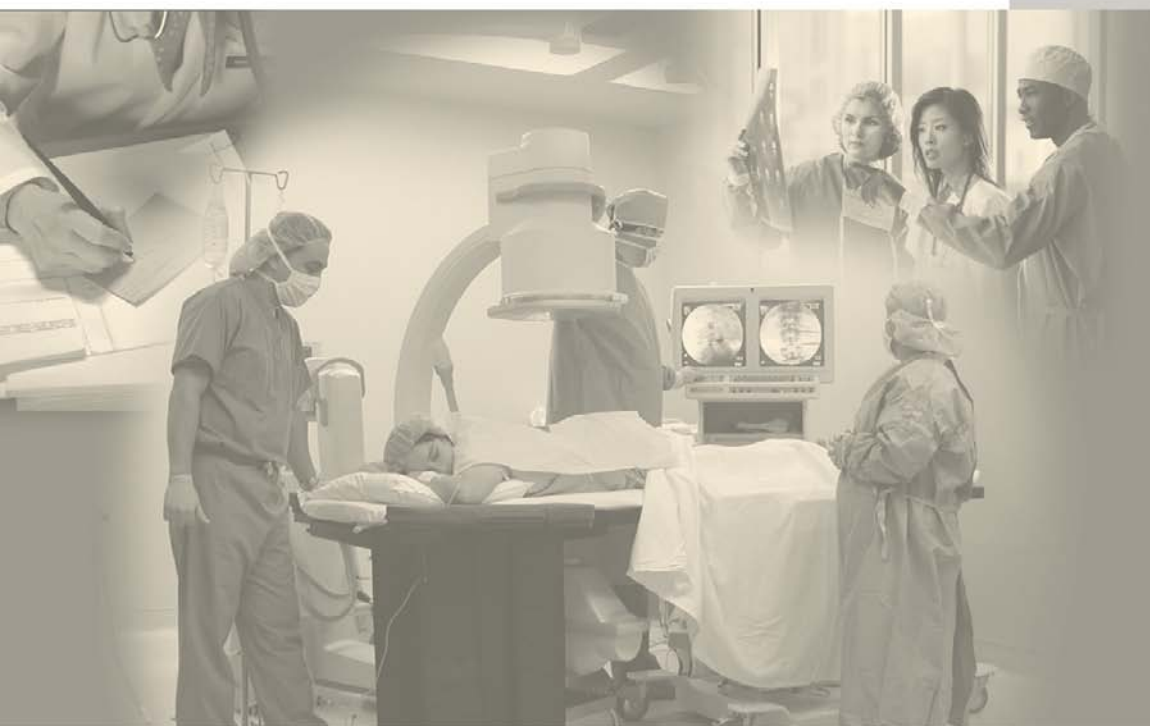




Volume 12

ADVANCES IN MEDICAL SOCIOLOGY

Sociology of Diagnosis



Edited by **PJ McGann** • **David J Hutson**

SOCIOLOGY OF DIAGNOSIS

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ADVANCES IN MEDICAL SOCIOLOGY VOLUME 12

SOCIOLOGY OF DIAGNOSIS

EDITED BY

PJ McGANN AND DAVID J. HUTSON

University of Michigan



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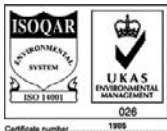
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INVESTOR IN PEOPLE

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PREFACE

In 2010, the American Psychiatric Association (APA) announced that it would soon issue a new, revised fifth version of its official compendium of psychiatric diagnoses: the Diagnostic and Statistical Manual (DSM). The APA had already revised the DSM several times, and DSM-V had been anticipated. What was new, however, was the way in which the announcement was made. For the first time, DSM-V was posted on the Association's website, and the public was invited to offer comments and suggestions. The appearance of DSM-V was immediately announced on *Nightly News*, along with critical comments on two of its most controversial features: adding overeating or "binge eating" to the list of eating disorders and the abandonment of "Asperger's disorder" in favor of a broader autistic spectrum (see Singh, this volume).

These events epitomize some of the defining features of contemporary diagnosis. They illustrate, for example, the degree to which diagnostic systems, once esoteric and impervious to public scrutiny, have become part of the public sphere, open to criticism and debate. Even more remarkable was the fact that much of the public sphere was now located in cyberspace and, moreover, that the APA had actually invited public comment. To be sure, this "democratization" may have been only illusory and failed to overturn decisions already made. What is noteworthy, however, is the acknowledgement by a somewhat conservative professional association that the public at least deserved a (limited) place at the table.

How do such diagnostic systems as the DSM come into being? What social and political processes cause diagnostic categories to emerge and disappear? How are they contested within and outside medicine? How are diagnostic categories applied to patients? How do diagnostic practices change? These are central questions to the sociology of diagnosis.

THE SOCIOLOGY OF DIAGNOSIS: WHY SO LATE?

