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The Ethical Boundaries of Patient and Advocate Influence on DSM-5

Rebecca A. Johnson, MA, Marna S. Barrett, PhD, and Dominic A. Sisti, PhD

This article discusses the relationship between disease-advocacy groups and the revision process for the *Diagnostic and Statistical Manual of Mental Disorders*. We discuss three examples in which patient-advocacy groups engaged with the DSM-5 revision process: Autism Speaks' worries about the contraction of the autism diagnostic category, the National Alliance on Mental Illness's support for the inclusion of psychosis risk syndrome, and B4U-ACT's critique of the expansion of pedophilia. After a descriptive examination of the cases, we address two prescriptive questions. First, what is the ethical basis for patient and advocate influence on DSM diagnoses? Second, how should the American Psychiatric Association proceed when this influence comes into conflict with other goals of the revision process? We argue that the social effects of, and values embedded in, psychiatric classification, combined with patient and advocates' experiential knowledge about those aspects of diagnosis, ethically justify advocate influence in relation to those particular matters. However, this advocate influence ought to have limits, which we briefly explore. Our discussion has implications for discussions of disease categories as loci for social movements, for analyses of the expanding range of processes and institutions that advocacy groups target, and for broader questions regarding the aims of the DSM revision process.

Keywords: Diagnostic and Statistical Manual of Mental Disorders, ethics, mental disorders, patient advocacy, social stigma

As the U.S. health care system moves toward a model of research and care in which patients shape patient-centered outcome measures for clinical trials,¹ influence patient-centered styles of shared decision making with physicians,² and give feedback on comparative effectiveness research projects funded by the new Patient-Centered Outcomes Research Institute,³ the appropriate boundaries of patient-centeredness merit examination. Several ethical principles underlie the reasons why patient influence is warranted in certain areas of medicine: respect for autonomy suggests that patients should provide input on treatment decisions, and beneficence suggests that research goals and endpoints should be receptive to the outcomes and needs that patients define. But which ethical principles support a new

form of patient-centeredness—namely, the invitation from the American Psychiatric Association (APA) for patients and advocates to comment on revisions to the *Diagnostic and Statistical Manual of Mental Disorders* (DSM)?

At the beginning of the revision process for the DSM-5, the APA announced that at various intervals it would publish online drafts of proposed changes for public feedback.⁴ By June 2012, the close of the third public commenting period, the task force reported that mental health clinicians and researchers, the medical community, patients, families, and advocates had submitted over 13,000 comments.⁴ In addition to soliciting this feedback, the APA has stated that patients should play an active role in the formation of diagnostic criteria for mental disorders, asserting that this active role is unprecedented: “We are unaware of any other area of medicine that has encouraged patient and family participation to the degree that we have attempted to do here with the DSM-5.”⁴

Comparing advocacy targets in other disease areas with advocacy targets in mental illness bolsters the APA's claim to a unique type of patient involvement. For example, patient advocacy movements for HIV/AIDS and breast cancer have influenced the inclusion criteria for clinical trials,^{5,6} protested schedules for disease screening,⁷ and rendered the boundaries between “lay” knowledge and “scientific” expertise less distinct.^{5,8} However, these groups have yet to focus their efforts on influencing antibody cutoffs for

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HIV diagnosis, biopsy analysis methods for breast cancer classification and staging, or other diagnostic criteria. In contrast to advocacy in these other disease areas, the APA has given individuals affected by mental illness, along with their advocates, the chance to influence not only the *process* of mental illness diagnosis but also specific diagnostic criteria. The reason for this unique chance may seem apparent: clinicians cannot diagnose mental illnesses via a blood test or examination of cells, as with infectious diseases or cancers. Mental illnesses, lacking diagnostic criteria that rely on biomarkers, are perhaps more amenable to patient and advocate input. But the lack of biomarker-based diagnosis seems to be a *descriptive* explanation of why advocacy groups *have* tried to influence those criteria. It does not provide an *ethical justification* for why advocacy groups *should* influence those criteria. No existing literature examines whether patient and advocate influence on the DSM revision process is ethically justified, an examination we begin in this article.

To provide context for present DSM-directed advocacy, the first part of the article briefly reviews changes in the U.S. advocacy movement in mental illness over time, highlighting the shift from the early adversarial stance of advocacy groups toward mainstream psychiatry, to the more collaborative approach of present-day mental illness advocacy groups.

The second part presents three case thumbnails of patient-advocacy responses to proposed DSM-5 revisions. Each of the cases represents a different nexus of two factors: first, the extent to which the group is an established actor on the mental illness advocacy landscape (defined roughly by a group's expenditures, membership size, and extent of collaboration with the APA and with DSM work group members), and second, the political riskiness of the diagnosis that the group targets, by which we mean the extent of public support, or lack thereof, for helping those who suffer from the condition that the group targets. The three cases are (1) Autism Speaks, which has criticized the decision to subsume Asperger's syndrome and pervasive developmental disorder under a single category of autism spectrum disorders (a well-established group targeting a diagnosis that is not politically risky), (2) the National Alliance on Mental Illness (NAMI) and its support of the proposed attenuated psychosis syndrome (a well-established group targeting a diagnosis that is more politically risky), and (3) B4U-ACT and its concern about proposed revisions to pedophilia (the least well-established group targeting the most politically risky diagnosis).

