criticized by feminist groups).

71. See Herb Kutchins & Stuart A. Kirk, *The Defeat of Masochistic Personality Disorder*, MAKING US CRAZY: DSM: THE PSYCHIATRIC BIBLE AND THE CREATION OF MENTAL DISORDERS 126, 133 (1997).

72. See Jeanne Maracek & Rachel T. Hare-Mustin, *A Short History of the Future: Feminism and Clinical Psychology*, 15 PSYCHOL. WOMEN QUART. 521, 525-526 (1991) (describing how feminists challenged dysphoric disorder for its “discriminatory impact” in only labeling women and worried that the inclusion of the disorder corresponded to pharmaceutical marketing interests rather than genuine female needs).

73. Holden, *supra* note 70, at 327.

and the stigmatization of “normal” female behavior. While earlier critics such as Foucault and Szasz had spoken in broad swaths about the pathologization of human deviance, critics of the DSM-III and DSM-III-R homed in on the ramifications that specific diagnoses, their names, and their criteria could have for certain sub-groups within American society.

Changes in the media coverage of mental illness also reflect a new cultural preoccupation with specific DSM diagnoses. As one empirical study of articles published in *Time*, *Newsweek*, and other periodicals confirms, articles focused on specific disorders rather than mental illness in general began to occupy a larger proportion of total articles on mental illness.<sup>74</sup> The proportion of disorder-specific articles grew from 36% of the sample in 1965 to 54% of the sample in 1988.<sup>75</sup> These empirical findings highlight that the DSM had become a very “public” document, with critics increasingly focused on specific mental illnesses rather than the nature of mental illness in general.

Paraphilic coercive disorder, which described persons who took delight in the coercive aspects of rape or sexual molestation, was critiqued not for the stigma it could introduce but the exoneration it could grant, with feminists voicing concern that the psychiatric label would help acquit rapists and molesters.<sup>76</sup> Again commentators adopted a different lens to view the constructs than the clinical and research focused lens adopted by the manual’s revisers. The legal import of a category, and an exemption from legal responsibility that a category might grant, stood at the root of the objection to paraphilic coercive disorder. As a commentator surveying the controversy noted, “critics seem to be operating from a somewhat different conceptual basis from the psychiatrists, one which . . . overtly acknowledges the political role of psychiatry.”<sup>77</sup> The DSM stood at the nexus of various political concerns—feminists’ focus on female equality; worries that judges and jurors viewed mental disorders as proverbial “get out of jail free” cards—and as the manual became more prominent across a diverse array of contexts—legal, insurance, cultural parlance—criticism of the manual along these diverse lines became more pointed.

Ultimately, the APA Work Group compromised with critics of the three additional categories, moving premenstrual disorder and self-defeating personality disorder to an appendix of the manual reserved for

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74. Otto F. Wahl & Arthur L. Kaye, *Mental Illness Topics in Popular Periodicals*, 28 CMTY. MENTAL HEALTH J. 21, 24 (1992).

75. *Id.* at 24.

76. Holden, *supra* note 70, at 327.

77. *Id.* at 328.



conditions “requiring further study” and excluding paraphilic coercive disorder entirely.<sup>78</sup>

The DSM-IV and the DSM-IV-R made similarly modest changes. Yet while critics indicted the third edition of the manual for the dramatic revisions it had made to psychiatric diagnosis—removing references to “neurosis”; defining disorders by observable symptoms rather than underlying psychic conflicts—many critics of the new editions had the opposite complaint: if the APA was only going to make modest and minor changes to the manual, what was the point of publishing revised manuals?<sup>79</sup> Critics began to accuse the APA of using the DSM as a substantial revenue stream and of failing to clearly articulate the reasons for a given revision.<sup>80</sup>

## 2. Four Themes across the Recent Editions of the DSM

Cutting across the DSM’s revisions from the 1980s to the current decade are four broad forces that have shaped the manual and its categories, each of which highlights the way that diverse stakeholders with diverse and sometimes divergent interests have influenced the DSM over the years.

### *Success and standardization*

The first force has been the unprecedented success of the DSM-III as compared to previous manuals. As discussed, clinicians at the time of the first two manuals viewed diagnoses as an ancillary aspect of clinical treatment, preferring a focus on a patient’s subjective life history and pattern of “inner turmoil.”<sup>81</sup> The DSM-III, which was influenced by researchers who prioritized a symptom-based diagnostic model, then cemented symptom-based diagnoses within clinical practice. The DSM lost its status as a handbook that was largely irrelevant to practitioners and became a “bible” in the United States that provided a common language

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78. Am. Psychiatric Ass’n, *Appendix A: Proposed Diagnostic Categories Needing Further Study*, in *DIAGNOSTIC AND STATISTICAL MANUAL OF MENTAL DISORDERS*: 367, 367-374 (Am. Psychiatric Ass’n eds., 1987). This diversionary tactic—sidelining an ethically contentious disorder to the manual’s appendix—was used again for controversial disorders proposed for the DSM-5, with proposed disorders for Internet addiction and “risk” for psychosis moving to the manual’s appendix after public critique. See John M. Gryhol, *Final DSM 5 Approved by American Psychiatric Association*, *PSYCH CENT.* (2012), at <http://psychcentral.com/blog/archives/2012/12/02/final-dsm-5-approved-by-american-psychiatric-association/>.

79. See generally Mark Zimmerman, *Is the DSM-IV needed at all?* 47 *ARCHIVES GEN. PSYCHIATRY* 974, 975 (1990).

80. *Id.* at 975.

81. See Sabshin, *supra* note 64, at 1270-1271 (describing the 1960s climate of little interest in empirically based psychiatric classification, which was viewed as “esoteric”).

for not only researchers and practitioners, but also insurance companies for reimbursement, pharmaceutical companies in research, federal grant-making bodies such as the NIMH, the FDA for drug approval processes, school districts for special education benefits, courts in determinations of insanity and civil commitment, and patient activist groups that form around a shared diagnosis. The manual exerted an influence not only across diverse settings but also across diverse localities. As one commentator summarizes,

European pharmaceutical companies that hoped to enter the American market knew that DSM-III criteria must be used for patients in clinical trials if those trials were to be accepted by the U.S. Food and Drug Administration. Moreover, clinical researchers in Europe understood correctly that publication in American journals would require, at a minimum, a DSM-III characterization of their patient sample. Pressures such as these . . . have little to do with the validity of the nomenclature.<sup>82</sup>

The manual's influence was self-reinforcing. The wide adoption researchers led to ubiquitous use in FDA approval and journal article review processes, which in turn led to wider adoption by researchers and drug companies adhering to the implicit or explicit "rules" and guidelines of those review processes.<sup>83</sup>

As Robert Spitzer argues, the DSM-III's success across these diverse settings and localities was largely unprecedented: sales of the DSM-I and DSM-II generated only "modest revenue," while sales of the DSM-III "primarily to non-psychiatrists" were, according to Spitzer, "enormous."<sup>84</sup> The DSM-III sold 600,000 copies worldwide in its seven years of publication,<sup>85</sup> a figure pointed to as evidence of its widespread appeal—

82. Jack D. Maser, Charles Kaelber, & Richard E. Weise, *International Use and Attitudes Toward DSM-III and DSM-III-R: Growing Consensus in Psychiatric Classification*, 100 J. ABNORMAL PSYCHOL. 271, 272 (1991).

83. For a discussion of the FDA's mandate to pharmaceutical companies to "target psychoactive drugs to biomedical conditions," see DAVID HEALY, *THE ANTIDEPRESSANT ERA* 100, 257 (1997) (discussing how the FDA began to try to modernize its regulatory process by encouraging the pharmaceutical industry to develop compounds that corresponded to a specific disease indication, and highlighting how drug studies worldwide have adopted the DSM criteria to meet this FDA requirement). For a discussion of how the DSM-III helped standardize research between different investigators, see ANDREW LAKOFF, *PHARMACEUTICAL REASON: KNOWLEDGE AND VALUE IN GLOBAL PSYCHIATRY* 12-13, 35 (2005) (arguing that the DSM-III led to a "diagnostic infrastructure" that helped specific mental illness serve as transferable entities across different countries and different types of research).

84. Robert L. Spitzer, *DSM-III and the Politics-Science Dichotomy Syndrome*, 40 AM. PSYCHOLOGIST 522, 523 (1985).

85. Lucille P. McCarthy, *A Psychiatrist using DSM-III: The Influence of a Charter Document in Psychiatry*, in *TEXTUAL DYNAMICS OF THE PROFESSIONS: HISTORICAL AND CONTEMPORARY STUDIES OF WRITING IN PROFESSIONAL COMMUNITIES* 358, 358 (Charles Bazerman & James Paradis eds., 1991).

”that the DSM-III has been responded to well is evident. . . in the rather startling number of copies that have been sold to date, a figure that is best grasped by the fact that more orders were received in the first six months following its publication than in both previous DSM editions combined, including 30-plus re-printings.”<sup>86</sup> The DSM-IV sold 961,324 copies; by comparison, there were only 42,000 psychiatrists and around 300,000 mental health professionals in the United States at that time.<sup>87</sup> The dominance of the DSM across this heterogeneous array of settings has made many potential stakeholder conflicts more visible, conflicts I will discuss in the next section of this paper.

### ***Uptake by Third-Party Payers for Reimbursement and Cost Control***

The second force cutting across the DSM-III to DSM-IV-TR revision process is utilization of the manual to determine the financing of mental illness treatment and to control the cost of this treatment. This has led to two developments: first, a divergence between the specialized practitioners who revise the manual and the generalist practitioners who use it and second, the labeling of patients with diagnoses that lead to more generous reimbursement regardless of their veracity in describing the patient’s symptoms.

Examining the first development, the rise of managed care and an emphasis on less expensive and more efficient psychiatric interventions has affected the practice of both psychiatry and clinical psychology. Cost-conscious health care favors brief interventions conducted by less expensive practitioners—for example, master’s degree social workers, B.A. level addiction counselors, or primary care physicians—rather than expensive psychiatrists and clinical psychologists.<sup>88</sup> The DSM, constructed by clinician-researchers who often specialize in a given disorder or even subtype of a disorder, may appear too burdensome and complex for non-specialist practitioners delivering an increasing amount of clinical care in a cost-conscious environment.

The second development occurs even among specialist practitioners who focus on a subset of diagnoses. Evidence shows that these practitioners often explicitly use the DSM more to facilitate reimbursement than to guide the treatment that it is provided. Sociologist Owen Whooley documents the “psychiatric workarounds” of the DSM that

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86. See Millon, *supra* note 2 at 807-8.

87. See Michael B. First, *The DSM Series and Experience with DSM-IV*, 35 *PSYCHOPATHOLOGY* 67, 68-69 (2002).

88. See generally TIMOTHY J. TRULL, *CLINICAL PSYCHOLOGY* 70 (7th ed. 2005).

some psychiatrists take—a psychiatrist may give a patient a disease code that distorts the patient’s problems to help that patient obtain insurance reimbursement for treatment.<sup>89</sup> Or as one interviewee in Whooley’s sample describes, “I purposely put down a more intense diagnosis, not ever to lie, but to sort of. If they might be dysthymic but there’s a possibility that they might have depression, I put down depression, so that they can get reimbursed.”<sup>90</sup> Another psychiatrist discusses the ethical tension between serving the patient’s interest in reimbursement and deceiving insurance companies.<sup>91</sup> Insurance companies’ perceptions of which diagnoses warrant generous coverage and which diagnoses do not have shaped clinical practice to adhere to reimbursement-granting DSM codes.

### *Divergence Between Clinical Utility and Research Utility*

Ever since the DSM-III’s shift away from the blurry continua of psychodynamic theory, some have argued that the DSM’s categorical approach—either you have the disorder or you do not—is an inaccurate codification of the dimensional facets of mental illness. The dissatisfaction stems from both clinical and research observations. First, clinicians often have to rely on “not otherwise specified” (“NOS”) diagnoses—“catch-all” categories within broader diagnoses—for patients who do not meet the criteria for a specific diagnosis, which may illustrate that highly-specific criteria that aid in inter-rater reliability fail to capture the “true heterogeneity of clinical populations.”<sup>92</sup> Second, the significant rate of comorbidity among DSM diagnoses raises questions about whether the same pathology has been falsely divided into discrete diagnostic silos.<sup>93</sup> These two problems may inevitably accompany *any* system of psychiatric classification, and the categories may be worthwhile even despite these drawbacks. Yet the problem of NOS diagnoses and significant comorbidities sheds light into clinical difficulties with the manual’s discrete categories.

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89. See generally Owen Whooley, *Diagnostic Ambivalence: Psychiatric Workarounds and the Diagnostic and Statistical Manual of Mental Disorders*, 32 SOC. HEALTH & ILLNESS 452, 452-469 (2010).

90. *Id.* at 461.

91. *Id.* at 461, 462.

92. Steven E. Hyman, *Diagnosis of Mental Disorders in Light of Modern Genetics*, in THE CONCEPTUAL EVOLUTION OF THE DSM-5, 7 (Darrel A. Regier, et al. eds., 2011). For example, one epidemiological study of a community sample labeled at high risk for depression gave 52% of the sample diagnoses of depressive disorder not otherwise specified (NOS). A national sample of persons with personality disorder found that 22.3% were best described as having personality disorder NOS. See Lee A. Clark et al., *Diagnosis and Classification of Psychopathology: Challenges to the Current System and Future Directions*, 46 ANN. REV. PSYCHOL. 121, 136 (1995).