The chapters PJ McGann and David J. Hutson have assembled for this volume are not only timely, coinciding with the appearance of DSM-V, but mark a defining moment in which a new subfield of medical sociology has

emerged. Diagnosis, which refers both to diagnostic categories and the process of creating and applying them, is a central feature (Blaxter, 1978) – if not *the* central feature of medical work. Annemarie Jutel, who has done much to build the sociology of diagnosis, has described the wide array of “work” diagnosis performs in the medical world:

Diagnosis is integral to medicine and the way it creates social order. It organizes illness: identifying treatment options, predicting outcomes, and providing an explanatory framework. Diagnosis also serves an administrative purpose as it enables access to services and status, from insurance reimbursement to restricted-access medication, sick leave and support group membership and so on... (Jutel, 2009, p. 278)

Given its importance to medicine, it is surprising that the sociology of diagnosis is only now beginning to coalesce. In fact, more than two decades have elapsed since Phil Brown (1990) first called for sociology of diagnosis. Although any attempt to explain why something did not happen is a perilous project, I will speculate on some of the reasons for the long delay. First, to be sure, medical sociologists *have* studied diagnosis. Some of the most important contributions of medical sociology have concerned the diagnostic change in which conditions once defined as crime, sin, or natural processes come to be defined and treated as illness (Conrad & Schneider, 1992). At the microlevel, medical sociologists have shown that even an ostensibly medical act, such as diagnosing illness, is shaped by myriad social considerations, including the patient’s perceived characteristics and the setting in which the diagnosis is made. But important as they are, these insights have been subsumed under the headings of medicalization, the social construction of illness, and health social movements. Diagnosis has not been recognized as a topic worthy of study in its own right.

A second hypothesis comes from criticisms sociologists of science have leveled at medical sociology. Medical sociologists, they argue, have been reluctant to study medical practice. Rather than studying what doctors actually *do* – the core of medical work – they have focused instead on its social penumbra (see Timmermans, 2006). As bureaucratic barriers to entrée have multiplied, and as the center of gravity in medical sociology has shifted to politics and policy, ethnographies of medical work – including diagnostic work – have become increasingly under-represented. Diagnosis, however, is at the heart of medical practice, and a sociology of diagnosis demands that sociologists study diagnosis directly in actual social contexts. To realize its full potential, then, a sociology of diagnosis demands that medical sociology return to its roots and place medical practice front and center. In the following section, I briefly describe the sweeping changes in diagnostic

practices that have taken place over the past two centuries, suggesting along the way, questions a sociology of diagnosis has asked, has not asked, or should ask.

DIAGNOSIS: FROM MEDICAL MATTER TO PUBLIC ISSUE

Emergence of Modern Diagnostic Practice

A major contribution of medical historians, such as Michel Foucault (1973), Charles Rosenberg (2002), and Stanley Joel Reiser (1978) to the sociology of diagnosis is the finding that modern diagnosis is a relatively recent invention. As Charles Rosenberg (2002) suggests, modern diagnosis did not emerge until the mid-nineteenth century. Before that time, diagnoses were fluid, fluctuating, and focused on the individual patient. Central to modern diagnosis was a conception of specific diseases that existed independently of individual patients. Each disease had a narrative or clinical course – a history, a present, and a prognosis, as well as an underlying mechanism (or pathophysiology). The practice of diagnosis, Rosenberg (2002) suggests, now consisted of locating the individual patient somewhere along this clinical narrative.

Along with diagnosis came an increasing growth and reliance on medical technology to diagnose disease. Before the nineteenth century, the physician diagnosed patients in their homes or even by letter. The primary source of data was the patient's subjective narrative, uninterpreted and accepted at face value. Beginning in the nineteenth century, the practice of diagnosis moved away from the patient's subjective narrative toward clinical signs of diseases, detected through the physician's unaided senses – palpation, observation, and percussion – which in turn gave way to a reliance on diagnostic technology. Originally designed to extend the doctor's senses, medical instruments, such as the stethoscope, otoscope, and laryngoscope, made it possible to detect "signs" of disease, apparent only to the expert. These technologies underwent exponential growth in the late nineteenth and early twentieth century, as the physician's diagnostic armamentarium expanded to include X-rays to see inside the patient's body, blood chemistries that could be measured quantitatively, and EEG's and EKG's, in which disease could be read from tracings on graphs. With the growth of diagnostic technology came changes in the social organization of medicine, as the spatial location of diagnosis moved from the patient's home to the examining

room, the laboratory, and the hospital needed to house the equipment and analyze test results. The new technologies also expanded the medical division of labor to include technicians needed to perform the tests and new medical experts and specialists needed to interpret them (Reiser, 1978).

What is significant for our purposes is the effect of diagnostic technology on physicians and patients. The new technologies solidified diagnosis as an expert system of knowledge, and augmented the power and authority of physicians, who now had a monopoly on the ability to interpret technological information – power that expanded when these diagnoses were used to determine insurance coverage, sick leave, or medical reimbursements. At the same time as diagnostic technology augmented the physician’s authority, it diminished the patient’s role in diagnosis. No longer could diagnosis rest exclusively on the patient’s subjective narrative and reported symptoms – now regarded with increasing suspicion (Reiser, 1978; Rosenberg, 2002). Rather, increasingly, numerical “tracings” and X-rays became necessary to render definitive diagnosis. Although medical students are taught to rely primarily on the patient’s history, in fact the language of case presentations and medical charts reveals a very different hierarchy, in which technology “reveals” or “shows”; the physician “notes” and “observes,” but patients “state,” “report,” “claim,” “admit,” “deny,” or “complain of” (Anspach, 1988).

Modern Diagnosis and the Hermeneutics of Suspicion

The growth of modern diagnosis and the increasing importance of diagnostic technology have created an interpretive wall between the patient’s experience of illness through pain, discomfort, and other subjective symptoms, and the physician’s technologically mediated “pictures” of disease. In this context, it made sense for social scientists to distinguish disease, a biological phenomenon, from the patient’s subjective experience of illness. As long as patients were willing to surrender their subjective experience to expert authority, the system worked well, allowing patients to make sense of their symptoms even when they could not be cured.