Whereas the second part presents a descriptive analysis of advocacy group input on DSM categories, the third part provides an ethical analysis of two questions. First, what is the ethical basis for granting patients and advocates influence on DSM diagnoses? Second, given this ethical basis for patient and advocate influence on diagnoses, how should the APA proceed when this influence conflicts with

other goals of the DSM revision process and of psychiatry as a profession? Examining these questions can help us understand both how advocacy groups *do* try to influence DSM diagnoses and the ethical principles that support why they *should* have this influence on certain aspects of mental illness diagnosis.

FROM "SURVIVOR" TO "CONSUMER" TO "RESEARCH SPONSOR"

The mental illness advocacy movement began in the 1960s and 1970s as psychiatry became engulfed in a wave of cultural criticism. The rise of the civil rights and other social movements contributed to new conceptions of the legal rights that patients could assert against psychiatrists, and a growing anti-psychiatry critique cast psychiatry as a profession that pathologized social deviance rather than as a scientifically grounded discipline.^{9,10} Mirroring this cultural critique, some early advocacy groups comprised former patients who labeled themselves "survivors" of what they saw as an oppressive and coercive psychiatric profession. They allied themselves with the anti-psychiatry movement, viewing mental disorders as different ways of being or as normal reactions to a dysfunctional world rather than as medical pathologies.^{11,12} These early advocates took an adversarial stance toward mainstream psychiatry, picketing at APA annual meetings and adopting names such as the *Oregon Insane Liberation Front* that highlighted antipathy toward psychiatry's means and methods of diagnosis.¹¹

The visibility of adversarial advocacy groups receded as cultural critiques of psychiatry faded in prominence. Nancy Tomes¹¹ documents how, as groups began to establish national organizations devoted to mental illness advocacy in the 1980s, differences emerged between the groups that maintained the "survivor" label and largely rejected the models of mental illness set forth in mainstream psychiatry, and the more moderate groups that adopted the label of "consumer" to indicate a greater willingness to work with mainstream mental health clinicians, researchers, and agencies. Rather than celebrating mental illness as an alternative way of being, these latter groups focused on goals such as spurring more humane treatment of psychiatric distress and increasing community support for families caring for deinstitutionalized persons.¹³

As advocacy groups began to take a less adversarial stance toward mainstream psychiatry, they began to occupy new roles within the mental illness landscape, supplementing a focus on access to services with a focus on increasing research support for mental illness. Picket lines morphed into research partnerships as advocacy groups began both to indirectly support mental illness research through lobbying of federal agencies such as the National Institutes of Health for increased research attention,^{14,15} and to directly support mental illness research via grants to scientists, with a particular focus on the biological origins of mental illness and better treatments for psychopathology.¹⁶

For example, in 1987, four mental illness advocacy groups came together to form the National Alliance for Research in Schizophrenia and Depression (NARSAD), a funding agency that characterized scientific research as the “purveyor of hope for improving the lives of the mentally ill.”¹⁶ This stance, which is radically at odds with the earlier antagonistic one of mental illness advocates, signaled the rise of a new model of hybrid “science-advocacy” groups.

CASE STUDIES OF MENTAL HEALTH ADVOCACY AND DSM-5

As an illustration of the increasingly collaborative relationship between advocacy groups and mainstream psychiatry, the APA explicitly sought to engage these groups in discussions of proposed diagnostic changes for the DSM-5. Previous research on the influence of advocacy groups on the scientific process has generally centered on how these groups have recast themselves as the direct beneficiaries of biomedical research funding decisions or on how the groups have demanded accelerated access to experimental interventions.^{17,18} By contrast, the influence of advocacy groups on the direction of diagnostic classification in psychiatry has received little attention. We therefore present three case thumbnails of groups that have targeted specific DSM revisions.

A complete analysis of advocacy group participation in the DSM revision process would document both sides of advocate influence: the comments on DSM diagnoses that advocacy groups make and the DSM-5 work groups’ incorporation of those comments into their revisions. However, limits in the transparency of the DSM revision process prevent us from addressing such issues. The APA publishes aggregate data on how many comments it receives, but does not provide the public with the comments themselves, the number of comments that each work group received, or the minutes from the work groups’ discussions that could show how a given work group considered and then rejected or incorporated advocacy feedback. Despite the APA’s having labeled the DSM-5 revision process as patient centered, the process’s lack of transparency sets it apart from patient-engagement efforts such as those of the Patient-Centered Outcomes Research Institute, which publishes not only the comments that it receives from patients and advocates but also the minutes of its meetings.¹⁹ As a result of the revision process’s limited transparency, our analysis of each case uses publicly available information to give a description of the general goals of each advocacy group, the group’s position on a proposed DSM change, what the group’s mission and position highlight about patient advocacy and DSM diagnoses, and the DSM-5’s final inclusion or exclusion of the targeted diagnosis.