93. Hyman, *supra* note 92, at 7.

From the perspective of research, some argue that the DSM's diagnostic silos impede fruitful research into the "molecular corollaries" of "higher order clinical phenomena."<sup>94</sup> Many of these concerns are raised by researchers interested in the genetic and neural mechanisms behind different forms of psychopathology, researchers who argue that a system of discrete categorizations based on a patient's *clinical* presentation impedes research into "causal networks that include cognition, emotion, hormones, neural circuits, and their molecular pathways and structures."<sup>95</sup> In response to these concerns, the Diagnostic Spectra Study Group for the DSM-5 was charged with proposing cross cutting dimensional assessments that transcend specific symptom-based diagnoses.<sup>96</sup> Although the group initially planned to create domains for symptoms that occur in many diagnoses (e.g. anxiety, sleeping issues) that could then be correlated with genetic variants or neurobiological processes, the final manual appears to have abandoned in this attempt.<sup>97</sup> Instead, and as I discuss in greater detail later, the National Institute of Mental Health ("NIMH") has taken up the mantle of creating cross-cutting dimensions for mental disorders through its Research Domain Criteria ("RDoC"), which aim to move psychiatric diagnosis away from symptom-based diagnoses to classification based on symptoms shared by many disorders such as "anhedonia or emotional appraisal bias or psychomotor retardation."<sup>98</sup> In turn, the NIMH hopes to link these cross-cutting assessments to shared neural substrates, shared biomarkers, shared genetic risk factors, or shared treatment response.<sup>99</sup> This intellectual shift to a system of disease classification more amenable to basic psychopathology research highlights that the DSM faces difficulty proving useful to both clinicians and biomedical researchers.

### *Patient Advocacy and the "Democratization" of the DSM*

The last societal force that has affected DSM development is the explosion of disease-specific advocacy groups over the past three decades. Daniel Carpenter has tracked the formation of over 3,100 disease-specific

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94. Charles Sanislow et al., *Developing Constructs for Psychopathology Research: Research Domain Criteria*, 119 J. ABNORMAL PSYCHOL. 631, 632 (2010) (arguing that molecular corollaries have failed to map on one-to-one with DSM disorders and that "the same [biological] mechanisms can be implicated in 'different' disorders, whereas multiple mechanisms can be implicated in 'one' disorder.").

95. *Id.* at 632.

96. American Psychiatric Association, Diagnostic Spectra Study Group, *Meet Us: Diagnostic Spectra*, at <http://www.dsm5.org/MeetUs/Pages/DiagnosticSpectra.aspx>.

97. American Psychiatric Association, *Highlights of Changes from DSM-IV-TR to DSM-5*, at <http://www.dsm5.org/Documents/changes%20from%20dsm-iv-tr%20to%20dsm-5.pdf>.

98. Thomas Insel, *Transforming Diagnosis* (Apr. 29, 2013) at <http://www.nimh.nih.gov/about/director/index.shtml>.

99. See generally Insel, *supra* note 98.

advocacy groups with at least some connection to political issues, and based on a review of founding dates, argues that there was a dramatic increase in “high-specificity health groups in the 1970s and especially the 1980s.”<sup>100</sup> As I will discuss in greater detail in the next section and in the case study of autism, patient lobbies coalesce around a DSM diagnosis and can exert significant influence on the regulatory and legislative process, whether arguing for expedited FDA approval of a pharmacological therapy targeting a specific diagnosis or for state-mandated insurance coverage of expensive treatments for a diagnosis.

One of the largest mental illness advocacy organizations, the National Alliance on Mental Illness (“NAMI”), has brought together grassroots advocates from different states since its founding in 1979.<sup>101</sup> The name of the group, highlighting mental *illness* and its mission statement, drawing analogies between mental illnesses and diseases such as diabetes and heart disease, coincided with the biomedical research into mental illness sparked by the DSM-III. The organization has recognized the DSM as an important tool in advocacy, and when the task force behind the DSM-5 opened a public comment period, NAMI issued a press release encouraging “individual and families to familiarize themselves with the draft of the new DSM.”<sup>102</sup> NAMI explained that, “the DSM historically has had a very significant impact on the treatment of mental illnesses and on the payment of mental health treatment and related services.”<sup>103</sup>

As I will discuss in greater detail in the next section, the APA task force’s confinement of “patient benefit” to the accuracy and reliability of a diagnosis in a clinical setting can clash with a broader conception of “patient benefit” espoused by some advocacy groups. A large degree of advocacy work is focused on economic issues such as insurance reimbursement for treatment, social issues such as the stigmatization of the mentally ill, or support of legislation linking a diagnosis with social service guarantees. Groups may be interested in DSM diagnoses for the way they advance or impede patient’s well-being in these settings rather than in clinical treatment alone. Despite these potential clashes, the APA has at least ostensibly welcomed the influence of these groups, publicizing the manual’s revisions through three public commenting periods in which

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100. Daniel Carpenter, *The Political Economy of FDA Drug Review: Processing, Politics, and Lessons for Policy*, 23 HEALTH AFF. 52, 57 (2004).

101. Agnes B. Hatfield, *The National Alliance for the Mentally Ill: A Decade Later*, 27 CMTY. MENTAL HEALTH J. 95, 98 (1991).

102. National Alliance on Mental Illness, *NAMI Encourages DSM-5 Discussion* (2010), [http://www.nami.org/Content/ContentGroups/Press\\_Room1/20102/February18/NAMI\\_Encourages\\_DSM-5\\_Discussion.htm](http://www.nami.org/Content/ContentGroups/Press_Room1/20102/February18/NAMI_Encourages_DSM-5_Discussion.htm).

103. *Id.*

over 12,000 comments have been submitted, stating “patients can and should play a more active role in the formation of diagnostic criteria for mental illness.”<sup>104</sup> David Kupfer, the chair of the DSM-5 Task Force, noted that it was the first time in the manual’s history that revisions to psychiatric categories would be integrated with patient and family input.<sup>105</sup> The “democratization” of input into the DSM categories—from a one-year, closed-door process led by a small subset of prominent researchers to a multi-year, highly public process where patients and advocates voice their opinion—is a development that clearly shows that stakeholders bring interests to the DSM revision process that are worth elucidating.

### 3. A Brief Note: the DSM and the ICD

While my focus in this paper is on the DSM, the manual is closely related to the International Classification of Diseases (“ICD”), which is also presently undergoing a revision process.<sup>106</sup> The ICD is under the authorization of the World Health Organization (“WHO”), and had little in common with the DSM until the DSM’s 1980 revision.<sup>107</sup> The international success of the DSM-III led to public pledges to make the two manuals align more closely, and in 1982, the ICD decided to adopt the DSM’s “operational approach” to symptom-based diagnoses.<sup>108</sup> The two are revised on roughly the same schedule, and have converged in recent years in establishing very similar diagnostic categories.

However, important differences remain. Some argue that these differences are desirable because they stem from different aims of two classification schemes.<sup>109</sup> They point to the ICD’s aim of creating a

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104. DARREL A. REGIER et al., *Patient Involvement in the Development of DSM-V* 73 PSYCHIATRY: INTERPERSONAL AND BIOLOGICAL PROCESSES 308, 308 (2010). See also Am. Psychiatric Ass’n, *DSM-5 Draft Criteria Draws Nearly 2,300 Responses* (2012), at <http://www.dsm5.org/Documents/12-30%20Final%20DSM%20Public%20Comment.pdf>. (describing the more than 12,000 comments submitted since 2010 over the three open commenting periods).

105. Emily A. Kuhl, David J. Kupfer & Darrel A. Regier, *Patient-centered Revisions to the DSM-5*, 13 JAMA ETHICS 873, 878 (2011).

106. The ICD has a later “due date” of 2015. See Norman Sartorius, *Revision of the Classification of Mental Disorders in the ICD-11 and DSM-V: Work in Progress*, 16 ADVANCES IN PSYCHIATRIC TREATMENT 2, 2 (2010).

107. See Robert E. Kendell, *The Relationship between DSM-IV and ICD-10*, 100 J. ABNORMAL PSYCHOL. 297, 299 (1991) (arguing that as a result of the dramatic revision of the DSM in the form of 1980’s DSM-III, the international community began to recognize the “benefits” of the DSM’s innovations and incorporate these innovations into the ICD to make the systems of classification more similar).

108. See Mario Maj, *Psychiatric Diagnosis: Pros and Cons of Prototypes vs. Operational Criteria*, 10 WORLD PSYCHIATRY 81, 81 (2011).

109. Kendell, *supra* note 107, at 299-300 (arguing that possible benefits of differences between the two manuals is that researchers will have a genuine choice between two very different diagnostic systems, the fact that many different countries with different resources, culture, and use the ICD codes while the DSM is ostensibly geared towards the United States, and the fact that mental illness such as sexual

comprehensive classification of diseases diagnosed by a range of health care professionals in countries with a wide range of health care resources versus the DSM's intended use for "one, or perhaps two, professions—psychiatrists and clinical psychologists"<sup>110</sup> in the United States. In this view, the DSM should be more detailed and complex, for it is geared toward highly-trained researchers and medical practitioners in a high-income nation. This explicit audience stands in contrast to the ICD's broad focus on public health professionals in countries that sit on a wide spectrum of economic development. Meanwhile, others argue that the differences between DSM and ICD criteria are undesirable because they undermine international research collaboration and because the U.S. requires under the Health Insurance Portability and Accountability Act (HIPAA) that ICD codes are used on all billing transactions.<sup>111</sup>

## II. STAKEHOLDERS IN THE DSM DIAGNOSTIC CATEGORIES AND POTENTIAL CONFLICTS

The previous section illustrated that the DSM has never been a project that exists solely within a scientific community of psychiatrists and clinical psychologists. Instead, the manual and its revisions are scrutinized and influenced by a diverse array of societal stakeholders with interests in how psychiatric disturbance is defined and categorized. The manual went from an oft-ignored and marginalized document even for those within the profession during its first two editions (the DSM-I and II) to a document that attracted scrutiny from cultural critics, third-party payers, those worried about its influence on legal exoneration, patient advocates, and others. Whether it is insurance companies underscoring the importance of clear categories and cost-efficient treatment, feminists protesting the psychiatric labeling of oppressive gender roles, or disease advocacy groups lobbying for greater funding for their specific condition, the DSM "bible" has become the common language of mental illness in the United States. In this section, I will discuss seven groups of stakeholders, each

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problems and eating disorders are likely over-emphasized in the U.S. relative to their importance in other countries).

110. *Id.* at 299.

111. See generally Michael B. First, *Harmonisation of ICD-11 and DSM-V: Opportunities and Challenges*, 195 *BRITISH J. PSYCHIATRY* 382, 382-90 (2009) (for example, the research agenda for the DSM-5 explicitly notes that "trivial differences in criteria wording, threshold number of symptoms, or exclusion criteria" between the ICD and DSM can substantially affect diagnostic concordance). In terms of the need for ICD codes on billing transactions, psychiatrists with the ICD code, and not realize that they just gave an ICD diagnosis; or they may record their clinical encounters in DSM terminology before converting to ICD. See Geoffrey Reed, *Toward ICD-11: Improving the Clinical Utility of WHO's International Classification of Mental Disorders*, 41 *PROF'L PSYCHOLOGY* 457, 458 (2010).



with significant interest in the construction of DSM diagnoses: clinicians, researchers, patients and their families, legal professionals, school districts, pharmaceutical companies, and insurance providers. In the next section, I will illustrate my discussion of how different stakeholders have different interests in the manual's uses through a case study of autism, where the interests of these stakeholders have sharply collided.<sup>112</sup>

### A. Clinicians

The DSM is first and foremost designed to aid clinicians in the process of the diagnosis and treatment of patients with mental illness.<sup>113</sup> We can separate clinical practice into two sets of interests: the Hippocratic and the administrative.

I argue that clinicians have so-called Hippocratic interests to relieve the patient suffering that brings him to the clinician in the first place. The classification of psychiatric disorders as clusters of signs and symptoms (the current model) or as biomarker-associated pathologies (what may become more common in the future) is only valuable to clinicians if these classifications can aid in treatment.<sup>114</sup> While a researcher may also be interested in classifications that correspond with appropriate treatments in order to work backwards from an effective treatment to an understanding of the underlying basis for the disorder, one should not gloss over the ways in which the clinician and researcher's interests may diverge. A clinician is only interested in the etiology or cause of a condition to the extent that knowledge of that etiology aids in treatment. Furthermore, the fact that primary care physicians provide a non-negligible amount of mental health service provision—one epidemiological survey found that 20% of patients receiving treatment for mental illness receive that treatment from a general medical physician—points to the fact that generalist clinicians may require a different level of detail and complexity than specialty psychiatry, biology, and genetics researchers.<sup>115</sup> For these reasons, Michael First, a

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112. As the battles between the Freudians and Kraepelinians illustrate, there is significant heterogeneity within each category of stakeholder, and the abstract interests I present could not possibly encompass the diverse array of interests present within each community.

113. For example, some argue that that the primary aim of the manual is to be a "helpful guide in clinical practice," an aim that supersedes the manual's other interests in aiding research, improving information surrounding disorders, and educating patients, litigators, legislators and others about psychopathology. See Michael B. First, *Clinical Utility: A Prerequisite for the Adoption of a Dimensional Approach in DSM*, 114 J. ABNORMAL PSYCHOL. 560, 560-61 (2005). See also Roel Verheul, *Clinical Utility of Dimensional Models for Personality Pathology*, 19 J. Personality Disorders 283, 286-95 (2005).

114. Robert Kendell & Assen Jablensky, *Distinguishing Between Validity and Utility of Psychiatric Diagnoses*, 160 Am. J. Psychiatry 4, 9-10 (2003).

115. See Phillip S. Wang, Olga Demler, & Ronald C. Kessler, *Adequacy of Treatment for Serious Mental Illness in the United States*, 92 AM. J. PUB. HEALTH 92, 94 (2002).

psychiatrist who specializes in the study of psychiatric classification, argues that user accessibility is one oft-neglected feature of the DSM, which involves *simplifying* criteria sets to make the manual easier to use in clinical practice to help patient suffering, even though a more complex criteria set may provide more detailed information for researchers.<sup>116</sup> Researchers may want categories with an increased number of subtypes that may correspond with different etiological pathways, different genetic predispositions, and other items of research interest, while clinicians may need to balance the desire for nuance and complexity with the fact that added detail may detract from rather than enhance that clinician's ability to help his or her patients.