But mid-twentieth century medical journals suggested that cracks in the wall were developing. Numerous articles now focused on the many patients whose subjective experience clashed with medicine, patients whose behavior had become troublesome to physicians, including: patients with “asymptomatic illness,” who refused to accept a diagnosis (denial); patients who sought their doctor’s advice only to disregard it (noncompliance); patients who delayed calling the ambulance for “real” heart attack symptoms

(appraisal delay); and the growing number of patients who presented in the doctor's office complaining of symptoms of pain and discomfort with no discernable organic basis (the "worried well"). In an age of chronic illness, increasing numbers of the latter group had become a fly in the ointment to their physicians, who now faced growing bureaucratic claims on their time. I refer to these patients whose symptoms showed no organic signs as having "unsignified illness" – to create symmetry with "asymptomatic illness" (signs without symptoms). Physicians, however, often looked to psychiatry for a rich vocabulary to account for the discrepancy between disease and illness experience, such as somatizing disorder, functional disorders, or hypochondriasis. These medical explanations for troublesome patient behavior reveal what philosopher Paul Ricoeur (1974) calls a "hermeneutics of suspicion" – in which the patient's narrative is read as distorted and the distortions attributed to an underlying mechanism. When physicians suspected such patients of exploiting their symptoms to acquire "secondary gains," such as excused absence from work or pain medications, they invoked a "hermeneutics of suspicion" in a very literal sense of the word.

Mid-century patients who found their subjective symptoms invalidated had little recourse: they could find a new doctor; follow their doctors' advice to seek psychiatric help and accept stigmatization; or go home. Increasingly, however, such patients sought help from acupuncturists or other alternative practitioners, whose practices had begun to flourish (Kotarba, 1982). As the gap between disease and illness widened to become a fault line, these experiences of disappointment and invalidation would become catalysts for political action.

From Private Matter to Public Issue

By the early twentieth century, physicians had earned the exclusive right to offer officially sanctioned diagnoses. However in the ensuing century, the door was opened to public controversies about how diseases were to be defined, diagnosed, and treated. For many, the experience of being diagnosed with a disease, surviving a life-threatening illness, or having a family member diagnosed with a disease led to involvement in one of the many voluntary associations or advocacy groups that proliferated throughout the twentieth century. These advocacy groups consist primarily of family members, often parents of those diagnosed with a specific medical condition; "survivors" of such a condition; as well as professionals, researchers, and celebrities seeking a charitable cause. They include, for example, the Learning Disabilities

Association, the National Alliance for Mental Illness, and Autism Speaks. The goals of these groups include providing information on new treatments, lobbying politicians to raise funds, and promoting or supporting research into treatments that will prevent, cure, or help those diagnosed to lead “normal” lives. These organizations share the dominant view of the condition as undesirable, to be prevented, cured, or eradicated.

Advocacy groups that promote prevention, cure, or normalization stand in sharp contrast to the more radical, highly politicized groups that emerged in the wake of the civil rights and anti-psychiatry movements of the 1960s. Composed of those diagnosed with medical conditions who advocate on their own behalf, these groups challenge, protest against, or redefine dominant medical understandings of their conditions through collective action. Much has already been written about these activist groups (for an early discussion, see Anspach, 1979; for more recent, see Brown, 1990; Jutel, 2009), but I will mention three variants that promote alternative visions of political action and identity. The first is the “identity politics” that emerged in the 1970s that reconfigured the boundary between normal and pathological by challenging *definitions* of disease, disability, or deviance. These include, for example, efforts by disability rights groups to promote a “social model of disability” – that locates the cause of disability in social exclusion. The second variant is groups that challenge dominant medical ideas about the *causation* of disease. This type of activism often bridges the boundary between activism and expertise. Local communities engaged in “popular epidemiology” and breast cancer survivors who investigate links between cancer and environmental exposure are examples (for a discussion, see Brown, Adams, Morello-Frosch, Senier, & Simpson, 2010). Many of these groups encountered fierce opposition from the corporate and state interests who feared the prospect of large financial settlements. The third variant is the much-discussed communities who seek medical recognition of “contested diagnoses” – multiple chemical sensitivity syndrome, chronic fatigue syndrome, fibromyalgia – unsignified illnesses in which the pain and discomfort patients experience has not been validated by medically recognized organic signs. In the past decades, numerous online communities, organized around a contested diagnosis have proliferated. These communities seek professional recognition of their conditions as physical diseases, develop collective explanations for their suffering and distress, supply information about sympathetic providers and offer strategies for credible presentation of symptoms (Conrad & Stults, 2010; Dumit, 2006).

Autism, a frequently diagnosed but poorly understood developmental disorder, illustrates public involvement in diagnosis and treatment. Initially,

psychoanalysts attributed autism to the poor parenting of unaffectionate mothers – a view discredited in the 1980s (Liu, King, & Bearman, 2010). Even today, there is little consensus as to what causes autism (genetics, environmental exposure, or gene-environment interaction); what is responsible for the alarming rise in its prevalence (now estimated at 1 in 150); or what are the most effective treatments.