Autism Speaks

DESCRIPTION OF GROUP AND ITS TARGET DIAGNOSIS Autism Speaks is a representative case of a well-established group

that targets a diagnosis that is not politically risky. The group characterizes itself as a dual “science-advocacy” organization, a characterization supported by its extensive support for research and its success in advocating for increased insurance reimbursement of expensive autism therapies. Autism Speaks, including the antecedent organizations from which it was formed—Cure Autism Now and the National Alliance for Autism Research—allocated more than \$337 million for autism research projects between 1997 and 2006 (compared to \$304 million allocated by the National Institutes of Health),²⁰ has successfully lobbied for the passage of over 29 state mandates for autism insurance coverage,²¹ and, in 2011, spent over \$41 million on a range of awareness, research, and other activities.²² Furthermore, as a measure of the increasingly collaborative relationships that have developed between advocacy groups and clinician-researchers, 70% of the DSM-5’s Neurodevelopmental Disorders Work Group members listed affiliations with Autism Speaks or its two antecedent organizations on their disclosure forms, indicating that they had received a grant from the organization, served on one of its advisory boards, or trained students funded by the group’s fellowships.²³

Examining the other dimension of how we selected cases (the riskiness of the targeted diagnosis), we argue that autism is not a “politically risky” diagnosis. Though the etiology of autism remains controversial, sufferers receive broad public support, as the 2006 federal “Combating Autism Act” and its 2011 reauthorization illustrate.²⁴ By contrast, no national legislation aims specifically at increased support for the more stigmatized diagnoses of schizophrenia or pedophilia, the DSM diagnoses we discuss in the next two case studies.

POSITION ON PROPOSED DSM REVISION Targeting the DSM-5, Autism Speaks publicly questioned the APA’s recommendation to collapse autism, Asperger’s disorder, and pervasive developmental disorder—not otherwise specified, into a single category labeled *autism spectrum disorder*. A retrospective study of a DSM-IV field trial on autism found that only 60% of the previously diagnosed participants met the new diagnostic criteria for autism spectrum disorder.²⁵ Though the study’s results were later challenged by other research showing a more modest rate of “excluded persons,” Autism Speaks was seriously concerned about this initial data and its potential consequences—namely, that the new criteria would no longer include many persons with Asperger’s, autism, and pervasive developmental disorder—not otherwise specified currently included within the category of autism spectrum disorder as defined by DSM-IV.

In its response to the proposed revision, how did Autism Speaks balance its dual role as an advocacy organization that lobbies for increased eligibility for autism services and as a science-funding source that supports better research into autism pathology? In its open letter to the

DSM-5 work group, the organization appeared to prioritize concerns about service access over concerns about how the revisions would affect scientific research into autism. Autism Speaks appeared to accept the scientific bases for the proposed changes but voiced concerns about the real-world impact of the new nosology on insurance reimbursement, special education eligibility, and other support services.²⁶ The group launched their own research initiative to determine the impact of the proposed revisions, and with the stated goals of both advancing the science and “ensur[ing] that any [DSM] revisions do not exclude individuals who have [autism spectrum disorder] and are in need of services.”²⁶ Therefore, in its public comments, the organization seemed more concerned with the impact that narrowing the category of autism spectrum disorder would have on service access than with fixing the scientific problems with the three DSM-IV-TR autism categories.

WHAT THIS POSITION HIGHLIGHTS ABOUT ADVOCACY AND DSM DIAGNOSES The Autism Speaks case study highlights two observations about advocacy groups’ attempts to influence the DSM. First is the shift from advocacy groups that critiqued the medicalization of certain forms of human behavior during the “survivor” movement to groups that criticize the perceived narrowing of DSM diagnoses. As contemporary groups such as Autism Speaks embrace DSM diagnoses as a focal point for organizing efforts and for the research, clinical, and health care financing power that the labels provide, narrower diagnostic categories become a source of concern rather than a means of checking diagnostic overreach.

Second is the role of advocacy groups in changing how DSM diagnoses and their benefits are framed. Ultimately, the APA stood by its proposal to combine the three autistic disorders into a single diagnosis,²⁷ but Autism Speaks’ critique of the revisions, coupled with the media coverage that it helped to spark, shifted the conversation surrounding the diagnosis to a greater emphasis on the diagnosis’ utility for service eligibility and reimbursement. The APA then had to defend the revision on these service-eligibility grounds rather than simply attending to scientific rationales for the proposed revision. For example, Susan Swedo, chair of the APA’s Neurodevelopmental Disorders Work Group, publicly acknowledged concerns that their proposal would adversely affect service eligibility: “It hurt like hell that newspapers were accusing us of trying to hurt kids by denying them services.”²⁸ Challenging the idea that the combined autism category would cause persons to *lose* access to services, Swedo argued that the new, combined category was more likely to identify girls and minorities with autism and that the study showing that persons would lose a diagnosis was “fatally flawed.”²⁸ Swedo’s defense of the diagnosis and rejoinder that it would help *more* persons (girls and minorities), not fewer, access services illustrates that Autism Speaks contributed to pressure on

the APA to defend the social impact of a DSM revision. The case highlights that, although even well-established groups may fail to change a proposed revision, those groups *can* shift the framing of DSM changes to include the consideration of how proposed revisions will affect service eligibility.