Though clinicians would likely enjoy living in an ideal world where the Hippocratic oath and patient care were their sole clinical concerns, in reality, clinicians have extensive administrative and other responsibilities that create a second set of interests in diagnostic categories. These include medical record keeping, filing for insurance reimbursement, clinical education, communication with other clinicians for the referral of patients, and cost pressures that may reduce their time with patients.

Significant changes to a new DSM may dampen its widespread usage if the changes impose significant administrative burdens or have other disruptive effects on clinical practice. For example, First has urged caution on transforming the DSM into a dimensional system that may "complicate medical records and the collection of vital statistics by creating a sharp disparity between diagnoses of mental disorders and diagnoses of general medical conditions."<sup>117</sup> In addition, First argues that the, "the extraordinary complexity of the current diagnostic system, with each revision including more categories, more subtypes, and more specifiers focused on increasingly fine distinctions,"<sup>118</sup> may also impede diagnosis, especially if clinicians experience time pressure when making contact with patients.

Addressing the concern of practical categories accessible to generalists or time-constrained specialists, one commentator retorts: "to

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116. It is worth noting that some forms of increased complexity in diagnostic descriptions can benefit even generalist clinicians. For example, the DSM-IV's addition of an "atypical features" specifier to various mood disorders helped clinicians recognize that patients in that subtype may respond poorly to tricyclic antidepressants. See Michael First & Drew Westen, *Classification for Clinical Practice: How to Make the ICD and DSM Better Able to Serve Clinicians*, 19 *Int'l Rev. Psychiatry* 473, 474 (2007).

117. See Michael B. First, *Clinical Utility: A Prerequisite for the Adoption of a Dimensional Approach in DSM*, 114 *J. ABNORMAL PSYCHOL.* 560, 561-64 (2005). See also Roel Verheul, *Clinical Utility of Dimensional Models for Personality Pathology*, 19 *J. PERSONALITY DISORDERS* 283, 283-302 (2005).

118. Geoffrey Reed, *Toward ICD-11: Improving the Clinical Utility of WHO's International Classification of Mental Disorders*, 41 *PROF'L PSYCHOL.* 457, 459 (2010).

those who argue that the DSM . . . ultimately must yield to important practical considerations, I respond with James Clerk Maxwell's famous dictum: 'There is nothing more practical than a good theory.'<sup>119</sup> Maxwell is correct in one sense: good theory can aid in research that ultimately improves treatment in the long run. Yet the precision and complexity that may aid in the formation of good theory, and that may be useful to specialized practitioners worked in research settings, may be simply too impractical for the primary care clinicians with limited time and limited psychiatry-specific training who treat many persons with mental illness. The precise mechanism behind neurotransmitter reuptake matters little to clinicians working in day-to-day practice. Instead, a clinician's good theory may be theory that aids in his patient's recovery and the administrative tasks that support effective treatment.

## B. Researchers

Many patients may receive a diagnosis and care from a primary care physician rather than more expensive specialists, such as psychiatrists or clinical psychologists, a descriptive reality that points toward diagnostic categories that avoid burdensome complexity. In contrast, researchers are almost always specialists. Though it is impossible to provide an exhaustive account of how different researchers may view diagnoses, I will focus on the interests of three types of investigators: biomedical researchers studying genetic or neural biomarkers associated with psychiatric disturbance, epidemiologists investigating the prevalence and social distribution of mental illness, and researchers investigating the comparative effectiveness of different treatments for the same condition.

### 1. Biomedical Researchers

The interests of biomedical researchers arguably diverge most sharply from the interests of clinicians, for the specific etiology of a disorder matters less to a clinician than how to improve the patient's well-being. As discussed, one notable development spanning across recent revisions of the DSM has been the manual's failure to accurately reflect the state of neuroscientific and genetic research into mental illness. Studies aimed at finding neural and genetic biomarkers that correspond to DSM diagnostic categories have shown that biomarkers or shared family history often fail to correspond to a shared DSM diagnosis.<sup>120</sup> A single family may

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119. Lee A. Clark, *Temperament as a Unifying Basis for Personality and Psychopathology*, 114 J. ABNORMAL PSYCHOL. 505, 516 (2005).

120. Hyman, *supra* note 92, at 8. Hyman, a member of the DSM-5 task force and neuroscience researcher,

contain patients with schizophrenia, bipolar disorder, and other diverse conditions and shared genetic variants may contribute to a person's risk for many different disorders.<sup>121</sup> Other studies find that biomarkers correspond to a multiplicity of disorders.<sup>122</sup> For example, research into the interaction between a boy's MAOA allele and physical abuse has shown that certain polymorphisms may moderate the effect of environmental stressors.<sup>123</sup> However, the MAOA polymorphism predicts vulnerability to a range of different disorders: attention deficit disorder, antisocial personality disorder, and general emotional problems.<sup>124</sup> Biomarker-based risk factors, therefore, have rarely mapped on to single DSM disorders, instead showing vulnerability to multiple DSM diagnoses.

For many researchers investigating the underlying basis of psychiatric disturbance, a different approach seems more promising—disaggregating the DSM's symptom-based discrete categories into dimensions in psychosis, mood disturbance, emotion regulation issues that transcend “well-bounded categories.”<sup>125</sup> Antisocial personality disorder may need to be disaggregated into aggression, aggression may require disaggregation into impulsivity, and each of these phenomena may extend across a broad range of disorders. Researchers have asserted that while DSM diagnostic categories may be well suited for clinical settings, studies into the neural and genetic bases of affective states or groups of behaviors look more promising than studies that neatly map onto to the DSM's highly specific and discrete symptom-based system.<sup>126</sup>

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contains that genetics and neuroscience studies have posed distinct challenges to the DSM classification scheme. Hyman states that “. . . far from providing the predicted validation of schizophrenia (or other disorders) as discrete categories . . . findings of family and genetic studies have posed serious problems for a system that builds highly specified categories from phenomenological building blocks.”

121. *Id.* at 8. See also Cross-Disorder Group of the Psychiatric Genomics Consortium, *Identification of Risk Loci with Shared Effects on Five Major Psychiatric Disorders: A Genome-Wide Analysis*, 381 THE LANCET 1371, 1371-79, 1-9 (2013), available at <http://press.thelancet.com/psychiatricdisorders.pdf> (discussing overlap in genetic risk factors for five DSM disorders: major depressive disorder, bipolar disorder, schizophrenia, autism spectrum disorders, and attention deficit hyperactivity disorder).

122. See generally Cross-Disorder Group of the Psychiatric Genomics Consortium, *Identification of Risk Loci with Shared Effects on Five Major Psychiatric Disorders: A Genome-Wide Analysis*, 381 LANCET 1371-1379 (2013) (describing how specific genetic variants are associated with three different adult-onset psychiatric disorders—schizophrenia, major depression, and bipolar disorder—and that these genetic risk factors thus have a broader phenotypic effect than mapping on to one specific psychiatric diagnosis).

123. See Julia Kim-Cohen et al., *Maltreatment, and Gene-Environment Interaction Predicting Children's Mental Health: New Evidence and Meta-analysis*, 11 MOLECULAR PSYCHIATRY 903, 903-13 (2006).

124. *Id.* at 907-8.

125. Hyman, *supra* note 92, at 9.

126. For example, a group of researchers assert that “[d]ependence on conventional nosologies leaves the enterprise of understanding mechanisms of psychopathology in the awkward position of assuming the validity of single disorders and organizing research accordingly. This approach implicitly assumes that a given disorder maps onto mechanisms amenable to discovery via suitable investigations. However, it is not clear that conventional diagnoses can fulfill this role, and it may be important for researchers to develop

## 2. Epidemiologists

For epidemiological researchers less interested in the underlying etiology of a specific behavior or affective state and more interested in tracking the incidence and prevalence rates of mental illness over time and across different communities, consistency across manuals is important for longitudinal research. Thus, while researchers may want to jettison the current system of discrete DSM classifications and move to a model focused more upon cross-disorder dimensions, the manual since the DSM-III has only made small, conservative changes, in part to maintain continuity in large-scale clinical trials or longitudinal epidemiological research.<sup>127</sup> In contrast to other researchers, epidemiologists are less interested in aggression levels over time or the number of patients with a specific neurotransmitter dysfunction. As a result, the discrete disease categories of the DSM may be more amenable to epidemiological research than to basic research into psychopathology, though vague diagnostic criteria that reduce inter-rater reliability can complicate the epidemiological picture.<sup>128</sup>

## 3. Comparative Effectiveness Researchers

The last category of investigators, those studying the comparative effectiveness of different therapeutic interventions, will receive more power and funding as the U.S. attempts to contain its health care costs. The American Recovery and Reinvestment Act of 2009 has allocated over \$1 billion for comparative effectiveness research that investigates the benefits and harms of different interventions in “real-world settings.”<sup>129</sup>

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constructs and theories that are not tightly bound to extant diagnostic conventions. Specifically, it may be necessary to deconstruct currently defined higher order clusters of complex behaviors (or subsets of these clusters) into intermediate functions that are not themselves clinical symptoms in order to understand the relationship of higher order “criterion” symptoms to lower order causal networks that include cognition, emotion, hormones, neural circuits, and their molecular pathways and structures.” See Sanislow, *supra* note 94, at 632.

127. Hyman, *supra* note 92, at 10-1. As Hyman notes, “. . . even small changes in wording could produce significant disruptions to epidemiology . . . such disruptions would militate against tinkering without very strong justification.”

128. However, some psychiatric epidemiologists have recently questioned whether the manual pays enough attention to their research needs. These epidemiologists have asserted that revisions of the manual need to more closely monitor differences in diagnostic prevalence by sex, ethnicity, income or geographic region. This response by epidemiologists, however, reiterates my argument about the fundamental usefulness of existing DSM diagnoses to epidemiologists. The epidemiologists do not want to radically revise psychiatry’s system of classification; instead, they want the existing system of classification (the DSM) to pay closer attention to variation in the prevalence rates of mental illness across communities to aid research into potential sources of this variation. See Helena B. Hansen, et al. *Independent Review Of Social And Population Variation In Mental Health Could Improve Diagnosis In DSM Revisions*, 32 HEALTH AFF. 1, 1-10 (2013).

129. See Jeffrey S. McCombs et al., *Applying Comparative Effectiveness Research Methods in Bipolar*

The Patient Protection and Affordable Care Act (“ACA”) enacted in 2010 established the Patient-Centered Outcomes Research Institute (“PCORI”), which will allocate \$600 million per year to comparative effectiveness research and spreading its findings when fully funded.<sup>130</sup> Comparative effectiveness research for psychiatric disorders has focused on different pharmacological and psychotherapeutic interventions.<sup>131</sup> How do comparative effectiveness researchers conceive of DSM categories and which changes to the DSM are desired or unwelcome? Do comparative effectiveness researchers have more in common with basic science researchers, epidemiologists, or practicing clinicians?

Comparative effectiveness researchers’ interest in DSM categories depends on various features of the methodology that they may employ. I will focus on two aspects: first, whether the study is conducted retrospectively or prospectively and second, the desired “pragmatism” of the study methodology.

In terms of retrospective versus prospective research, researchers relying on retrospective observational research that uses insurance claims data, electronic medical records, or other sources of health data across time may have an interest in minimal changes to categories across editions.<sup>132</sup> Frequent changes interfere with the interpretation of data sets that may transcend multiple DSM editions. These retrospective researchers are bound by what is noted in the insurance claim or electronic health records—information likely limited to a diagnostic code—so continuity between manual editions is important for these researchers in the same way that it is important for many epidemiologists tracking diseases across time/locality. In contrast, comparative effectiveness researchers launching prospective studies that follow patients *forward* over time and that do not rely on data from insurance claims or electronic health records have more flexibility with regards to the DSM diagnoses. For example, the Biomarkers for Rapid Identification of Treatment Effectiveness in Major Depression (“BRITE-MD”) comparative effectiveness study finds that a biomarker—prefrontal brain activity as measured by electroencephalography—can predict response and recovery rates to antidepressants with up to 74% accuracy, and, after a week of treatment,

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*Disorders*, 130 *J. Affective Disorders* 145, 145-6 (2011).

130. See Michael Lauer and Francis Collins, *Using Science to Improve the Nation’s Health System*, 303 *JAMA* 2182, 2182 (2010).

131. See generally Phillip S. Wang, Christine M. Ulbricht, & Michael Schoenbaum, *Improving Mental Health Treatments Through Comparative Effectiveness Research*, 28 *HEALTH AFF.* 783, 783-91 (2009).

132. For a description of retrospective analyses using electronic health records, see Walter F. Stewart et al., *Bridging the Inferential Gap: The Electronic Health Records and Clinical Evidence*, 26 *HEALTH AFF.* w181, w184 (2007).

help predict whether a patient will respond better to an SSRI or non-tricyclic antidepressant.<sup>133</sup> This type of comparative effectiveness research, which can look at biomarkers and subtypes in addition to discrete diagnoses, has more in common with the needs of basic science researchers than with the needs of epidemiologists.

The second methodological feature of CER that will dictate the usefulness of DSM categories is the desired “pragmatism” of the experimental design.<sup>134</sup> CER that is more pragmatic tries to mimic the “real-world” conditions in which most treatment takes place: it features non-specialized practitioners rather than specialized researchers and includes heterogeneous patient populations, such as patients with multiple co-morbidities, rather than a homogeneous patient population only suffering from one condition.<sup>135</sup> The more pragmatic a CER design is, the more it may be bound to the DSM and its diagnoses because these diagnoses are widely used by non-specialized practitioners seeing patients with a complex mix of conditions. Comparative effectiveness research that features specialized practitioners in academic settings treating patients with only one, rather than multiple disorders, in contrast, may be able to use more specialized diagnostic tools than the DSM categories, such as biomarker-based stratification of patients with a given disorder into different subgroups.