As mothers no longer received the courtesy stigma (Goffman, 1963) of having caused their children's autism, they formed advocacy organizations that lobby for legislation, promote research, and provide families with support or information on treatments. Autism Speaks, the largest fundraiser for mainstream research, advocates an "evidence-based" approach and advises parents to vaccinate their children (<http://www.autismspeaks.org>). By contrast, Generation Rescue, often identified with its spokesperson, Jenny McCarthy, supports ideas and treatments outside mainstream medicine: the view of autism as triggered by exposure to vaccines and other toxins, as well as treatment that includes a gluten and casein-free diet and chelation therapy, said to remove toxins from the body¹ (<http://www.generationrescue.org/recovery/>). Despite their differences, these groups share a view of autism as a disease to be prevented or cured, whether by conventional or unconventional means.

The internet has made it possible for persons with autism to form bonds of friendship and solidarity without face-to-face interaction, sometimes leading to identity politics. Online communities among "Aspies" (those diagnosed with Asperger's disorder), for example, have transformed a stigmatizing diagnosis into a powerful positive identity. Many members of these communities have expressed dismay at the recent decision of the APA to eliminate the diagnosis from the DSM-V (see Singh, this volume). The neurodiversity movement has provided a fundamental challenge to mainstream perspectives on autism. Neurodiversity advocates suggest that the autism spectrum should be viewed as a naturally occurring expression of the human genome. Rather than categorizing people as "normal" or "abnormal," they view normalcy, like the autistic spectrum, as a continuum that includes both neurotypical and autistic behavior. Like deaf communities that resist efforts to eradicate their culture, neurodiversity activists view autism as a way of life that should be accepted and appreciated rather than a disorder to be cured, treated, or prevented. The concept of neurodiversity offers a more complex view than can be captured by the terms "medicalization" or "demedicalization." Rather, beginning with a genetically essentialist view of autism, they use the tools of genetization to attack the very notion of normalcy, thereby turning the tools of medicalization against itself (see Blume, 1997, 1998; Solomon, 2008).

In short, the wide variety of organizations and social movements that have emerged around diagnoses suggest that the work of defining, classifying, and treating no longer belongs to medicine alone. Rather, the meaning of diagnosis is now politically negotiated among a variety of stakeholders: pharmaceutical companies with a stake in medicalizing a condition, patients with contested diagnoses who have a stake in obtaining sick leave or disability benefits; corporations that protect themselves from liability for causing illness; and advocacy organizations with a stake in presenting a disease as an alarming epidemic to secure funding or services, to name a few. But the stakes often transcend the financial: patients, who want a narrative to validate their condition or make sense of their suffering; mothers, who want to protect their children from harm; and activists, who want to be accepted rather than cured (to which we might add researchers with a stake in magnifying the scope and importance of a disorder and social constructionists with a stake in promulgating revisionist theories).

Cyberdiagnosis and the Growth of Hybrid Diagnostic Repertoires

The internet not only served as a vehicle for political action, but had other far-reaching effects. For the 80% of Americans on one side of the digital divide, it is now possible to gain access to medical information that had once been available only to health professionals. With the aid of a search engine, it is possible to find one of the hundreds of websites that have proliferated, from PubMed to Web M.D., and treatments (including alternative treatments) for virtually any medical condition.

“Cyberdiagnosis” is, of course, not the same as a medical diagnosis of a physical condition or illness, which can rarely be made on the basis of symptoms alone, and, for this reason, is unlikely to replace physicians. This said, information that was once tightly controlled by professionals is now widely available to those who own or have access to a computer. Medical sociologists (e.g., Glaser & Strauss, 1965) were once concerned with the reluctance of physicians to fully inform their patients, especially when this meant bearing bad news. Now with a click of a mouse, patients can learn all (or more than) they want to know about the medical condition they have and the kind of future (or lack thereof) that might await them.

The democratization of diagnosis, then, has narrowed the gap once separating the expert system of medicine from lay understandings, or disease from illness. To use a medical metaphor, the membrane separating the two worlds has become increasingly permeable, and medical knowledge has

diffused into popular culture (see McGann, this volume). Thus, some patients no longer have a “lay” or “everyday” experience of illness, but rather a hybrid diagnostic repertoire, a highly heterogeneous collection of medical information acquired online; a medical narrative, consisting of a history, diagnosis and prognosis; their own experience of pain and suffering, their understanding of how the disease has affected their lives and relationships, and indeed their ideas about doctors and healthcare. Much work has focused on the accuracy of medical information on the internet (for a summary, see [Conrad & Stults, 2010](#)). We do know that many patients use the internet but continue to visit physicians ([Conrad & Stults, 2010](#)). However, we know less about how patients map medical knowledge onto cultural knowledge – or how, for example, they articulate medical definitions of obesity with the popular, far more negative, connotation of the term. How patients understand and make sense of medical information acquired from the internet and other media, and how they assimilate this knowledge to their own personal experience is an important question for future research.

To be sure, as [Rosenberg \(2002\)](#) acknowledges, medicine and the lifeworld, disease and illness, have never been closed systems, and medical diagnoses, nosology, and nomenclature have always been influenced, if not shaped, by everyday life. The mass media have long served to bridge medical and popular culture. Moreover, medical diagnoses have always been influenced by popular culture. In the early twentieth century, when eugenics held sway, what is now called intellectual disability and what was then called “feeble mindedness” was divided by Henry Goddard into the moron (IQ 50–69), the imbecile (IQ 26–50), and the idiot (IQ 25 or below). To escape the pejorative connotations the terms had acquired, psychologists introduced the term “mental retardation.” But renaming does not always bring reframing, and by the 1950s, the term had become an insult, leading to subsequent name changes ([Trent, 1995](#)). Popular culture can also influence medical understandings. As historian [Thomas Laqueur \(1990\)](#) noted, the idea of male and female anatomy as fundamentally distinct resonated with ideas about sexuality in the Victorian era. Consider also a relatively new diagnosis: executive function disorder, applied to people who are disorganized and have trouble following schedules or remaining “on task.” As one website explained, “Think of executive function as what the chief executive officer of a company must do – analyze, organize, decide and execute” (<http://www.additudemag.com/adhd/article/7051.html>). The very idea of an executive function that resides in the cerebral cortex and directs subordinate functions illustrates how the metaphors of corporate capitalism are inscribed in the architecture of the human brain. Thus, expert systems are at least in part cultural products.