National Alliance on Mental Illness

DESCRIPTION OF GROUP AND ITS TARGET DIAGNOSIS Just as Autism Speaks has embraced DSM diagnoses for the treatment access that they grant and for the organizing locus that they provide, NAMI also emphasizes the value of certain diagnostic categories for its members. Formed in 1979, NAMI is a well-established advocacy group that, in its comments on DSM revisions, targeted diagnoses that are more politically risky than autism but that are less politically risky than pedophilia, the focus of our third case study. NAMI had over 200,000 members at last counting (in 2002) and, according to its 2011 financial disclosure forms, expenditures of over \$7.1 million on advocacy activities, making it more poorly financed than Autism Speaks but better financed than B4U-ACT.^{29,30} NAMI also has close connections with the APA. In a 2012 article, APA president Dilip Jeste described how “partnerships with advocates” strengthen the APA and highlighted its “close and fruitful” relationship with NAMI.³¹ Likewise, leaders of NAMI have explained how,

at the national level, the NAMI Board of Directors and the APA Board of Trustees have already held a joint session, and the national staff of both organizations work closely together around a variety of issues such as advocating for funding of psychiatric research. . . . NAMI has become an essential ally to APA.³²

That is, it is evident that NAMI is a well-established group with a collaborative APA relationship.

Although NAMI is technically focused on all mental illnesses, in the context of the DSM-5 it released position papers for the diagnoses of schizophrenia, substance use disorders, and temper dysregulation disorder (a new mood disorder for children)³²—all of which are more politically risky than autism. Involuntary treatment and links with violence are matters of ongoing debate in the case of schizophrenia,³³ as are the costs associated with contact with the legal system (especially when an arrest results) in the case of substance use disorders³⁴ and the perceived overuse of pharmacological treatment for childhood mood disorders.³⁵ NAMI thus serves as an example of a well-established organization targeting diagnoses with moderate degrees of political riskiness.

POSITION ON PROPOSED DSM REVISION Whereas Autism Speaks was critical of a perceived diagnostic contraction, NAMI supported a diagnostic expansion in the form

of *attenuated psychosis syndrome*, a proposed category intended to alleviate the distress of persons experiencing subthreshold psychotic symptoms and to identify persons with an elevated risk (35%–50%) of developing overt psychosis.^{36,37} NAMI argued that the proposed category offered the potential benefits of more rapid recovery, avoidance of the more devastating consequences of no treatment such as homelessness or contact with the criminal justice system, and education and support for persons at risk and their family members.³⁸ According to NAMI, potential drawbacks of the category included stigma and potential discrimination, the fact that the large majority of individuals diagnosed with the disorder will never develop a psychotic disorder, and the inappropriate use of antipsychotics for persons who should not receive medication until conversion to full-blown psychosis.³⁸ Weighing these risks and benefits, NAMI supported the proposed inclusion of the new category, arguing by analogy that just as early intervention is an important strategy for young persons at risk for diseases such as diabetes, asthma, and obesity, the new category would enable a similar early intervention approach to schizophrenia.³⁸ Other commentators, though agreeing with NAMI's identification of the relevant risks and benefits, nevertheless argued against including attenuated psychosis syndrome in the main text of the DSM; in the assessment of these commentators, the risk was too great that community clinicians would inappropriately prescribe antipsychotics that, for those with subthreshold psychotic symptomology, have a poor risk-benefit profile.³⁹

WHAT THIS POSITION HIGHLIGHTS ABOUT ADVOCACY AND DSM DIAGNOSES The NAMI case study highlights two further observations about attempts by advocacy groups to influence DSM diagnoses. The first is the possibility of conflicts between the interests of the funding sources that advocacy groups rely on and the interests of the patients that the groups aim to represent. NAMI receives significant funding from pharmaceutical sources. In 2010, the primary year of commenting on the DSM-5, pharmaceutical companies with antipsychotics either on the U.S. market or in clinical testing contributed over \$2.8 million to NAMI—over 39% of the group's funding for that year.⁴⁰ Pharmaceutical contributions included support for NAMI programs such as “First Episode,” which focused on earlier identification of, and intervention in, psychotic disorders.⁴¹ Whereas pharmaceutical companies had a clear interest in formalizing attenuated psychosis syndrome because of the likelihood that DSM inclusion would contribute to increased antipsychotic prescriptions, the interests of patients in the proposed diagnoses were ambiguous. Currently, patients with suspected psychosis risk can seek treatment at U.S. research clinics that emphasize information and counseling, and that discourage the use of antipsychotics as a first-line treatment.^{42–44} These clinics judge that it is in the interests of patients to try non-pharmacological forms of treatment

before trying pharmacotherapy. NAMI thus faces a conflict between the interests of pharmaceutical funders, who may support attenuated psychosis syndrome's inclusion due to their stake in expanding the market for antipsychotics, and the interests of patients, who may be well served by existing research clinics that do not rely on formalized DSM diagnoses and that deemphasize antipsychotics. While NAMI adequately managed this conflict in drafting its position paper on attenuated psychosis syndrome—recommending DSM inclusion of the diagnosis but strongly advising clinicians to set a high threshold for antipsychotic use—the conflict still serves as a potential source of bias, illustrating the importance of advocacy groups' stated commitments to decreasing their reliance on industry funding.⁴⁵