Despite these documented divergences between basic science researchers, epidemiologists, and comparative effectiveness researchers, all are currently bound by the ubiquity of DSM diagnoses among grant making institutions and journal review boards. As a result, researchers, regardless of the methodology they use, often find themselves framing their research with reference to the DSM, regardless of the manual’s warnings that it is not, “designed or intended to further basic science.”<sup>136</sup>

### C. Patients and their Families

The main interest of patients and their families aligns with the clinician’s Hippocratic interest in helping the patient improve and

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133. Andrew F. Leuchter et al., *Comparative Effectiveness of Biomarkers and Clinical Indicators for Predicting Outcomes of SSRI Treatment in Major Depressive Disorder: Results of the BRITE-MD Study*, 169 PSYCHIATRY RES. 124, 124-31 (2009).

134. For an overview of making research more “pragmatic,” see generally Kalipso Chalkidou et al., *The Role for Pragmatic Randomized Controlled Trials (pRCTs) in Comparative Effectiveness Research*, 9 CLIN. TRIALS 436, 436-446 (2012).

135. *Id.* at 439.

136. Helena C. Kraemer, *DSM Categories and Dimensions in Clinical and Research Contexts*, 16 INT’L J. METHODS PSYCHIATRIC RES. S8, S9 (2007).

recover.<sup>137</sup> As a result, I will not repeat myself in reiterating the way in which a physician's Hippocratic interest aligns with DSM categories; like physicians, patients are interested in DSM diagnoses insofar as those categories aid in treatment and improvement. In this section, I will highlight two especially strong concerns that are unique to patients: interest in minimizing out-of-pocket treatment expenses and interest in or rejection of a disease community. Furthermore, I will note where a patient's interests may diverge from the interests of his or her family.

One pronounced interest of patients is in insurance reimbursement. A patient who allocates a certain amount of his income to insurance premiums will presumably want that paid-for plan to cover as much of their treatment as possible, with affordable co-payments or co-insurance and minimal out-of-pocket expenses for therapy or medication.<sup>138</sup> As a result, a patient may have a clear *financial* interest in having DSM diagnoses that are as broad as possible. While clinicians may be interested in diagnoses that are highly predictive of patient response to treatment, and researchers may be interested in diagnostic categories that aid in biomedical, epidemiological, or comparative effectiveness investigation, patients' financial interest in diagnoses may be more basic. If a patient is distressed and believes that an intervention—therapy, pharmacological, or other—will help alleviate that distress, the patient has an interest in minimizing the amount they must pay for the distress-alleviating intervention.

The utility of DSM diagnoses in reducing a patient's personal financial responsibility for treatment is strengthened by laws such as 1996's Mental Health Parity Act ("MHPA") and 2008's Mental Health Parity and Addiction Equity Act ("MHPAEA"), which require that insurance companies ensure that financial requirements such as co-pays, deductibles, and treatment limitations are no more restrictive for mental illnesses than for physical illnesses.<sup>139</sup> As of 2010, the DSM was cited over 320 times in state-level legislation clarifying these requirements.<sup>140</sup> The

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137. This statement is complicated by the fact that Axis II personality disorders are sometimes labeled "ego-syntonic;" they can be a welcome part of an agent's stable self-identity and the agent may have no interest in recovery. However, since many DSM diagnoses contain an explicit mention that the patient must experience distress or impairment in functioning from his or her symptoms, this section will operate off the assumption that most patients and their families want to improve and "recover" to a higher level of functioning.

138. However, it's worth noting that more generous employer-based insurance coverage may result in lower wages for a given patient, complicating the extent to which more generous mental health coverage may ultimately benefit a patient financially.

139. U.S. Dep't. of Labor, *The Mental Health Parity and Addiction Equity Act of 2008 (MHPAEA)* (2010), available at <http://www.dol.gov/ebsa/newsroom/fsmhpaea.html>.

140. Ralph Slovenko, *DSM in Litigation and Legislation*, 39 J. AM. ACAD. PSYCHIATRY L. 6, 6 (2011).



successful passage of the Patient Protection and Affordable Care Act (“ACA”) in 2010 further promotes these parity requirements by setting forth Essential Health Benefits (“EHBs”) that must be offered by each insurance plan offered in individual and small group markets.<sup>141</sup> One of the ten categories of EHBs is “mental health and substance use disorder services, including behavioral health treatment,”<sup>142</sup> and nothing in the legislation or its implementation likely requires such coverage for persons who lack an explicit DSM diagnosis but believe they would benefit from mental health services anyways. As a result, patients have a strong financial interest in their distress having an accompanying DSM diagnosis, because private or public payers often require this diagnosis.

The other way in which broadly defined categories may promote a patient’s interests is by lending support for public awareness, attention, and resource allocation to a given DSM diagnosis. Several disease specific advocacy organizations have argued that the prevalence of the disease for which they are lobbying has increased to the level of epidemic.<sup>143</sup> To the extent that this public attention and resource allocation translates into improved health outcomes and service eligibility for a patient with a specific diagnosis, broad disease categories promote a patient’s interests through contributing to a perception of a disorder’s high prevalence.

While financial and resource allocation interests may increase a patient’s interest in broad DSM diagnoses, there are several other non-financial interests that impact a person’s interest in receiving a psychiatric diagnosis, including the stigmatization of mental illness and membership in a disease community. Stigma complicates the *homo economicus* portrait of mentally ill patients as utility-maximizing health care consumers. In the U.S., two-thirds of people who meet the DSM-criteria for a clinical disorder receive no treatment, and researchers point to stigma and discrimination as significant barriers that perpetuate this treatment gap.<sup>144</sup>

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141. The Patient Protection and Affordable Care Act of 2010, (PL 111-148, March 23, 2010). United States Statutes at Large, 119 (2010) pp. 163-166. See generally Amanda Cassidy, *Health Policy Brief: Essential Health Benefits*, HEALTH AFF. 1, 1-4 (2012).

142. Patient Protection and Affordable Care Act, *supra* note 141, at 124.

143. See e.g. Mark Roithmayr, *I in 88: We Need a Strategy* (Mar. 19, 2012) at <http://www.autismspeaks.org/blog/2012/03/29/>

1-88-we-need-strategy (where the Director of the Autism Speaks advocacy organization argues that autism “can officially be declared an epidemic” and that this epidemic status warrants a national strategy aimed at increasing research funding for the disease). See also Alzheimer’s Assoc., *Alzheimer’s Association Applauds Obama Administration For Dedication Of New Resources To Alzheimer’s Epidemic*, at [http://www.alz.org/news\\_and\\_events\\_alz\\_association\\_applauds\\_obama\\_administration.asp?WT.mc\\_id=enews2013\\_04\\_10](http://www.alz.org/news_and_events_alz_association_applauds_obama_administration.asp?WT.mc_id=enews2013_04_10) (where the Alzheimer’s Association thanks the Obama administration for allocating earmarking \$100 million of the FY2014 budget to fund research and caregiver support efforts).

144. See generally Kathleen M. Michels et al., *Stigma and Global Health: Looking Forward*, 367 LANCET

A patient may eagerly seek to avoid receiving a DSM diagnosis, especially one such as schizophrenia or antisocial personality disorder that laypeople associate with violence or destructive behavior; he or she may have an interest in highly-specific symptom-based categories that *do not* reflect his or her specific form of distress. In turn, a patient's desire to avoid a diagnosis may diverge from his family's interest in getting him appropriate treatment for his disturbance.

Disease communities have complicated the phenomenon of stigma, providing spaces for sufferers of stigmatized conditions to coalesce around a shared DSM diagnosis and turn what some perceive as a disability into a source of identity-based pride.<sup>145</sup> Though a detailed sociology of which DSM diagnoses have flourishing disease communities is outside the scope of this paper, Asperger's disorder is one prominent example. Asperger's, or "Aspie," pride groups have proliferated, with one website extolling Asperger's as a cultural identity rather than a medical condition.<sup>146</sup> These pride groups have an ambivalent relationship with DSM diagnoses. They are somewhat dependent upon these diagnoses to recognize each other as fellow group members yet many reject attempts to describe their condition as a "medical disease" that needs curing, instead emphasizing the need for social support services.<sup>147</sup> Further complicating the picture, and revealing that "pride" groups may be in a minority, there are many disease communities, such as NAMI, that actively support the definition of mental illness as a disease entity in need of treatment and thus have a more explicit interest in DSM diagnosis-based insurance reimbursement.<sup>148</sup>

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538, 538-39 (2006); See also Gerald T. Keusch, Joan Wilentz, & Arthur Kleinman, *Stigma and Global Health: Developing a Research Agenda*, 367 LANCET 525, 525-27 (2006).

145. See generally Renee R. Anspach, *From stigma to identity politics: Political activism among the physically disabled and former mental patients*, 13 SOC. SCI. MED 765, 767-769 (arguing that identity-based social movements reject the societal conception of a given disorder as stigmatizing and instead demonstrate through activism their pride in the condition).

146. ASPERGIAN PRIDE, at <http://www.aspergianpride.com/about/>.

147. For example, transgender activists have an ambivalent relationship to the DSM category of "gender identity disorder." While some activists initially sought to have the diagnoses removed from the manual entirely, arguing that the diagnosis seemed to imply that having a transgender identity is pathology, activists wanted to keep some reference to the disorder in the new DSM-5 to assist in reimbursement for hormone therapy and other treatments. The compromise was a new disorder called "gender dysphoria." See Moni Basu, *Transgender No Longer a Mental 'Disorder'*, CNN BLOG (Dec. 27, 2012), at <http://inamerica.blogs.cnn.com/2012/12/27/being-transgender-no-longer-a-mental-disorder-in-diagnostic-manual/>.

148. The concept of disease-pride communities has provoked much controversy that I do not have room in this section to address. For example, eating disorder researchers almost always condemn pro-anorexia ("pro-ana") disease communities, which offer tips on starvation-techniques and photographs of fashion models as "thinspiration," citing the harm these communities may cause to the patient in enabling her to resist recovery. See generally Mark Norris et al., *Ana and the Internet: A Review of Pro-Anorexia Websites*, 39 INT'L J. EATING DISORDERS 443, 443-7 (2006).

### D. Legal Professionals

The preface to the DSM-IV-TR explicitly warns against the use of the manual for forensic purposes, arguing that its use in legal contexts poses significant risks that the information will be misused or misunderstood. The APA argues that this misuse/misunderstanding will occur because of the “imperfect fit between the questions of ultimate concern to the law and the information contained in a clinical diagnosis.”<sup>149</sup> Despite this official caveat, one researcher describes how the manual has been cited in over 5,500 court opinions.<sup>150</sup> Furthermore, the DSM itself notes that:

When the presence of a mental disorder is the predicate for a subsequent legal determination (e.g. involuntary civil commitment), the use of an established system of diagnosis enhances the value and reliability of the determination . . . DSM-IV may facilitate the legal decision makers’ understanding of the relevant characteristics of mental disorders . . . Finally, diagnostic information regarding longitudinal course may improve decision making when the legal issue concerns an individual’s mental functioning at a past or future point in time.<sup>151</sup>

While clinicians should be interested in diagnostic categories that aid in the design of treatment options, legal professionals should be seeking a related but distinct set of information. For example, the DSM diagnostic category of schizophrenia may be useful for practicing clinicians, since the signs associated with the category of schizophrenia are helpful for treatment, but the category itself should not be used as a heuristic for judges and others in the legal systems. In the U.S., an insanity defense requires that a defendant lacks substantial capacity to appreciate the criminality/wrongfulness of his conduct, a determination that DSM categories in and of themselves (should) provide little insight in making.<sup>152</sup>

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149. AMERICAN PSYCHIATRIC ASSOCIATION, DIAGNOSTIC AND STATISTICAL MANUAL OF MENTAL DISORDERS: FOURTH EDITION - TEXT REVISION xxxiii (2000).

150. Slovenko, *supra* note 140, at 6.

151. AMERICAN PSYCHIATRIC ASSOCIATION, *supra* note 138, at xxxiii.

152. Kendell & Jablensky, *supra* note 114, at 10. Unfortunately, an expanding body of evidence shows that DSM categories do substantially affect legal procedures such as sentencing. For example, a recent study presented 181 state trial judges with a hypothetical vignette containing “expert testimony” on a case of aggravated battery describing the perpetrator as a “diagnosed psychopath.” Vignettes that contained this diagnosis plus “testimony” from a neurobiologist testifying about the biological mechanism behind the disorder, gave significantly shorter sentences than judges reading the diagnosis alone. See Lisa G. Aspinwall, Teneille R. Brown, & James Tabery, *The Double Edged Sword: Does Biomechanism Increase or Decrease Judges’ Sentencing of Psychopaths?*, 337 SCI. 846, 846-9 (2012). Thus, as DSM diagnoses

Since the relationship of the DSM to the law has received extensive treatment elsewhere,<sup>153</sup> I will focus on one topic out of the many that lie at the boundaries of law and the DSM: the way in which small changes in DSM wording can have outsize legal ramifications.