To the extent that they exist simultaneously in the culture of medicine and the lifeworld, physicians may also be said to have hybrid diagnostic repertoires. In addition to the knowledge acquired through years of medical school, physicians also have a stock of commonsense knowledge about patients including, for example, terms loosely borrowed from psychology (“denial”), ethnopsychology or folk theories about, for example, the psychological effects of receiving bad news (see [Anspach, 1993](#)), as well as cultural schemas about gender, class, and the behavior of various ethnic groups. The process of applying categories to individual cases is never simple or straightforward ([Cicourel, 1972](#)), and commonsense knowledge is likely to come into play. This may explain medical sociologists’ recurrent finding that patients’ perceived characteristics influence the kind of diagnosis they receive, so that, for example, women’s complaints are less likely to be taken seriously (for a summary, see [Anspach, 2010](#)). Both kinds of knowledge, guided by a hermeneutics of suspicion, are used to understand patients’ complaints of pain that are not accompanied by organic signs of disease. Is the patient “really” in pain, is she over-reacting, or (perish the thought) seeking drugs to sell on the street? Both professional and commonsense knowledge come into play when physicians decide what questions to ask the patient and how to ask them, and how likely patients are to understand what they are told.

In short, given the democratization of diagnosis and the co-mingling of professional and popular culture, I would propose that the disease/illness binary is no longer applicable to contemporary diagnosis. Rather, I suggest we use the term “hybrid diagnostic repertoires” to refer to the mix of expert cultural knowledge both physicians and patients bring to the medical encounter. The practice of diagnosis thus involves two kinds of diagnostic repertoire: the first, a highly heterogeneous collection of medical information, centered on the individual patient’s experiences and the second, an expert knowledge system of numerous diseases, intertwined with commonsense knowledge. The two repertoires meet in the examining room, sometimes colliding, sometimes coinciding.

Replacing the disease/illness binary with a view of diagnosis as the intersection of hybrid repertoires allows us to ask a new set of questions. First how does medicalization actually take shape in organizations? The process of redefining forms of deviant behavior from badness to sickness ([Conrad & Schneider, 1992](#)) is far from linear or uniform: ideas about bad behavior (juvenile delinquency) continue to exist in popular culture alongside the medical model (e.g., ADHD). Since “badness” and “sickness” exist in both professional and lay hybrid repertoires, we can ask which children are viewed as bad, and which children as sick; which children are

controlled with medication and which are sent to the principal's office or juvenile hall, and whether and how race, class, and gender enter into the process. This suggests that medical sociologists should examine not only medicalization as an historical process but medicalization-in-action, that is, how it works in actual social contexts.

Second, how does the democratization of diagnosis influence the medical encounter? To what extent and under what circumstances does using the computer give patients a kind of "cultural capital" or "cybercapital," that allows them to master medical terminology, hone their self-presentation, and narrow the social distance between themselves and their physicians, giving patients greater latitude in negotiation with their physicians? Under what circumstances are such patients treated more collegially, and under what circumstances are they rebuffed and admonished that "a little knowledge is a dangerous thing?" Does using the internet to find health information or participating in online support groups maximize patients' chances of having their complaints taken seriously, receiving expensive tests, obtaining pain medication, or obtaining a parking sticker for persons with disabilities? Do computer users consume more of physicians' time by asking technical questions, or do they save time? Are physicians more generous with their time with such patients, are they intimidated by them, or, alternatively, do they tell them to look up the details online, thereby using the internet as a substitute for face-to-face communication?

Finally, what happens to the ever-shrinking proportion of patients – estimated in 2007 to be 20% (Conrad & Stults, 2010) – who find themselves on the other side of the digital divide and, lacking access to the internet, are unable to form hybrid diagnostic repertoires? Will lack of access to the internet augment the social distance between these patients and their physicians? Will these patients, who may lack the kind of cybercapital the internet provides, find their complaints more likely to be dismissed or less likely to be taken seriously? Will they receive less time from their physicians, whose time is now consumed by internet users? Patients who do not use the internet are disproportionately African-American or Latinos (Conrad & Stults, 2010), the very patients who are likely to receive much of their primary care in emergency rooms, to receive less information about their medical care (Anspach, 1993), and to lack access to pain medication and a variety of high-technology medical treatments, from mammograms to angiograms and coronary bypass, some of which may be life-saving (Smedley, Sitith, & Nelson, 2002). Will lack of access to the internet only increase the likelihood of their receiving unequal treatment? In short, will these patients find themselves doubly disadvantaged? These are questions we have not even begun to answer.

In sum, the democratization of diagnosis raises new questions for medical sociologists about the content of both professional and patient diagnostic repertoires and what happens when they intersect in the medical encounter. As medical sociologists, we must explore these issues if our knowledge is to keep pace with changing realities.