The second observation is that, although advocacy organizations may influence the discourse surrounding a diagnostic revision for patients, they face difficulty altering the actual outcomes of the revision process. Just as Autism Speaks' critique of the revision failed to tangibly alter the outcome of the diagnostic change, the DSM-5 Psychotic Disorders Work Group ultimately decided to not include attenuated psychosis syndrome in the main body of the manual; instead, the work group placed the diagnosis in the appendix for disorders requiring further study.⁴⁶ Though it is difficult to pinpoint the precise cause of this outcome, the decision seemed to largely stem from the failure of DSM-5 field trials to recruit a large enough sample of patients to measure diagnostic reliability and, as mentioned above, from worries among leading psychosis-risk researchers that including the disorder in the DSM's main text rather than an appendix could spark inappropriate antipsychotic prescribing by community clinicians.^{47–49} The failure of well-established groups such as NAMI to change revision outcomes illustrates the distinction between the APA's public support for advocate feedback and the question of whether work groups actually incorporate advocate suggestions. In the discussion we explain why this distinction between openness to advocate feedback and incorporation of advocate comments is justifiable, and we explore in more detail the reasons why the APA may decide to reject the recommendations of patients and advocates.

B4U-ACT

DESCRIPTION OF GROUP AND ITS TARGET DIAGNOSIS Whereas Autism Speaks and NAMI are well established as advocates, our third case study focuses on a group that is far less so and that focuses on one of the most politically risky DSM diagnoses: pedophilia. B4U-ACT is a Baltimore-based coalition whose stated mission is, in part, as follows: “To publicly promote services and resources for self-identified individuals (adults and adolescents) who are sexually attracted to children and seek such assistance; to educate mental health providers regarding the approaches helpful

for such individuals.”⁵⁰ The organization describes itself as a group of “about 25 people”—tiny by comparison with Autism Speaks or NAMI. Likewise for its annual expenditures: whereas Autism Speaks and NAMI have budgets exceeding \$40 million and \$7 million, respectively, B4U-ACT’s most recent IRS disclosure form, dating to 2008, lists only slightly more than \$7,000 in yearly expenditures.⁵¹

B4U-ACT has attempted to cultivate alliances with the organization APA and with leading researchers, but the relationship seems to have not taken hold. In June of 2010, members of B4U-ACT held a conference call with DSM revision officials and stated afterwards, “B4U-ACT seeks to work with the APA as a resource both to fulfill its mission to seek input from stakeholder groups and to help ensure that the recommended changes are accurate and scientifically-based.”⁵² But when B4U-ACT invited representatives from the DSM-5 Sexual and Gender Identity Disorders Work Group to participate in a scientific symposium in August of 2011 focused on issues with the DSM’s proposed revisions, the invitation was ignored (Kline H, email communication, 19 September 2012). Moreover, no members of the same DSM-5 work group disclosed funding or advising relationships with B4U-ACT, compared to 9 out of 13 DSM-5 Neurodevelopmental Disorders Work Group members who have had a relationship with Autism Speaks or its antecedent organizations and 3 out of 12 Psychotic Disorders Work Group members who have had a relationship with NAMI. A combination of factors likely hurts B4U-ACT’s attempt to establish APA collaborations, including the advocacy group’s small resource base and its depiction in the media as a “pro-pedophilia” organization.⁵³

POSITION ON PROPOSED DSM REVISION B4U-ACT criticized the proposal by the DSM-5’s Sexual and Gender Identity Disorders Work Group for a new subtype of pedophilic disorder, *hebephilia*, defined as attraction to pubescent minors aged 11 to 14.⁵⁴ With this change, the DSM-5 pedophilic disorder would have contained three subtypes—a classic type in which a person is sexually attracted to prepubescent children, a hebephilic type in which a person is attracted to early adolescent children, and a mixed type where a person is sexually attracted to both groups.

Criticism of the addition of hebephilia stemmed from three sets of concerns: philosophical questions about the boundary between disordered sexual desires and normal sexual desires, worries about the legal implications of DSM category changes, and questions about the scientific basis for grouping certain disorders into the same category. First, from a boundaries perspective, Richard Kramer, B4U-ACT’s director of operations, questioned whether hebephilic desires—sexual arousal for early adolescent children—is a genuine psychiatric disorder that the DSM ought to consider abnormal or is, instead, merely a “taboo in current Western culture.”⁵⁵

Second, from a legal perspective, the group worried that individuals who express such desires may be inappropriately detained under involuntary civil commitment laws. The federal government and many states have clauses in sexually violent predator regulations that allow for the involuntary commitment of sexually violent predators who have completed their sentences but who have a serious mental disorder or abnormality.⁵⁶ In practice, DSM diagnoses are often used to convince review committees that a person has a serious mental disorder and poses a continued threat after the completion of his sentence.⁵⁷ Thus, at a scientific symposium sponsored by B4U-ACT, a speaker expressed concern that an expansion of the pedophilia category to include men aroused by early adolescents will give courts more power to involuntarily detain sexually violent predators past their sentences.⁵⁷

Third, B4U-ACT supporters questioned whether there was a scientific consensus that attraction to minors (pedophilia) and attraction to early adolescents (hebephilia) stem from the same underlying condition and should be grouped into the same overarching diagnosis. Questioning the existence of such a consensus, B4U-ACT’s supporters noted that professional societies have strongly rejected the hebephilia subtype within pedophilia, with 31-1 vote against this subtype among forensic psychiatrists at a 2010 meeting of the American Academy of Psychiatry and the Law and a 100-1 vote against it among members of the International Association for the Treatment of Sexual Offenders.⁵⁷