One example of a small change with large ramifications involves sexually violent predator (“SVP”) involuntary commitment statutes, which are based upon two criteria in most states: the offender must have been convicted of or charged with a crime of sexual violence and must suffer from a mental abnormality or personality disorder that makes the person likely to engage in “predatory acts of sexual violence.”<sup>154</sup> It is important to note that, at least on a federal level, the definition for “mental abnormality” is deliberately de-coupled from the DSM. In *Kansas v. Hendricks*, the Supreme Court stated that, “The term mental illness is devoid of any talismanic significance . . . We have traditionally left to legislators the task of defining terms of a medical nature that have legal significance . . . Often, those definitions do not fit precisely with the definitions employed by the medical community.”<sup>155</sup> Yet the de-coupling is not so clear-cut in other Supreme Court statements. In 2002, the court in *Kansas v. Crane*, specifically argues that the “presence of what the ‘psychiatric profession itself classified . . . as a serious mental disorder’” helped the *Hendricks* court decide whether the offender’s uncontrollable dangerousness merited civil commitment.<sup>156</sup> Furthermore, some commentators have argued that despite these judicial reiterations that “mental abnormality” should not be conflated with a DSM diagnosis, in practice, diagnoses of paraphilia are a significant contributor to civil commitment decisions.<sup>157</sup> For example, one analysis of 450 incarcerated sex offenders under consideration for civil commitment found that paraphilia not otherwise specified (“NOS”) demonstrated a strong and significant association with recommendation for commitment, with variables such as an offender’s statement of intent to commit a new sex

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spur research into the genetic and neural mechanisms behind disorders, judges may view this evidence, rightly or wrongly, as a mitigating factor in sentencing.

153. See generally Ralph Slovenko, *PSYCHIATRY AND THE LAW/LAW IN PSYCHIATRY* (2nd ed. 2009).

154. Michael B. First & Robert Halon, *Use of DSM Paraphilia Diagnoses in Sexually Violent Predator Commitment Cases*, 36 J. AM. ACAD. PSYCHIATRIC L. 443, 443 (2008).

155. *Kansas v. Hendricks*, 521 U.S. 346, 359 (1997). For a discussion, see generally, Douglas Tucker & Samuel Brakel, *DSM-5 Paraphilic Diagnoses and SVP Law*, 41 ARCH. SEX. BEHAV. 533, 533 (2012).

156. *Kansas v. Crane*, 534 U.S. 407, 413 (2002). See generally First & Halon, *supra* note 154, at 444. Furthermore, looking at 2010’s *U.S. v. Carta*, the First Circuit Court of Appeals reiterated that an assessment of mental abnormality does not need a corresponding DSM diagnosis to be valid for SVP civil commitment purposes, a DSM diagnosis of *paraphilia not otherwise specified (hebephilia)* could indeed qualify an offender for civil commitment. See *U.S. v. Carta* 592 F.3d 34 (2010).

157. First & Halon, *supra* note 154, at 444.

crime or a prior probation failure playing a lesser role than a DSM diagnosis.<sup>158</sup>

The heavy reliance on DSM diagnoses in legal contexts raises the question: to what extent should the diagnosis' wording be aimed at warding off conflated uses of the diagnosis in SVP commitment cases? For example, some have argued that a slight change in wording between the DSM-III-R and the DSM-IV in one criterion for sexual disorders was gravely misinterpreted and misapplied in the legal context.<sup>159</sup> The changes in criterion A between the two editions were as follows:

**DSM-III-R:** "recurrent sexual urges and fantasies . . . over a period of six months."<sup>160</sup>

**DSM-IV:** "recurrent, intense, sexually arousing fantasies, sexual urges *or behaviors* . . . over a period of six months."<sup>161</sup>

As a result of this slight change in wording, an offender's sexually violent behavior by itself could be construed as evidence pointing toward a "mental abnormality" used to justify civil commitment. In other words, the act of rape alone could justify a diagnosis of a mental disorder, regardless of whether that rape was motivated by abnormal and uncontrollable sexual urges. In the APA's defense, Allen Frances, the head of the DSM-IV task force and an outspoken critic of many of the current manual's proposed changes, contends that the task force did not predict the legal reverberations of this slight change in wording:

Work group members do not understand that the DSM is read very differently by lawyers and by psychiatrists and other mental health practitioners. Even when the DSM criteria sets and text are written with a consistency that is sufficient for clinical, research, and educational purposes, the wording does not always stand up well to the technical rigor of precise legal dissection. By training and inclination, lawyers parse every

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158. Jill S. Levenson & John W. Morin, *Factors Predicting Selection of Sexually Violent Predators for Civil Commitment*, 50 INT'L J. OFFENDER THERAPY & COMPARATIVE CRIMINOLOGY 609, 618 (2006).

159. See Allen Frances, *The Forensic Risks of DSM V and How to Avoid Them*, J. AM. ACAD. PSYCHIATRY & L. 11, 11 (2010).

160. AM. PSYCHIATRIC ASS'N, DIAGNOSTIC AND STATISTICAL MANUAL OF MENTAL DISORDERS, 161 (Am. Psychiatric Ass'n eds., 3rd ed. 1987).

161. AM. PSYCHIATRIC ASSN, DIAGNOSTIC AND STATISTICAL MANUAL OF MENTAL DISORDERS 524, 524-5 (Am. Psychiatric Ass'n eds., 4th ed. 1994).

phrase for meanings never foreseen by those writing primarily for a psychiatric audience.<sup>162</sup>

Though Frances' defense of the persons revising the DSM perhaps exaggerates the "technical rigor of precise legal dissection" to exempt the drafters for responsibility for the ramifications of the wording change, the work groups *are* composed of psychiatrists and researchers rather than legal professionals with knowledge of how various diagnoses may be used or abused in courts. All of the members of the DSM-5 Sexual and Gender Identity Disorders work group either have PhDs in clinical psychology or medical degrees.<sup>163</sup> None have an explicit educational background in law.<sup>164</sup> In the conclusion of this paper, I argue that the APA task force, despite its liability-averting preface, must retain sensitivity to the use of the DSM in legal and other contexts. One small step to cultivating this sensitivity is to include lawyers who are trained in parsing "every phrase" for its legal implications on the Work Groups for disorders that are frequently cited in court cases and legislation.

### E. School Districts

Just as the DSM's usage extends beyond the clinical context and into legal proceedings, the manual is also used by school districts in the determination of special education benefits. The Education for All Handicapped Children Act, passed in 1975, gives an evaluation committee that includes the child's parents, teachers, and qualified professionals the power to determine what educational services are provided to the child under the requirement that every child has the right to a "free and appropriate public education" ("FAPE").<sup>165</sup> In addition, the committee is required to use the diagnostic criteria outlined in the Code of Federal Regulations ("CFR"), rather than the DSM.<sup>166</sup>

States are given the power to determine their own specific special education disability criteria, as long as the categories are more generous than the federal guidelines.<sup>167</sup> As discussed more fully in the next section,

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162. Frances, *supra* note 159, at 11.

163. AM. PSYCHIATRIC ASS'N, *Sexual and Gender Identity Disorders Work Group*, available at <http://www.dsm5.org/meetus/pages/sexualandgenderidentitydisorders.aspx> (2012).

164. *Id.*

165. Education for All Handicapped Children Act of 1975, 20 U.S.C. § 1400.

166. Jaclyn MacFarlane & Tomoe Kanaya, *What Does it Mean to be Autistic? Inter-State Variation in Special Education Criteria for Autism Services*, 18 J. CHILD. & FAM. STUDIES 662, 662 (2009).

167. See Craig J. Newschaffer, Matthew D. Falb, & James G. Gurney, *National Autism Prevalence Trends from United States Special Education Data*, 115 PEDIATRICS e277, e280 (2005) (discussing how although

many states' CFR criteria for autism, for example, are identical to the DSM diagnostic guidelines, Attention-Deficit/Hyperactivity Disorder ("ADHD") often falls under the "other health impaired" category, and the CFR definition of "emotional disturbance" has been discussed with reference to the DSM's Major Depressive Disorder, Antisocial Personality Disorder, and Conduct Disorder.<sup>168</sup> The close interplay between Individuals with Disabilities Education Act ("IDEA") regulations and DSM diagnoses raises the question: what are school districts seeking in DSM diagnoses? I will look at two sets of interests: Deweyan and financial.

The Deweyan interests, loosely named after the educational philosopher, are similar to the clinician's Hippocratic interests. School districts should want the children in that district to succeed, and to the extent that individualized education plans ("IEP") mandated by the IDEA allow that child to flourish, school districts have an interest in DSM diagnoses that help accurately pinpoint children who may suffer from psychiatric issues that require special educational attention. Even if a DSM diagnosis is perhaps too broad and "falsely" diagnoses people whose disturbance lies below the threshold of a *DSM* disorder, it is difficult to see how an IEP will harm a student, except for issues with social exclusion or stigmatization that may stem from observable educational accommodations. If I have some of the symptoms for ADHD, for example, but not enough to meet the DSM's diagnostic threshold, it is possible that an IEP that involves extra time on tests, homework accommodations, and assignments tailored to my preferred learning style will lead to better educational outcomes than a non-tailored plan. As a result, a school's set of Deweyan interests may favor broad diagnostic criteria that err on the side of inclusivity.

Often competing with the Deweyan interest in educational flourishing is a school district's interest in containing educational expenditures to a reasonable level, though it remains ambiguous whether broad or narrow diagnostic categories aid in this cost containment. Special education spending has grown faster than regular education spending since the 1980s, and now represents a large share of district budgets.<sup>169</sup> Though a

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the IDEA provides a standard definition for each disability category, individual states develop their own eligibility criteria).

168. See Carl B. Gacano & Tammy L. Hughes, *Differentiating Emotional Disturbance from Social Maladjustment: Assessing Psychopathy in Aggressive Youth*, 41 *PSYCHOL. SCH.* 849, 849-50 (2004).

169. See generally Hamilton Lankford & James Wyckoff, *Where Has the Money Gone? An Analysis of School District Spending in New York*, 17 *ED. EVALUATION & POL'Y ANALYSIS* 195, 195-218 (1995). See also Todd B. Parrish, *Who's Paying the Rising Cost of Special Education?*, 14 *J. SPECIAL ED LEADERSHIP* 4, 412 (2001).

detailed analysis of the reasons for this increase is beyond the scope of this paper, one group of researchers describes how states' policies of reimbursing a large portion (usually 30-50%) of a school district's special education costs can create a financial incentive for schools to label children "disabled" if they are on the borderline between the two classifications. This occurs because "services delivered to students with a 'disability' label are likely to be either partly or fully reimbursed by the state, whereas the same services given to students without a recognized disability are not."<sup>170</sup> As a result, school districts may face competing financial interests with regard to broad or narrow DSM criteria. Broad criteria may help schools label a child "disabled" and thus receive some state support for specialized education services, yet narrow criteria may help schools avert these expensive services in the first place if parents are unable to obtain a diagnosis that proves that their child requires special accommodations. As the case study of autism in the next section illustrates more concretely, parents have often filed litigation against school districts that refuse to pay for expensive behavioral treatments in the context of special education, showing that financial pressures *do* play a role in shaping schools' interest in DSM diagnostic criteria.

## F. Pharmaceutical Companies

From a purely economic standpoint, pharmaceutical companies have a stake in high prevalence rates for a given disorder. As marketplace agents, they hope to have a large population of potential consumers to whom a given medication can be marketed, and hope that these consumers will require a given medication for a long length of time. Psychotropic drugs represent a sizable source of profit for pharmaceutical companies; antidepressants, for example, are the most commonly prescribed class of drugs and have annual sales exceeding \$9 billion.<sup>171</sup> Though sinister critiques of the role of pharmaceutical companies in supporting broad and vague DSM diagnostic criteria abound,<sup>172</sup> pharmaceutical companies also

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170. Donna L. Terman, Mary B. Lerner, Carol S. Stevenson, & Richard E. Behrman, *Special Education for Students with Disabilities: Analysis and Recommendations*, 6 FUTURE CHILD. 4, 6 (1996).

171. See Mark Olfson & Steven C. Marcus, *National Patterns in Antidepressant Medication Treatment*, 66 ARCHIVES GEN. PSYCHIATRY 848, 848 (2009) (stating that in 2005, anti-depressants became the most commonly prescribed class of medications in office-based and outpatient-based medical practice, surpassing anti-hypertensives); See also IMS HEALTH, *Top Therapeutic Classes by U.S. Sales*, available at [http://www.imshealth.com/deployedfiles/imshealth/Global/Content/StaticFile/Top\\_Line\\_Data/Top%20Therapy%20Classes%20by%20U.S.Sales.pdf](http://www.imshealth.com/deployedfiles/imshealth/Global/Content/StaticFile/Top_Line_Data/Top%20Therapy%20Classes%20by%20U.S.Sales.pdf) (for a description of the amount of U.S. sells of antidepressants).

172. For example, see critiques that the pharmaceutical industry profitably capitalized on broadened criteria for illnesses such as social anxiety disorder; See generally Michelle Cottle, *Selling Shyness*, NEW



have an interest in restricting diagnostic categories to only include those with a pathology that is responsive to pharmacological intervention. With FDA approval contingent upon demonstrated effectiveness data from clinical trials, pharmaceutical companies have an interest in diagnostic categories that appropriately screen out patients who will not exhibit improvement during the clinical trial. For example, as one group of researchers note, citing six separate studies, “the response to antidepressant therapy is greater for patients that are severely depressed at baseline measurement as compared to patients with less severe depression.”<sup>173</sup> To the extent that overly broad diagnostic criteria dilute a treatment’s demonstrated efficacy in a clinical trial patient population, pharmaceutical companies have an interest in more stringent or more accurate diagnostic criteria, an interest that competes with their financial interest in high disease prevalence rates.