CONCLUDING REMARKS: DIAGNOSIS AND THE PRACTICE OF MEDICINE

A sociology of diagnosis demands that medical sociologists focus on what they have ignored for some time, if sociologists of science are to be believed: the practice of medicine, or what doctors actually do when they render a diagnosis. These practices have, as I have argued, changed dramatically over the past two centuries. At the beginning of the nineteenth century, physicians based their diagnoses on patients' accounts of their subjective symptoms, accepted at face value. By the century's end, physicians regarded patients' narratives with skepticism, and required objective signs, often obtained from technology only experts could interpret. In the twentieth century, diagnostic practice moved out of the examining room and was contested publicly, as organized patients, families, and corporations debated how diseases were to be defined, diagnosed, and treated. In the past two decades, the internet democratized diagnosis, as medical information became publicly available online to all those with access to a computer. No longer, I have suggested, were expert knowledge of disease and the patient's experience of illness two distinct cultural systems, but rather hybrid diagnostic repertoires that meet in the medical encounter. Much more can be learned about the changes in diagnostic practice that have already taken place and those likely to occur in the future.

Whether the disease is Asperger's disorder, PTSD, or ADHD, a sociology of diagnosis demands that we examine the full array of sites in which diagnosis is practiced, from the examining room to the court room, to the laboratory, to radiology departments – to which we now must add cyberspace. Because diagnosis is no longer merely a medical matter, we need to study more than the physicians and patients mentioned in this essay. A focus on diagnosis as practice suggests that we must consider all of the actors involved in diagnosing illness, including, to name a few, physicians' assistants, laboratory assistants, phlebotomists, X-ray technicians, pathologists, teachers, psychologists, pharmaceutical executives, insurance adjusters, and parents.

Throughout, I suggested some questions sociologists can and should ask, including, for example, the content of patient and professional hybrid

diagnostic repertoires, and what happens when these repertoires are called into play in the medical interview. But there are many other questions to be asked. We might ask, for example, about the health consequences of diagnosis (see Timmermans & Haas, 2008) – the impact of receiving a diagnosis of terminal or stigmatized illness on patients' health and well-being. Does the stigma of obesity lead patients to change their health behavior or only magnify their depression? Finally, we might ask whether and how changing diagnostic practices affect diseases themselves. For example, as Liu et al. (2010) have suggested, once mothers were no longer blamed for causing autism (viewed at the time as a rare disorder), they were eager to have their children who might otherwise have been diagnosed with ADHD or developmental delay, given a diagnosis of high- or low-functioning autism to make them eligible for services that would otherwise not have been available. This, in turn, contributed to the rising rates of autism some call an "epidemic." In this sense diagnosis may be seen as performative, transforming the very phenomenon it describes.

These questions are important, but a sociology of diagnosis must begin by examining how diagnosis is actually performed in actual situations. I conclude by retelling an often-quoted story told by Harold Garfinkel:

In 1954 Fred Strodtbeck was hired by the University of Chicago Law School to analyse tape-recordings of jury deliberations obtained from a bugged jury room. Edward Shils was on the committee that hired him. When Strodtbeck proposed to administer Bales Interaction Process Analysis categories, Shils complained: 'By using Bales Interaction Process Analysis I'm sure we'll learn what about a jury's deliberations makes them a small group. But we want to know what about their deliberations makes them a jury.' (Garfinkel, Lynch, & Livingston, 1981, p. 133)

To extrapolate: our goal as medical sociologists should not only be to ask what makes medicine a profession or an institution of social control – however important these questions may be. Rather, our fundamental goal should be to understand the *practice* of medicine or what makes medicine "medicine." Because diagnosis is at the center of medical practice, this volume is an important step in that direction.

NOTE

1. The widely-publicized view linking vaccines to autism suffered a recent blow when its principal medical proponent, Dr. Andrew Wakefield, was accused of misrepresenting his data in an article *The Lancet* removed from the journal (Deer, 2004).

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INTRODUCTION: LOOKING WITHIN FROM WITHOUT

Throughout the late 19th and early 20th centuries, one of the many techniques used by physicians and psychiatrists to diagnose patients involved external and highly public examination. Typically conducted as a lecture to other medical experts and students, the patient was placed in the center of a round room with onlookers arranged in tiered seating to guarantee an unobstructed view. As the lead physician detailed the list of symptoms, using the patient's body as an illustration, observers witnessed the behavioral signs for themselves and discussed the possible underlying conditions or pathologies. This process of consultation and naming worked to increase the relative reliability among experts and bolster the professional reputations of medicine and psychiatry alike (Conrad & Schneider, 1992; Gillis, 2006; Grob & Horwitz, 2010). As researchers have noted (Aronowitz, 2001; Foucault, 1973), this change from focusing on disparate, idiosyncratic symptoms as expressions of individual illness to a system that recognized disease states comprised of symptom clusters marks a historical turning point in the history of medicine. The shift toward a classification scheme that linked medicine with science and technology bolstered medical authority and the power of physicians. In addition to professional credentials, accumulated knowledge, and institutional legitimacy, the authority of modern medicine both rests on and is expressed by medicine's decisive power to name and categorize through diagnosis (Jutel, 2009). Even as medical prestige has eroded, ceding some of its power to other entities,¹ physicians remain the final arbiter of official medical categories (Pescosolido, 2006), judges of what is, and what is not, a "real" diagnosis. In the diagnostic process, one looks *within* to reveal the nature of disease from *without* – empirical observation becomes immutable fact. Of course, as critical perspectives on medicine have long pointed out (Conrad & Schneider, 1992; Zola, 1972), the scientific "fact" of one time and place is the mythology or ignorance of another. Diagnosis, as both category and process (Blaxter, 1978), is infused with all manner of things social, historical, and cultural. This volume explores some of these infusions. In so doing, it aims to clarify and contribute to the emerging

sociology of diagnosis – an endeavor first called for by [Brown \(1990\)](#), but more recently revived by [Jutel \(2009\)](#).