WHAT THIS POSITION HIGHLIGHTS ABOUT ADVOCACY AND DSM DIAGNOSES This case study suggests two further observations about disease advocacy groups and the DSM. The first is that, just as advocacy groups can shift the public discourse surrounding proposed revisions from the scientific rationale for the changes to the changes’ anticipated social effects, these groups can spark debate about the values inherent in psychiatric classification. B4U-ACT questioned whether attraction to early adolescents falls within the boundaries of psychopathology that the DSM is intended to document; other critics have echoed B4U-ACT’s line of questioning, commenting that “the use of provocatively attired adolescent girls is certainly not uncommon [in advertising campaigns]. . . . It is fallacious to assert that having sexual urges regarding pubescent youngsters is sufficient for a diagnosis of a mental disorder.”⁵⁸ Whereas Autism Speaks and NAMI have supported diagnostic expansions for certain disorders because of resulting broader eligibility for services, groups such as B4U-ACT have tried to limit diagnostic expansion out of concern that “normal” forms of sexual attraction may be improperly labeled as dysfunctional and as warranting professional attention.

The second observation is that the DSM revision process is opaque regarding work groups’ responses to advocacy feedback. The Sexual and Gender Identity Disorders Work

Group ultimately decided not to include hebephilia in the final DSM-5 revisions. Ironically, perhaps, B4U-ACT—the least well-established group targeting the most risky diagnosis in our cases—was able to obtain the revision outcomes that it wanted, whereas Autism Speaks and NAMI were not.²⁷ One commentator attributes the noninclusion of hebephilia to pressure from “senior psychiatrists” in the APA rather than pressure from B4U-ACT or other advocacy groups.⁵⁹ Though this claim cannot be confirmed in the absence of more transparent work group deliberations, it does raise the question whether, despite the APA’s call for patient and advocate feedback, the public input from those groups has had less impact on the DSM revision process than the private input of prominent APA members.

DISCUSSION: ETHICAL BASIS FOR PATIENT AND ADVOCATE INFLUENCE

These three case thumbnails raise ethical questions about whether patient and advocacy groups should influence the DSM revision process and whether the APA should limit that influence to certain aspects of diagnosis. In addressing these ethical questions, we argue that two claims are relevant: one about the descriptive realities of mental illness and particular diagnoses for patients and advocates, and another that these patients and advocates have the requisite knowledge to comment on those descriptive realities. These two claims combine to support the ethical notion of *transparency for the purpose of informed community consent*; that is, by participating in the DSM revision process, patients, advocates, and other members of a disease community can grant consent to the anticipated social effects of, and values embodied in, the final revisions that are made.

Turning to the descriptive realities of mental illness that support patient and advocate input into the DSM revision process, we argue that there are two: first, the social tradeoffs involved in defining particular diagnoses, and second, the values embedded in those diagnoses and their criteria.

Social Effects and Diagnosis

Examining the first descriptive reality—the social tradeoffs involved in particular diagnoses—the use of diagnostic categories has positive social effects in that it identifies persons who can benefit from treatment and also enables reimbursement of that treatment, but many psychiatric diagnoses also have the social tradeoffs of stigmatization, devaluation in the eyes of society,⁶⁰ perceived dangerousness, and a desire for social distance.⁶¹ Patients, caregivers, and advocacy groups have first-hand familiarity with these tradeoffs, and since their knowledge of these social effects is experiential rather than technical in nature,⁶² their comments on anticipated social effects of DSM revisions are both warranted and desirable.

In our three thumbnails, each of the advocacy groups expressed concern about an anticipated social effects of a proposed DSM change. Autism Speaks voiced concern about the “loss” of a diagnosis for some persons and the problems that this loss would cause for persons needing to obtain reimbursable services.²⁶ NAMI issued a press release to its members encouraging “individuals and families to familiarize themselves with the draft of the new DSM,” explaining 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.”⁶³ B4U-ACT focused on the anticipated social harms of increased deprivation of liberty that might accompany an expanded definition of pedophilia. While social science researchers have the technical knowledge to systematically document these social effects, we contend that patients and advocates have the experiential knowledge to comment informatively on such effects. And when, for example, the expansion of a DSM diagnostic category results in increased stigma but also increased access to important services, patients and advocates will at least have had an opportunity to influence the criteria and thereby to shape the social tradeoffs involved.

Value Judgments and Diagnosis

Examining the second descriptive reality—the values embedded in psychiatric diagnoses—the philosophy of psychiatry has cogently argued that psychiatric diagnoses incorporate some societal values regarding the deviations from normal functioning that warrant psychiatric attention.⁶⁴ For example, Jerome Wakefield’s hybrid concept of harmful dysfunction, in which a mental disorder is both harmful according to society’s values and involves some disruption of natural functioning, is one well-respected approach to psychiatric classification that acknowledges how the line between normal and abnormal is influenced by both factual and value judgments.⁶⁴ Viewed through this lens, DSM diagnoses incorporate value judgments about dysfunctional behaviors that we as a society believe to be harmful and to warrant professional attention. Epistemologically, patients, advocates, and even the public at large have the requisite knowledge to comment on whether a given behavior included in proposed DSM criteria should count as harmful in the eyes of society.