The pharmaceutical industry’s interest in stringent criteria for the sake of approval, however, may be weakened by two developments in pharmaceutical prescribing and marketing. First, health services research shows that many patients who lack a DSM diagnosis for which antidepressants are FDA-approved nevertheless receive prescriptions for antidepressants, indicating that although pharmaceutical companies may need persons with severe enough disorders to respond to treatment for the purpose of clinical trials, a broad range of persons may take the drug post-approval.<sup>174</sup> Therefore, pharmaceutical companies could perhaps construct clinical trial inclusion criteria that both require participants to have a DSM diagnosis and require them to exhibit a certain disease severity level; then, post-approval, market the drug to everyone with the disorder regardless of severity. Second, and bolstering the first development, are recent changes to the regulation of pharmaceutical “off-label” marketing. In 2012, a U.S. appeals court ruling stated that the government cannot prosecute pharmaceutical manufacturers and their representatives for speech promoting the lawful, off-label use of an FDA approved drug.<sup>175</sup> This ruling may further undermine a pharmaceutical company’s interest in accurate diagnostic criteria—as long as a drug works well enough to be

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REPUBLIC (Aug. 2, 1999) at 24-9.; See also HORWITZ, *supra* note 39, at 211-2.

173. Arif Khan, Amritha Bhat, James Faucett, Russell Kolts, & Walter A. Brown, *Antidepressant-placebo Differences in 16 Clinical Trials over 10 Years at a Single Site: Role of Baseline Severity*, 214 PSYCHOPHARMACOLOGY 961, 962 (2011).

174. See generally Ramin Mojtabai & Mark Olfson, *Proportion of Antidepressants Prescribed without a Psychiatric Diagnosis is Growing*, 30 HEALTH AFF. 1434, 1436-8 (2011).

175. U.S. v. Caronia, No. 09-5006-cr (2nd Cir, Dec. 3, 2012). For a discussion of the ruling on off-label marketing, see generally Marcia M. Bournil, *Off-label Marketing and the First Amendment*, 368 NEW ENG. J. MED. 103, 103-5 (2013).

approved for one psychiatric (or other) indication, it can be marketed for a wide array of disorders.

### G. Third-Party Payers

Third-party payers, by contrast, have a financial interest in a healthy population pool that invests in generous health insurance but rarely utilizes expensive medical services. While insurance companies maligned the DSM in the 1960s and 1970s as a voracious consumer of insurance dollars, mental health care is no longer an expensive and budget-draining medical expenditure compared to other medical services and technologies.<sup>176</sup> As a result, private insurers do not have a pressing financial interest in more restrictive diagnostic categories, though, as discussed in the next section, private insurers *have* been reluctant to cover extremely expensive behavioral therapies for autism.

The private insurance data is perhaps skewed, however, by the large number of mentally ill patients who are either uninsured or receive healthcare through Medicaid.<sup>177</sup> This data suggests that state and federal governments have a more pressing financial incentive to support more narrow DSM diagnostic categories that exclude patients from reimbursement, while private insurers face less financial pressure due to their smaller proportion of mentally ill beneficiaries.

## III. AUTISM CASE STUDY

In the previous section of this paper, I illustrated the heterogeneity of stakeholder interests in DSM diagnostic categories. These heterogeneous interests highlight the DSM's power across a broad array of domains. The manual guides clinical care, impedes or facilitates biomedical investigation into the etiology of psychiatric disturbance, determines patient's out-of-pocket health care costs by aiding in insurance reimbursement, enables

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176. One study of private insurers found that behavioral health expenditures, including expenditures for psychiatric drugs, constituted only 5.2% of all health expenditures in the sample. Expenditures on behavioral health contributed to only .3% of the growth in total health care spending. See generally Tami L. Mark, Rita Vandivort-Warren, & Kay Miller, *Mental Health Spending by Private Insurance: Implications for the Mental Health Parity and Addiction Equity Act*, 63 PSYCHIATRIC SERVICES 313, 315-6 (2012).

177. See generally Rachel L. Garfield et al., *The Impact of National Health Care Reform on Adults With Severe Mental Disorders*, 168 AM. J. PSYCHIATRY 486, 490 (2011). The study finds that, "because they are more likely to meet the income eligibility criteria (because of low income) and categorical requirements for coverage (because of mental health-related disability), nonelderly adults with mental disorders are over three times more likely than those without to be covered by Medicaid." Therefore, it seems that Medicaid has a higher proportion of persons with mental illness than private insurance for multiple reasons: mental illness is associated with low income levels *and* mental illness can help a person qualify for disability benefits that then make him or her Medicaid eligible.

disease communities to coalesce around a shared diagnosis, is referenced in thousands of court cases, affects special education criteria and expenditures, and contributes to pharmaceutical profits. My aim in this section is to bring into focus the sometimes dramatic clash of these interests through a case study of the DSM-5's proposed changes to autism spectrum disorder ("ASD"). In choosing autism as a case through which to highlight the different interests that stakeholders bring to psychiatric classification, I chose a case that acutely highlights the clashes between different interests and for which the clashes have received large amounts of public attention. It is important to note that my selection of the autism case has two methodological limitations: first, autism is a DSM disorder that has provoked significant public controversy, both regarding its etiology (e.g. genetics, environmental exposures, vaccines) and its degree of improvability; therefore, the stakeholder conflicts for autism are perhaps more pronounced than for other disorders because of its contested nature. Second, is the fact that as a developmental disorder, autism implicates a unique constellation of stakeholder interests—parents, school districts, insurers due to the expensive nature of behavioral treatment—that are different than the unique constellation that another DSM disorder may implicate.

With these methodological limitations noted, I believe the case study has import for highlighting clashes of interests in diagnoses beyond autism. I begin with an overview of the proposed changes and controversy and then discuss the way in which the main stakeholders in the conflict—clinicians and patients' families—invoke the notion of "patient benefit" to justify opposing positions.

### **A. Evolution of DSM Autism Diagnosis and Proposed Changes**

The measured prevalence of autism spectrum disorder (ASD) has increased dramatically in recent decades: a recent report by the Centers for Disease Control and Prevention (CDC) estimates that one in eighty-eight children in the U.S. has been identified with autism spectrum disorder, a 23% increase since 2009 and 78% increase since 2007.<sup>178</sup> Researchers have

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178. Center for Disease Control & Prevention, *Why Are Autism Spectrum Disorders Increasing*, at <http://www.cdc.gov/Features/AutismPrevalence/>. However, scholars debate about whether the increase in *measured* prevalence reflects an increase in actual prevalence, pointing to the broadening of *DSM* criteria for the disorder and the introduction of autism as a reporting category under the Individuals with Disabilities Education Act ("IDEA"). See Morton A. Gernsbacher, Michelle Dawson, & H. Hill Goldsmith, *Three Reasons Not to Believe in an Autism Epidemic*, 14 *CURRENT DIRECTIONS PSYCHOL. SCI.* 55, 55-8 (2005).

failed to find a specific cause that accounts for the dramatic increase.<sup>179</sup> As a result, the CDC is careful to note that although the reasons for the increase in the identified prevalence of ASD are not completely understood, “some of the increase is due to the way children are identified, diagnosed, and served in their local communities, although exactly how much is due to these factors is unknown. Also, it is likely that reported increases are explained partly by greater awareness by doctors, teachers, and parents.”<sup>180</sup>

Other researchers have been less cautious than the CDC, asserting that *much* rather than *some* of the increase in identified prevalence stems from the broadening diagnostic criteria between editions of the DSM.<sup>181</sup> Before the DSM-III, autism was often grouped with other developmental disorders labeled “childhood schizophrenia.”<sup>182</sup> The DSM-III included autism, but was focused on the most severely affected individuals, and was “monothetic,” requiring that each potential patient meet every diagnostic requirement.<sup>183</sup> The DSM-III-R introduced a set of “polythetic” criteria, where an individual must meet a certain number of criteria across different diagnostic sub-categories, thereby increasing the inclusiveness of the diagnosis.<sup>184</sup> This inclusiveness increased even further in the DSM-IV and DSM-IV-TR, where the category of Asperger’s disorder was added, thereby including individuals without cognitive disability but with social impairments.<sup>185</sup> Autism is characterized by social delays, language delays, and repetitive or obsessive behavior; Asperger’s is distinguished by later delays in communication and language usage, average or above average intelligence, and obsessive behaviors; Pervasive Developmental Disorder-Not Otherwise Specified (“PDD-NOS”) refers to children who do not meet the criteria for autism because of the late onset of their symptoms or other factors.<sup>186</sup> These categories often end up being associated with different levels of functioning and severity, with autism as the lowest

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179. Center for Disease Control & Prevention, *supra* note 190.

180. *Id.*

181. Gernsbacher, *supra* note 178, at 55-6.

182. James C. McPartland, Brian Reichow, & Fred Volkmar, *Sensitivity and Specificity of Proposed DSM-5 Diagnostic Criteria for Autism Spectrum Disorder*, 51 J. ACAD. CHILD & ADOLESCENT PSYCHIATRY 368, 369 (2012).

183. *Id.* at 369.

184. *Id.* at 369.

185. Mark Bertin, *Understanding the DSM-5 Autism Criteria*, PSYCHOLOGY TODAY (Jan. 30, 2012), at <http://www.psychologytoday.com/blog/child-development-central/201201/understanding-the-dsm-5-autism-criteria>.

186. Marja-Leena Mattila, *Autism Spectrum Disorders According to DSM-IV-TR and Comparison with DSM-5 Draft Criteria: An Epidemiological Study*, 50 J. AM. ACAD. CHILD & ADOLESCENT PSYCHIATRY 583, 583-4 (2011).

functioning/most severe of the three and Asperger's and PDD-NOS as less severe/higher-functioning.

The DSM-5 has proposed collapsing these three sub-categories into a single autism spectrum disorder. A study examining over 900 participants in a DSM-IV autism field trial, some of whom were diagnosed with either autism, Asperger's, or PDD-NOS, found the new criteria to be more restrictive.<sup>187</sup> Only 60% of the previously diagnosed participants met the new diagnostic criteria for the collapsed autism spectrum disorder.<sup>188</sup> The subjects excluded under the new criteria had higher-cognitive functioning and were more likely to previously have a diagnosis of Asperger's or PDD-NOS.<sup>189</sup> The authors argue that the large reduction in the number of individuals who meet criteria for the disorder indicates that the new diagnostic criteria reduces *sensitivity*—the criteria's ability to “pick up” on everyone who has the disorder—while increasing *specificity*: the criteria's ability to correctly exclude individuals from a diagnosis.<sup>190</sup>

In January of 2012, four months before the results were formally published, one of the study's authors, Fred Volkmar, ignited controversy after a preliminary presentation of the results at a meeting of the Icelandic Medical Association.<sup>191</sup> A *New York Times* article declaring that the proposed DSM changes would make it more difficult for individuals to receive a diagnosis was picked up by a variety of general interest news media outlets, underscoring the DSM's transformation from a rarely-used text at the periphery of the psychiatric community to a locus for public discussion and debate about mental illness.<sup>192</sup> In turn, this discussion revealed substantially different conceptions of how “patient benefit” ought to be construed for persons with autism and Asperger's.

## B. Objections to Changes and Three Clashes of Interests

Objections to the proposed changes stemmed from anxieties about the impact the new criteria would have on access to services for patients with autism. The introduction to McPartland and Volkmar's paper explicitly emphasizes the “public health” ramification of the analysis,

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187. McPartland, *supra* note 82 at 368-382.

188. *Id.* at 369.

189. *Id.* at 380.

190. *Id.* at 381.

191. Benedict Carey, *New Definition of Autism Will Exclude Many, Study Suggests*, N.Y. TIMES (Jan. 19, 2012), available at [http://www.nytimes.com/2012/01/20/health/research/new-autism-definition-would-exclude-many-study-suggests.html?\\_r=1](http://www.nytimes.com/2012/01/20/health/research/new-autism-definition-would-exclude-many-study-suggests.html?_r=1).

192. Media covering the proposed changes ranged from *The Huffington Post* to *Biomed Middle East*, with a “Google News” search turning up over 600 articles on the topic.

arguing that “reducing the number of individuals in the general population who meet criteria for ASD could result in lost eligibility for service for individuals who stand to benefit.”<sup>193</sup> In interviews with the media, Volkmar presented the reduced eligibility for services as the study’s alarming and important conclusion, arguing that, “given the potential implications of these findings for service eligibility, our [McPartland, Reichow, and Volkmar] findings offer important information for consideration by the task force finalizing *DSM-5* diagnostic criteria.”<sup>194</sup> Interestingly, only one of the three authors has a research career explicitly focused on the provision of *services* for autism, while the other two researchers conduct more basic investigations into autism’s neurobiology. Despite the researchers’ backgrounds, the study’s “marketing” in the news media was directly targeted at parents as stakeholders. What interests do these parents have and how are they promoted or threatened by certain changes to the DSM category? What interests do other stakeholders have in the autism revisions, and how do these interests coincide and diverge?

In this section, I review three potential clashes between stakeholders discussed in the Part II: parents versus school districts, disease advocacy groups versus insurance companies, and parents versus their children with autism. In highlighting each of these clashes, I show the interests that are at stake and the way the DSM stands at the nexus of these different interests.

### 1. Parents and School Districts

As discussed, the IDEA grants an individual state the authority to create its own eligibility criteria for autism special education as long as this meets or exceeds the minimal requirements set forth in the federal disability category of “autism.”<sup>195</sup> Because states are allowed to define their own criteria for autism-related special education eligibility, there is significant inter-state variation in the criteria for receiving autism-related special educational benefits.<sup>196</sup> Researchers have documented this extensive variation, illustrating the some states simply copy the federal criteria for autism, others copy the DSM-IV-TR criteria, and others use a

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193. McPartland, *supra* note 182, at 370.

194. Karen N. Peart, *Autism Redefined: Yale Researchers Study Impact of Proposed Diagnostic Criteria*, YALE NEWS (Jan. 20, 2012), available at <http://news.yale.edu/2012/01/20/autism-redefined-yale-researchers-study-impact-proposed-diagnostic-criteria>.

195. Newschaffer, Falb, & Gurney *supra* note 167 at e280 (discussing how for autism, state special education eligibility criteria may or may not include higher-functioning children on the autism spectrum).