If diagnosis may be characterized as “looking within from without,” the project of developing a coherent sociology of diagnosis, oddly enough, involves the same process in reverse – looking out from within. To create space for a sociology of diagnosis it is necessary to look beyond the boundaries of medical sociology, even while standing firmly inside its borders. Medical sociology and diagnosis both connect and diverge; yet effort to disentangle the two is necessary. As [Jutel \(2009\)](#) explains:

... the sociology of diagnosis does not have a clear identity or literature, hanging more on the coat tails of medicalisation, disease theory and history of disease. It's not that diagnosis has been excluded from medical sociology, it's simply that it has been well buried in these and other areas of focus, and whilst pivotal, it hasn't been clearly isolated from these interests. (p. 279)

In this vein, we have developed a volume that more clearly delimits the boundaries of the field, beginning with diagnosis and then moving outward to medical sociology and beyond. Indeed, by expanding the purview of a sociological approach to diagnosis we work toward greater precision in examining and explaining issues related to health, illness, and medicine. With this said, it is clear that a “sociology of medicine” framework alone is insufficient to account for the wide variety of social phenomena linked to diagnosis. Again, diagnosis constitutes one of the many topics medical sociology has engaged, in studies of the construction of medical knowledge and contested illness, for example. But while diagnosis has been intertwined with medicalization ([Jutel, 2009](#)), it has also extended beyond medical sociology to the sociology of deviance, culture, social movements, and the sociology of knowledge.

The latter is perhaps especially intriguing given that calls for sociological work focused explicitly on diagnosis were issued within a month of each other from separate ends of the globe. As this volume was being conceptualized, *Social Science & Medicine* was preparing a call for papers for a special issue on diagnosis to be edited by Annemarie Jutel and Sarah Nettleton. After lying dormant for years, the field of diagnosis grew exponentially within a very short period. Between these efforts, the focus and purpose of a sociology of diagnosis has begun to take shape – its boundaries and topics defined, theoretical affinities mapped, and its relationship to health, medicalization, and medical sociology clarified.

This volume explores and surveys the breadth of diagnosis through empirical reports, theoretical statements, and conceptual contributions that

investigate diagnoses and the diagnostic process from diverse perspectives. This breadth is possible because diagnosis does a substantial amount of cultural “work” in health and medicine (Bowker & Star, 2000). Diagnoses “organize” illness (Balint, 1964) and give individuals “permission to be ill” (Jutel, 2009, p. 278; see also Nettleton, 2006). They guide the parameters of medical treatment (Rosenberg, 2002), are integral to resource allocation and research (Horwitz, 2002), and allow access to various goods and health services (Dumit, 2006). Diagnoses are embedded in social relationships, serve as the basis of identity formation and management, and are a driving force in social movements (Brown & Zavestoski, 2004; Kirk & Kutchins, 1992; Klawiter, 2004). Additionally, diagnoses reflect and shape social concerns (Conrad & Potter, 2000; Scott, 2006), operating as cultural signposts helping to define what is abnormal and deviant (Armstrong, 1995; Conrad & Schneider, 1992). Diagnostic processes intersect with a host of issues tied to inequality including sexuality (Jutel, 2010; McGann, 2006), gender (Bryant, 2006; Dreger, Chase, Sousa, Gruppuso, & Frader, 2005), race (Thornton, 2010), and body shape/size (Ferraro & Holland, 2002). As such, diagnoses often become sites of contestation (Zavestoski et al., 2004), turf battles (Brown, 1995), and opposition to institutional authority (Mayes & Horwitz, 2005; Whooley, 2010). Indeed, as this volume illustrates, diagnosis accomplishes all these things and more.

To encompass the multifaceted nature of diagnosis, the volume is arranged in five parts that outline and elaborate the contours of the field thus far: Frameworks, Context, Contestation, Identity, and Social Control. We begin by framing conversations around diagnosis – reviewing extant knowledge, differentiating diagnosis from areas such as medicalization, and specifying the social grounding of diagnosis and its functions. Next, we consider how diagnostic work is contextualized and how context influences the process of diagnosis. Here authors explore diagnosis in relation to nation, culture, institutions, local organizations, and face-to-face interaction. The third part takes up the question of how context matters when invoked in contests over authority, definition, and disciplinary turf. Because these struggles often relate to identity formation and management, the fourth part considers how diagnoses shape and are shaped by social identities. Finally, we step back and take a broader view to consider how diagnosis connects all of these topics through social control processes. That the theme of social control emerges to differing degrees throughout the book highlights the power dynamics involved with nosological pursuits.