The advocacy groups in our case studies took positions on these values, just as they took positions on the anticipated social effects of diagnostic revisions. NAMI argued that the symptoms characterized in attenuated psychosis syndrome should be considered sufficiently harmful by society to warrant professional attention, and B4U-ACT argued that attraction to early adolescents may be a normal form of attraction that the advertising and entertainment industries, for example, explicitly capitalize on by using young, sexually provocative models. Whether or not we agree with advocacy groups’ positions on whether

these behaviors should count as abnormal, the APA's public commenting process has provided these groups with the opportunity to comment on the associated value judgments. This opportunity renders it more likely that patients will consent to the values embedded in the final formulations of the relevant DSM diagnoses.

Our analysis of the ethical basis for allowing patients and advocates to participate in the DSM revision process explains why the APA is justified in allowing such participation. But how should the APA proceed when such participation potentially conflicts with other goals of the DSM revision process or of psychiatry? In the next sections, we examine two potential conflicts. One is whether the participation of patients and advocates conflicts with beneficence: does the increased transparency of the DSM revision process lead to categories that ultimately do less to relieve the suffering of persons with mental illness? The other is whether such transparency conflicts with psychiatry's legitimacy: does the increased transparency of the DSM revision process undermine psychiatry's professional and scientific legitimacy?

Beneficence and DSM Diagnosis

DSM diagnoses are designed to provide a common language between research and treatment efforts, with the ultimate goal of better relieving patient suffering through an improved understanding and clinical treatment of psychiatric disorders. This aim is rooted in the ethical principle of beneficence—to help patients by treating their illnesses. Advocacy directed at DSM diagnoses raises questions about how revisions to the DSM can best promote the interests of patients. Do diagnostic changes that improve the reliability of psychiatric diagnosis lessen patient suffering? Or do broader diagnoses that are perhaps less reliable but that facilitate social-service eligibility and insurance reimbursement provide the most benefit for patients? Or are narrower diagnoses of more benefit for some disorders since a person's civil liberties are less likely to be restricted (e.g., for certain forms of pedophilia)? The answer, we contend, is that patient suffering is best relieved by a mix of the three aims: reliable diagnoses that improve research and treatment, that are respected by third-party payers so that treatment is reimbursed, and that are not used inappropriately in forensic settings to undermine a person's civil liberties.

Two of the advocacy groups, Autism Speaks and NAMI, appear conflicted in their public statements about how diagnoses can best benefit patients. Autism Speaks contends that narrower diagnostic categories fail to benefit the persons who “lose” a diagnosis, without acknowledging that the reliability issues associated with the three separate DSM-IV-TR categories may decrease the extent to which those diagnoses benefit patients.^{65,66} NAMI appears similarly conflicted about how patients can best benefit from a diagnosis, arguing that the attenuated psychosis syndrome may benefit patients by providing access to educational support about

schizophrenia but that it may harm the patients who, statistically, will never convert into full-blown psychosis and who may inappropriately receive antipsychotics from community clinicians. By contrast, B4U-ACT is less conflicted about how DSM revisions can best benefit patients: the organization clearly sees an expanded pedophilia diagnosis as not working to the benefit of persons attracted to early adolescents; the expanded diagnosis is subject to misuse in forensic contexts.

Although advocacy groups may have conflicting ideas about the diagnostic changes that best benefit patients, the APA, as a professional organization comprising clinicians and researchers whose expertise lies in the scientific and clinical aspects of diagnosis, should have more focused, determinate goals. The APA can be most beneficent to persons with mental illness and their families by attending to scientific and clinical concerns regarding DSM diagnoses—in particular, to questions about diagnostic validity, reliability, and utility of diagnoses for treatment. The impact of diagnostic changes on social-service eligibility is certainly one aspect of nosology that affects sufferers of mental illness.⁶⁷ But problems such as low reliability and low specificity of categories can also affect sufferers of mental illness by impeding fruitful research into mental illness etiology, provoking payer skepticism about the scientific bases for categories, and contributing to other long-term harms associated with scientifically murky diagnoses. The APA and its DSM work groups should emphasize that categories incorporating beneficence would necessarily attend to these long-term aims of psychiatric diagnosis and would need to balance those aims against the social-service and value concerns expressed by patients and advocacy groups. Indeed, our argument appears to align with the APA's own approach to inviting patient and advocate feedback. The APA argued that patients and advocates' knowledge about the “social dimensions of long-term illnesses” was one of the organization's chief rationales for inviting such feedback but that the work groups would weigh that information against the knowledge of clinicians with “advanced backgrounds in psychiatric theory, assessment, diagnosis, and/or treatment, which aids in increasing diagnostic reliability.”⁴

Psychiatry's Legitimacy and DSM Diagnoses

Beneficence is not the only value underlying the APA's diagnostic revisions. Psychiatrists and, by extension, the APA (the professional organization that seeks to represent them) have interests in maintaining a sense of expertise in identifying and treating mental illness, and these goals undergird both the legitimacy of the psychiatry profession and the trust of patients. We have argued that inviting patients and advocates to participate in the revision process is partially rooted in the belief that psychiatric diagnoses incorporate some value judgments about the forms of dysfunction that society should characterize as harmful. But is psychiatry's legitimacy as a profession threatened by acknowledging

that psychiatric diagnoses incorporate some values and by inviting patients and advocates to comment on this aspect of diagnosis?