196. See generally MacFarlane & Kanaya, *supra* note 166.

mix of both.<sup>197</sup> Furthermore, some states include students with Asperger's as special education eligible and others do not.<sup>198</sup> An important distinction between the federal disability criteria and DSM criteria is that the former explicitly emphasizes impairment in educational functioning while the latter does not, yet the prevalence of states that simply copy the DSM criteria to determine eligibility indicates that many states fail to distinguish between the two types of diagnostic constructs. Therefore, a change to DSM restrictiveness is likely to have a reverberating impact on special education eligibility.

The clash between parents as stakeholders in DSM categories and school districts' special education service provision is highlighted through the large amount of litigation filed by parents dissatisfied with their school district's services.<sup>199</sup> Many courts have ruled that school districts are not required to provide Applied Behavior Analysis, an expensive therapy for autism that can cost over \$30,000 per year,<sup>200</sup> as long as the school covers an alternative program that gives the child *some* meaningful benefit.<sup>201</sup> Despite these less than successful outcomes for parents, the frequency of autism court cases increased steadily in five-year increments from 1981-2000.<sup>202</sup>

Perry Zirkel has examined whether this increase in the frequency of litigation is merely a byproduct of autism's increased prevalence, or whether autism occupies a disproportionate amount of special education litigation relative to the condition's frequency. Zirkel finds that autism cases account for approximately one-third of court decisions related to special education, despite autistic students only composing one-tenth of special education enrollees, and that the proportion of autism cases in litigation has been markedly higher than the proportion of autistic students enrolling in special education that same year.<sup>203</sup> In explaining this disproportionality, Zirkel points to the economic costs of providing special education services for an autistic child and the heterogeneity of children

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197. See generally MacFarlane & Kanaya, *supra* note 166.

198. MacFarlane & Kanaya, *supra* note 166, at 662-669.

199. See generally Perry A. Zirkel, *Autism Litigation Under the IDEA: A New Meaning of 'Disproportionality'?*, 24 J. SPECIAL EDUC. LEADERSHIP 92, 92 (2011).

200. See Deanna L. Sharp & Dana L. Baker, *Financial Issues Associated with Having a Child with Autism*, 28 J. FAM. & ECON. ISSUES, 247, 251 (2007).

201. See Sheryl Dicker & Emily Bennett, *Engulfed by the Spectrum: The Impact of Autism Spectrum Disorders on Law and Policy*, 45 VAL. U. L. REV. 415, 426 (2011). Dicker and Bennett argue that the precedent for the "some meaningful benefit" requirement and other similar cases is the 1982 Supreme Court's *Rowley v. Hendrick*, which argued that a school district does *not* need to "maximize" a child's learning but instead needs to offer a program that provides the child with some educational benefit.

202. Zirkel, *supra* note 199, at 93.

203. *Id.* at 93.

diagnosed with autism, which creates difficulty in interpreting which interventions will produce *any* benefit for a given child.<sup>204</sup>

Zirkel's research points to two conflicting parental interests in the construction of the autism diagnostic categories with regards to special education. First, parents may seek a diagnostic category that is as broad as possible, for the absence of an autism diagnosis makes it difficult to obtain special education support due to many states' de facto linking of the two constructs. Yet the inclusiveness and heterogeneity of the diagnostic category perhaps impedes more conclusive research into effective autism interventions. In turn, this scientific uncertainty about the etiology and treatment for autism may make it more challenging for parents seeking special education services, since the benefits of many treatments remain unproven.<sup>205</sup> Parents concerns about the contraction of the DSM autism diagnosis, and the impact of this contraction on their abilities to successfully pressure school districts to provide expensive special education services, is one clash of stakeholder interests that the DSM changes implicate.

## 2. Disease Advocacy Groups and Insurance Companies

Facing the enormous budgetary burden of providing in-school services for children with autism, school districts have argued that autism is a *medical* rather than education-related disorder and that services should be conducted out of school and covered through medical insurance. Yet health care expenditures for children with autism are estimated at between three to ten times those of other children and insurers have resisted the burden of responsibility for these expenditures.<sup>206</sup> Both private and public insurers have argued that behavioral therapies for autism are either experimental or should be a part of special education services.<sup>207</sup> Insurers' reluctance to cover autism therapies has brought the industry into contact with another force affecting DSM development: disease-related advocacy groups.

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204. *Id.* at 93.

205. Meanwhile, amidst this scientific uncertainty, school districts are straining to provide these services. For example, one court case estimated the cost of a preschool educational program for a child with autism at \$50,000, which made up one-eighth of the district's entire yearly budget for all students in all preschools in the district. Zirkel, *supra* note 199, at 97.

206. See Stacy K. Dymond, Christie L. Gilson, & Steve Myran, *Services for Children With Autism Spectrum Disorders: What Needs to Change?* 18 J. DISABIL. POLICY STUD. 133, 142 (discusses how in interviews with parents of children with autism, the parents describe how insurance companies refuse to pay for services because the treatment was considered educational in nature rather than medical. Some parents suggested changing autism's disease designation to a "neurological disorder" rather than a developmental disorder to increase insurance support for autism services).

207. Dicker & Bennett, *supra* note 201, at 448-449.



*Autism Speaks* is the most prominent autism advocacy group, and was formed from a merger of the National Alliance for Autism Research (“NAAR”) and Cure Autism Now (“CAN”) in February of 2005.<sup>208</sup> Before 2005, only one state—Indiana—had passed legislation mandating private insurance coverage for autism services, but from 2007 to the beginning of 2012, twenty-nine additional states passed autism insurance reform laws.<sup>209</sup> In addition, *Autism Speaks* has carefully tracked the DSM revision process, with official letters from the organization voicing concern that the proposed revision may discriminate against persons living with autism.<sup>210</sup> Following the April publication of Volkmar’s results, *Autism Speaks* argued that since the findings were worrisome for members of its organization, it has funded its own study into the proposed DSM changes to help verify or expand upon the results.<sup>211</sup>

Autism Speaks’ concern about the diagnostic changes was partially tied to its success in conflicts with insurance companies over coverage of autism treatment through its passage of state insurance mandates. The DSM diagnosis is the tool that the disease advocacy group drew upon in demands for legislation that mandates insurance coverage for expensive autism-related services and the legislation often specifically states that the child must meet the DSM criteria for autism.<sup>212</sup> As the DSM revisions

208. Jennifer Singh et al., *Trends in US autism research funding*, 39 J. AUTISM & DEV. DISORDERS 788-95 (2009).

209. See Autism Votes, Autism Speaks State Autism Insurance Reform Initiatives, at [http://www.autismvotes.org/site/c.frKNI3PCImE/b.3909861/k.B9DF/State\\_Initiatives.htm](http://www.autismvotes.org/site/c.frKNI3PCImE/b.3909861/k.B9DF/State_Initiatives.htm). However, these mandates may not cover a substantial portion of persons with private insurance due to the Employee Retirement Income Security Act (“ERISA”) of 1973, which exempts self-insured plans from state insurance benefits legislation. Though the amount of firms within a state that self-insures varies by area, the Kaiser Family Foundation estimated in 2000 that between 33% and 50% of employees in the U.S. are exempt from state-level mandates due to 1974’s Employee Retirement Income Security Act. See Susan H. Busch & Colleen L. Barry, *New Evidence on the Effects of State Mental Health Mandates*, 45 INQUIRY 308, 311 (2008). At the federal level, the passage of the Affordable Care Act and the Department of Health and Human Services’ recent announcement has led to new advocacy efforts. HHS granted individual states the authority to define their own essential health benefits (“EHB”) using one of four benchmark plan types, which has led Autism Speaks and its sister organization, Autism Votes, to focus lobbying efforts on ensuring that expensive behavioral health treatments for autism will be included within states’ EHB definitions. See Letter from Mike Doyle, U.S. Congressman, to Kathleen Sebelius, Jan. 12, 2012, available at <http://doyle.house.gov/2012%2001%2012%20ABA%20Coverage%20to%20HHS%20vert.pdf>.

210. AUTISM SPEAKS, *Autism Speaks Statement on Proposed Revisions to the DSM Definition of Autism Spectrum Disorder* (Feb. 2, 2012), at <http://www.autismspeaks.org/science/policy-statements/statement-revisions-dsm-definition-autism-spectrum-disorder>

211. Autism Speaks pointed out that Volkmar’s study only analyzed clinical data, while their newly-funded study will also look at community prevalence rates.

212. For example, Connecticut’s statute specifies that it applies that “autism spectrum disorders,” “means the pervasive developmental disorders set forth in the most recent edition of the American Psychiatric Association’s ‘Diagnostic and Statistical Manual of Mental Disorders,’ including, but not limited to, Autistic Disorder, Rett’s Disorder, Childhood Disintegrative Disorder, Asperger’s Disorder and Pervasive Developmental Disorder Not Otherwise Specified.” See An Act Concerning Health Insurance Coverage For Autism Spectrum Disorders, CONN. GEN. STAT. § 38a-514b (as amended by S.B. 301 (2009)).

threatened to reduce the number of persons who met the diagnosis of autism, it also threatened the political work of disease advocacy groups in successfully mandating certain forms of insurance coverage for the disorder.

### 3. Parents and Children

The proposed changes and possibly exclusion of persons with Asperger's from the spectrum has also highlighted clashes between the patients and their parents. *Autism Speak's* website features a story, "Mixed Emotions," showcasing the mixed reactions to the proposed DSM changes. Wills, a 14-year-old with Asperger's, says that to be considered "not autistic, simply overjoys me."<sup>213</sup> He describes, "When I saw Brian Williams say that 'Aspergers might not be considered autism,' I jumped for joy along with everyone with Aspergers, I assume."<sup>214</sup> Yet others with Asperger's were less overjoyed, calling the proposed changes "unfairly stringent" and mourning the loss of the "pride of self-identity" within the Asperger's community.<sup>215</sup> These patients argued that the identity has "definite value" in creating a community, regardless of whether or not the diagnosis aids in service provision.<sup>216</sup>

Meanwhile, the response from parents appears far less equivocal, at least as revealed in statements to media outlets and in blog posts.<sup>217</sup> Wills' mother was far from overjoyed at the changes, describing the proposed category as "heartbreaking." She argues that if the category had been restricted when Wills was younger, "he would not have received the services that have been instrumental in his improvement . . . . My worry is that children like Wills will no longer be eligible for the services he received—the very services that gave him a chance at living his life as a relaxed person, fully integrated into society."<sup>218</sup> In these instances, we see the different interpretations of the DSM category between patients versus their caregivers. Patients are often focused on the DSM diagnosis as an identity that is either stigmatizing or provides an entrée into a welcome

213. Monica Hallway, *A Mother's and Son Response to the DSM-5 Change*, AUTISM SPEAKS BLOG (Feb. 2, 2012), at <http://blog.autismspeaks.org/2012/02/02/mixed-emotions-a-mother-and-son-response-to-the-dsm-5-change/>.

214. *Id.*

215. Dania Jekel, *Letter To The AANE Asperger Community In Response To The Recent DSM-5 News*, ASPERGER'S ASSOC. OF NEW ENGLAND, available at [http://www.aane.org/about\\_asperger\\_syndrome/dsm5\\_letter.html](http://www.aane.org/about_asperger_syndrome/dsm5_letter.html)

216. Jean W. Gardner, *Revised DSM Criteria for Autism Raises Questions*, WASH. POST (Jan. 29, 2011), at <http://communities.washingtontimes.com/neighborhood/autism-unexpected/2011/jan/29/revised-DSM-criteria-autism-raise-questions/>.

217. This is admittedly a self-selecting sample.

218. Hallway, *supra* note 213.

community. In contrast, parents are more explicitly focused on the economic burden of treatment for the condition and anxiety about the loss of service provision.

This conflict can manifest itself not only in response to the diagnostic changes themselves, but to areas of service provision that the changes impact. For example, although special education litigation often assumes that the parents' preferences for an IEP represent the best interests of the child,<sup>219</sup> especially for IEPs that involve conspicuous alteration of activities or placement in a different classroom setting, children with autism may resent the IEP services that hinge on their diagnosis while parents may welcome these services. In this sense, the autism case study illustrates the way in which parental and child interests with respect to psychiatric diagnostic changes can diverge.

### C. The APA's Avoidance of "Pragmatic" Concerns

Just as those within the "Aspie" community remain divided on the proposed changes, the study on the change's potential impact on prevalence rates has created public polarization within the autism clinician and researcher community. The journal that published the Volkmar study also published a defense of the proposed changes from the DSM Neurodevelopmental Disorders Work Group. In a commentary, the Work Group condemns the "attention-getting media" that preceded the study's publication and criticized the study itself as suffering from serious methodological flaws.<sup>220</sup>

The DSM Work Group pointedly rebutted the accusation that the change to autism's criteria was motivated by a desire to reduce inflated prevalence statistics, instead arguing that the new criteria would lead to an *increase* in the identified prevalence of autism among girls and racial and ethnic minorities.<sup>221</sup> The commentary emphasized the amount of time

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219. See Ralph D. Mawdsley and Jacqueline J. Cumming, *Students' Rights and Parents' Rights: A United States Perspective of the Emerging Conflict Between Them and the Implications for Education*, 10 AUSTRALIA & NEW ZEALAND J. OF L & EDUC. 19, 25 (2005) (arguing that courts tend to assume that parents represent the best interests of their children during special education meetings and litigation).

220. Susan Swedo et al., *Commentary from the DSM-5 Workgroup on Neurodevelopmental Disorders*, 51 J.ACAD.CHILD & ADOLESCENT PSYCHIATRY, 347 (2012). The authors argue that it is methodologically unsound to take an archival sample from the *DSM-IV* field trials and attempt to apply the new diagnostic criteria to this sample. Furthermore, they argue that the researchers falsely elevate the *DSM-IV* criteria to a "gold standard" of diagnosis, ignoring the criteria's issues in diagnosing persons outside the 5 to 8-year old age range.

221. *Id.* at 348 (arguing that the *DSM-IV* autism criteria "demonstrated deficits in their ability to accurately identify girls and women with autism and lacked the cultural sensitivity needed to identify cases in ethnic or racial minorities." The Work Group also argued that one of their chief questions when revision the criteria was whether they were "accidentally excluding any patients," highlighting that the Work Group

devoted to constructing the criteria, five years and 6,000 hours of in-person meetings and teleconferences, and contended that all the deliberations were guided by the Hippocratic clinician interest I discussed in the previous section. The changes are rooted in, “our clinical mandate to ‘first do no harm,’ so that every decision was considered from multiple perspectives to determine: ‘how will this decision impact individuals with ASD? ‘Are we accidentally excluding any patients?’ And ‘Have we ensured that the change is an improvement over DSM-5?’”<sup>222</sup> The Work Group members maintained that their most important question was, “Have we succeeded in accurately capturing all individuals with ASD with the diagnostic criteria proposed for DSM-5?”<sup>223</sup> Thus, the APA’s commentary deliberately emphasizes the clinical benefit of the new diagnosis rather than the benefits for systematic research investigations into the disorder’s etiology and treatment.

The Work Group’s explicit framing of the changes as guided by the organization’s clinical mission guiding the changes rather than the desire to construct a more scientifically valid category is somewhat unexpected and differs from the APA’s framing of the changes in other contexts. In other forums and publications, the changes have often been justified with reference to *both* clinical and scientific concerns. For example, the Work Group’s website stated that one (out of two) rationale for the changes is that a single spectrum disorder is a “better reflection of the state of knowledge about pathology.”<sup>224</sup> This state of knowledge includes a meta-analysis showing differences in gray matter volume in autistic spectrum patients when compared to healthy controls, but no differences between patients within the spectrum diagnosed with autism versus Asperger’s.<sup>225</sup> Another meta-analysis, reviewing twenty-four studies, showed the lack of distinction between patients with autism and patients with Asperger’s in terms of familial transmission, executive functioning, and language

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was not trying to reduce the identified prevalence of autism but to make the autism diagnosis better suited to the symptom profile of a more diverse range of patients).

222. *Id.* at 348.

223. *Id.* at 348.

224. The original rationale was published under the title. Am. Psychiatric Ass’n, *A 09 Autism Spectrum Disorder: Rationale* (2012), at <http://www.dsm5.org/ProposedRevisions/Pages/proposedrevision.aspx?rid=94#>. However, following the public commenting period, the Work Group’s rationale was removed from the DSM-5 website. A summary and explanation of this now electronically-inaccessible rationale can be found at Natalie Berger, *Proposed DSM-5 Changes to Autism Spectrum Disorders Diagnosis* (2012), at [http://www.macmh.org/C\\_Waiver\\_2012/Handouts/32%20DSM5%20Changes%20to%20ASD%20Diagnosis.pdf](http://www.macmh.org/C_Waiver_2012/Handouts/32%20DSM5%20Changes%20to%20ASD%20Diagnosis.pdf).

225. See generally Esther Via et al., *Meta-Analysis Of Gray Matter Abnormalities In Autism Spectrum Disorder: Should Asperger Disorder Be Subsumed Under A Broader Umbrella Of Autistic Spectrum Disorder?*, 68 ARCHIVES GEN. PSYCHIATRY 409, 409-418 (2011).

ability.<sup>226</sup> The Work Group, by drawing on the clinical language of the Hippocratic oath rather than the empirical language of these meta-analyses in its public attempts to quell outcry over proposed changes, deliberately presents the DSM changes as motivated by concern for helping the patient improve. The group aligns itself with parents concerned with recovery rather than researchers seeking a better DSM reflection of the current state of autism research.

The task force's commentary illustrates the malleability of "patient benefit" in the hands of different stakeholders. Volkmar and parent advocacy groups define patient benefit in terms of diagnoses that err on the side of inclusivity, linking patient benefit to insurance reimbursement and special education eligibility. "Higher-functioning" patients who may be excluded from a diagnosis under the new criteria are bitterly divided; some construe "patient benefit" as the escape from a stigmatizing DSM label while others welcome this label for the identity it provides and the community it creates. Members of the APA publicize different notions of "patient benefit" in different forums; in some public statements, the APA defines "patient benefit" with sole reference to improved clinical outcomes; in other public statements, the APA also references the importance of diagnostic constructs better reflecting the scientific consensus about the lack of an empirically-based distinction between the three autistic disorders.

#### **IV. GOING FORWARD: TOWARD A MORE "IMPURE" MANUAL**

At first glance, these distinct definitions of "patient benefit" appear incommensurable. How can a DSM that is appropriated for such a heterogeneous array of stakeholder aims mediate between the inevitable conflicts that arise? In this section, I suggest two improvements to the process of DSM development. Each of these improvements is aimed at acknowledging the social forces that shape the DSM, while preventing these forces from overwhelming the manual's focus on diagnostic criteria useful for clinicians.

##### **A. Diversity and Representation**

The first suggestion is for a more explicit acknowledgment of what I referred to in the introduction as the DSM's "impurity": the influence of

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226. See generally Andrea N. Witwer & Luc Lecavalier, *Examining The Validity Of Autism Spectrum Disorder Subtypes*, 38 J. AUTISM & DEV. DISORDERS, 1611, 1611-24 (2008).

economic, social, and other non-clinical forces on the manual and the way in which the manual is used in a diverse array of non-clinical contexts. While the APA's overarching priority during the development process should be on the manual's clinical utility, there is one small step the APA can take to acknowledge these other contexts: create more diverse DSM Work Groups. Though the APA is a professional organization largely composed of psychiatrists and some clinical psychologists, the manual has clearly evolved beyond its status as a niche, professional publication solely used by this narrow demographic. While the Work Groups should remain largely composed of APA members, for disorders that are especially salient to legal proceedings or educational outcomes, the Work Group should contain members who are representative of these interests. For example, paraphilic disorders and personality disorders are often referenced in legal proceedings. A Work Group's inclusion of a lawyer trained to dissect how the precise wording of a diagnosis may be used in litigation can help avoid costly errors such as the DSM-IV's harmful change to the wording of sexual disorders. Similarly, the Work Groups for developmental disorders that are referenced in the provision of special education benefits should include lawyers or education policy analysts familiar with the aims of the IDEA and litigation advancing those aims.<sup>227</sup>

My proposal to expand Work Groups to include one to two representatives who are aware of certain non-clinical impacts of DSM revisions faces three challenges. First is that because psychiatrists who view the diagnostic changes in light of their clinical and research impacts will outnumber other representatives, the perspectives of these other representatives may not prevail over the research and clinical perspectives in the case of conflict. While this challenge is valid, I argue that the DSM, as a document that is used first and foremost to guide clinical practice, *should* give greater weight to psychiatrist perspectives. Furthermore, there are likely to be cases where the perspective of a non-psychiatrist—for example, an education policy analyst commenting on special education uses of a DSM developmental disorder—will align with the clinician's interest in improving patient suffering and will thus provide additional insight into category construction rather than a perspective that sharply dissents from that of a clinician-researcher. The second challenge is the risk that stakeholder participation will be “tokenistic” rather than substantive, with persons being included in name but marginalized in the

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227. In addition, I am purposely excluding private sector agents from inclusion on the Work Groups because of the ways in which their obligations to their shareholders may conflict with their obligations to improve patient benefit.

discussion and revision process. While this implementation challenge is valid, it seems premature to argue that because these other representatives may face difficulty having their perspectives incorporated into revision outcomes, that these representatives should not be included at all. Instead, representatives should be included with efforts at encouraging a substantive rather than tokenistic contribution. The third challenge is that the psychiatrist members of the APA may view the inclusion of other perspectives as a threat to their professional and/or scientific legitimacy; in other words, it may challenge psychiatrists' views of themselves as the type of professional with the knowledge and the authority to address mental illness. However, my proposal explicitly aims to include professionals who add insight into uses of DSM diagnoses that *do not* fall under psychiatry's professional purview, such as legal perspectives about how changes will be interpreted in the adversarial setting of criminal prosecution or educational perspectives about the use of diagnoses in special education. Therefore, the inclusion of these other perspectives seems to supplement rather than challenge psychiatry's professional and scientific legitimacy.

With these challenges in mind, I maintain that the APA should move forward from its current Work Groups, fairly homogeneously composed of well-respected psychiatric researchers and researcher-clinicians, to at least some inclusion of other professional perspectives. Since patient outcomes for DSM categories such as sexual and developmental disorders are often tied to non-clinical interests and contexts (legal proceedings, special education eligibility), the task force's interest in "clinical utility" and patient well-being supports the modest inclusion of these perspectives.

### **B. Publicity of Reasons**

The second improvement to the DSM revision process would be better articulation by the task force of how carefully constructed diagnoses are likely in the patients' long-term interests. The controversy over the possible restriction of the autism diagnosis illustrates that many patients and patient advocacy groups are often fixated on the short-term ramifications of diagnostic changes. Families are rightfully worried about the immediate financial impact of "losing" a diagnosis, but less concerned with the long-term viability of research into the pathology of a given disorder. While some research may never translate into improved clinical outcomes, other research will ultimately lead to better treatment for patients, though this translation is certainly far from immediate. Many patient advocates have vilified the task force for "restricting" the autism

diagnostic category, yet few have stopped to ask whether the vagueness and inconsistency of the current diagnostic category has impeded researchers' search for more effective therapeutic interventions. Though it may be unrealistic to persuade patients and other stakeholders to postpone their short-term anxieties about diagnostic changes for the sake of far-off and uncertain improvements in research, the task force should try to publicly articulate the importance of these long-term aims for better treatment for existing and future generations. Publicity of the reasons behind DSM decisions—in other words, opening up the “black box” of deliberation about proposed revisions—can have two effects. First, forcing Work Groups to publicize their rationales for changes can increase their motivation to root these changes in reasons that patients and the public find justifiable. Second, those who rely on the manual and its categories for various social services can understand the theoretical and long-term motivations behind manual changes.

The revision process for the DSM-5, which debuted on May 17, 2013, the APA appears to be taking two important steps that begin to incorporate my suggested improvements. First, the creation of a public commenting period allows some degree of diversity in influence on the manual if not at the influential level of Work Group membership. Second, the online publication of the rationale for the proposed changes to the manual has led to open critique and debate about whether the changes are made for reasons that are acceptable to those affected, such as the debates over the rationale for changes to the autism category and debates about whether the proposed inclusion of a risk syndrome for schizophrenia was driven by adequate scientific support for schizophrenia prevention or by pharmaceutical marketing interests. To improve this process of publicizing reasons for changes and incorporating feedback in future revisions, the DSM should increase the transparency of the public commenting process even further. During the DSM-5's public commenting process, there was no public record of the comments submitted and no publicly available statements or transcripts of how a Work Group incorporated a given set of comments. To improve the transparency of this public commenting process, the APA could borrow some of the methods used in the notice and comment step of federal agencies' rule-making process.<sup>228</sup> When the public offers comments on a proposed rule by a federal agency, these comments are made publicly available so that persons can analyze the

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228. For a description of this process, see Susan W. Yackee, *Sweet-talking the Fourth Branch: The Influence of Interest Group Comments on Federal Agency Rulemaking*, 16 J. PUBL. ADM. RES. THEOR. 103, 104 (2005) (describing how during the notice and comment period of federal agency rulemaking, any individual or group can provide written comments regarding an agency's proposed rule).



effect the public comments had, if any, on the final outcome of the proposed rule.<sup>229</sup> The APA has taken the first step of soliciting public comments. For future revisions, it should make this process more robust and allow public access to the submitted comments so persons can measure the impact of these comments on the outcome of DSM revisions.

Despite this limitation, part I has highlighted the DSM's pronounced shift from its original, closed-doors gestation. Its framers have begun to incorporate elements of inclusivity and accountability that are necessary for the manual's continued legitimacy among its many diverse stakeholders.

### CONCLUSION

The APA has begun to realize that the DSM is far from a "pure" document that ought to be shielded from social scrutiny by the general public and other stakeholders. Inclusion of a more heterogeneous array of stakeholders in the manual's revision process coupled with a reiteration of the manual's long-term aims, are important steps in the evolution of the DSM's self-depiction. The DSM is no longer thought of as a document handed down from scientific forces to the general public every five to thirteen years, representing a "victory of science over ideology."<sup>230</sup> Instead, the APA is beginning to open up its categories to public scrutiny and critique, a move that has spawned public criticism of many proposed revisions but that arguably leads to greater public legitimacy for changes to the DSM.

As the DSM continues to evolve, it remains to be seen whether the manual can accommodate the diversity of interests discussed in this article or whether the manual will cede ground to new systems of classification that are more closely tailored to the needs of different stakeholders. For example, the National Institutes of Mental Health has begun a project on "Research domain criteria" ("RDoC"), which will enable researchers to investigate broad constructs such as fear response or executive control rather than constraining themselves to a single DSM diagnosis.<sup>231</sup> Will these criteria have a reverberating impact across multiple contexts—for example, the emergence of expert testimony about a defendant's RDoC impulsivity rating rather than his or her DSM antisocial personality

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229. For an example of this scholarly analysis of how public comments impacted the outcome of a proposed agency rule, see *Id.* at 112-113.

230. Sabshin, *supra* note 64, at 1272.

231. See generally Thomas Insel et al., *Research Domain Criteria (RDoC): Toward a New Classification Framework for Research on Mental Disorders*, 167 AM. J. PSYCHIATRY, 748-751 (2010).

disorder diagnosis—and therefore face similar issues as the current DSM? The answer to this question remains to be seen. In this article, however, I have highlighted the importance of inquiring into these “impure” applications of the DSM.