We argue that no such threat exists, especially when we consider two factors that would actually threaten a profession's legitimacy: doubts about a profession's efficacy and perceptions that a profession violated its boundaries by claiming authority over areas where its members have no special knowledge.⁶⁸ Examining the first of these two threats to professional legitimacy—perceptions of inefficacy—inviting and taking into account patient and advocate feedback concerning the social and value-based elements of psychiatric diagnosis does not threaten psychiatry's efficacy as a profession unless the DSM work groups allow such feedback to overshadow problems with diagnostic constructs that impede psychiatry's effectiveness in treating mental illness. Likewise, by setting boundaries on the types of input that patients and advocates are allowed to provide—namely, the values embodied in psychiatric diagnosis and the social impact of diagnostic changes—the APA can balance a commitment to patient and advocate inclusion against a legitimate need to assert its jurisdiction over science-based areas of psychiatric nosology such as reliability and clinical utility.

The second threat to professional legitimacy—perceptions of a profession overreaching its boundaries—is also not applicable to the APA's invitation for patients and advocacy groups to comment on the social and value-based elements of diagnosis. Indeed, in offering an opportunity to participate in the DSM revision process, psychiatry has *acknowledged* its professional boundaries rather than overreached those boundaries. The most persuasive critiques of modern psychiatry have characterized the profession as claiming authority to treat behaviors—most famously, homosexuality—that society should not consider harmful. By indirectly acknowledging that its work groups and its members have no special knowledge of the value-based aspects of diagnosis, and by inviting patients, advocates, and the public to comment on these aspects, the APA has tried to strengthen psychiatry's legitimacy as a profession.

CONCLUSION

At the outset of this article, we raised two questions: (1) what is the ethical basis for patient and advocate involvement in the DSM revision process, and (2) what should be the limits of such involvement when it conflicts with other goals of the revision process? Our answers are as follows. First, patients' and advocates' knowledge of the social effects and values implicated in proposed revisions provides a strong rationale for inviting patients and advocates to comment on those aspects of DSM diagnoses. Furthermore, since such social effects and value judgments affect patients and advocates, inviting their feedback bolsters their consent to the shape that the revisions

ultimately take. Second, the APA should limit patient and advocate feedback to the social and value-based aspects of diagnosis and should balance this feedback against a clear commitment to more reliable and clinically useful diagnostic constructs. This balance enables psychiatry to acknowledge its boundaries as a profession but to ensure that it increases its efficacy in relieving patient suffering through better diagnostic constructs.

Four main areas deserve additional research. First, we chose to focus on three advocacy case studies in detail rather than provide a broad overview of mental illness advocacy and the DSM; a more systematic survey is needed that outlines the landscape of mental illness advocacy, the positions that each mental advocacy group took on proposed DSM-5 changes, and which factors explain the successful incorporation of an advocacy group's position into the final version of the DSM-5. Furthermore, this more systematic survey should connect analyses of DSM-directed advocacy with broader sociological analyses of embodied health movements, defined roughly as movements that draw upon the illness experience of sufferers to challenge scientific conclusions about disease.⁶⁹ How do groups draw upon the illness experience of their members to critique changes to DSM criteria? We argued that advocates are justified in commenting on anticipated social effects of diagnosis, but how should the APA mediate between different social harms that are salient for different advocacy groups—such as autism caregivers' concerns about service loss versus autism patients' concerns (advocating for themselves) about the loss of a collective identity?

Second, as we acknowledged at the outset, our analysis examined only public statements made by patient advocacy groups. Further research is needed to determine how DSM task force members perceive advocacy input, whether and how such input entered into their deliberations, and how individual members who serve on work groups and also affiliate themselves with specific advocacy groups manage these dual roles. Although questions concerning conflicts of interest of DSM work group members have focused on pharmaceutical funding that members receive,^{70,71} our commentary raises a parallel question with regard to group members who receive funding from advocacy groups. That is, when the goals of the APA and those of advocacy groups diverge regarding DSM revisions, how have these members balanced those divergent goals?

Third, just as DSM work group members must ensure that pharmaceutical funding sources do not inappropriately influence their positions on DSM revisions, advocacy groups that rely on pharmaceutical funding face a similar task. Commentators have pointed to NAMI's reliance on pharmaceutical funding as a cause for concern since the organization engages in public sector advocacy regarding state and federal legislation.⁷² As advocacy groups expand their targets from the arena of policy to the arena of diagnostic criteria, future research should explore effective conflict-of-interest management

for these groups. For instance, advocacy groups could refrain from taking positions on DSM revisions when one of the group's for-profit funding sources supports a certain revision outcome.

Fourth, future commentators should address the question of whether designating specific periods for public comments is the best way to incorporate advocacy concerns or whether a different process would better achieve that purpose. For example, some have proposed the creation of an independent research review body that monitors social issues surrounding DSM revisions.⁷³ Or as one of us has suggested elsewhere, the APA could diversify the membership of its work groups to include advocacy representation in addition to clinician-researchers.⁷⁴

These future explorations will help us to better understand the nuanced role of patient advocacy in shaping the DSM. As the APA recasts the manual as a living document that is regularly updated, this nuanced understanding can help shape future revisions of the manual and its diagnoses.⁷⁵

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