In Part I, “Frameworks,” we present several essays in the sociology of diagnosis that situate the volume and the field more generally. Annemarie

Jutel's (2009) touchstone essay provides a roadmap of recent literature surrounding the terrain of diagnosis. As she makes clear, medical sociology has often encompassed aspects of diagnosis, but the field has not yet coalesced. Jutel's essay sets an ambitious agenda that the authors in this volume take up wholeheartedly. While Jutel better situates diagnosis in relation to medical sociology, Karl Bryant takes some of these connections apart by clarifying the distinction between medicalization and diagnosis. Since diagnosis has often been subsumed under the rubric of medicalization, his analysis of their differences and similarities stands as an important contribution. Using the case of Gender Identity Disorder in Children (GIDC), Bryant illustrates how diagnoses may simultaneously solidify the medicalized status of a given phenomenon *and* create resistance to that status. Although we typically think of diagnosis in relation to individuals, Thomas DeGloma shows that posttraumatic stress disorder (PTSD) is a powerful cultural script that can also be wielded to diagnose the *social* realm. Through this, DeGloma reminds us that diagnoses are not only influenced by moral and political agendas but may be used to *set* them as well.

Part II, "Context," moves into classic sociological territory, exploring how cultural, institutional, and interactional contexts shape diagnoses. Manuel Vallee's essay illustrates how nation and temporality impact the process of diagnosis through an analysis of French child psychiatry's resistance to *DSM-III* AD/HD classification and its associated biological reductionism and emphasis on pharmaceutical treatments. Although many analyses have noted diagnostic differences between developed and developing countries, Vallee's study shows how cultural differences between "developed" countries structure diagnostic categories. While the cultural lens provides a wide-angle look at diagnostic context and practice, Kerry Dobransky's essay narrows the view by exploring how local institutional contexts influence patient treatment in a mental health care facility – sometimes in ways that conflict with official psychiatric labels. Dobransky shows that "organizational labels" determine treatment and shape staff interactions as powerfully as do the labels imposed by psychiatric authorities. These unofficial labels then loop back on patients such that therapeutic treatment plays out in punitive fashion. Lastly, Rebecca Godderis details how standardized institutional and interactional contexts influence the diagnosis of highly individualized distress experience. Relying on in-depth interviews with psychiatrists, Godderis provides a counter-point to the many critiques of standardization – even while calling for a more critical look at specific practices that construct and support this same standardizing trend.

In Part III, “Contestation,” authors consider the contested nature of diagnoses as sites for definitional struggle, turf battles, and sometimes, compromise. Georgiann Davis analyzes intersex terminology to explore a case of *intergroup* contestation. She documents how advocates and activists successfully reframed intersex as a social, rather than biological issue. In doing so, a nomenclature shift from “intersexuality” to “disorders of sex development” (DSD) occurred, which allowed physicians to reclaim some authority over intersex. Davis’ work, therefore, is an important contribution to the long-standing tradition of scholarship on turf battles and diagnostic struggle. Mary Burke investigates the much more rare phenomenon of *intragroup* contestation. Whereas medicalization studies document patient resistance to diagnosis and the expansion of medicine, literature on contested illness documents how would-be patients work to achieve diagnosis and thereby increase medicalization (Conrad & Stults, 2008). Burke’s research illustrates the contest over a diagnosis within a “patient” community, as some transgender activists work to end medicalization by dismantling the Gender Identity Disorder (GID) diagnosis, while others work to reform the diagnosis and thereby preserve medicalization. The former see GID as constricting and pathologizing, while the latter counter that GID helps secure treatment access. As a result, GID is constructed in a contradictory symbolic position – simultaneously normalizing and stigmatizing. Finally, Paul Fuller investigates how lay people and professionals navigate contradictory knowledge claims and conflicts around AD/HD diagnoses. He finds that lay and professionals use similar navigation techniques, but for very different purposes – purposes that are often at odds with each other. Taken together, the case studies in Part III suggest that whether between or within groups, contestations over diagnosis have profound implications for people’s relationships to each other and to diagnosis.

Part IV, “Identity,” presents contributions from scholars who link diagnoses to both individual and social identities. Jennifer Singh details the efforts of the Asperger’s community, as members attempt to maintain a diagnosis-based identity even as the diagnosis disappears. With the approach of *DSM-V*, Asperger’s disorder “vanishes” into the autism spectrum disorders, taking with it the institutional basis of the “Aspie” community. Thus, members are left to define new boundaries of both individual and collective identity. Elizabeth Bringewatt also explores how diagnoses are related to identity, but by understanding the positive and negative implications for children diagnosed with AD/HD. Because parents often act as intermediaries for their children, the identity ramifications of an AD/HD diagnosis may not be immediately clear. Indeed, in her interviews

with adults diagnosed with AD/HD as children, Bringewatt finds that people eventually understand the diagnosis as simultaneously empowering and stigmatizing – providing relief, while being something they often keep secret. Satoko Itani explores how the introduction of the GID diagnosis in Japan increased social awareness of transsexual identity. At the same time, however, the diagnosis led to a form of “transsexual fundamentalism” that reinforced the traditional gender binary and created distinct and opposing groups: normal transsexuals with a legitimate GID diagnosis and perverted transsexuals without. Itani’s analysis illustrates how a diagnosis may bring recognition to a condition and act as the basis of an identity claim, while delegitimizing other claims and cutting off access to institutional resources.

We began the book with broad analytic themes, narrowed in to consider contexts and contestations, and then narrowed further still to look at individuals and identities. In Part V, “Social Control,” we reverse the trajectory, moving from individuals and their interactions to contexts, where we consider dynamics that link back to general social processes and larger social arrangements. Sarah Whetstone and Teresa Gowan detail how the state becomes a *de facto* agent of diagnosis when sentencing criminal offenders as “drug addicts.” In drug courts, offenders are encouraged and motivated to identify as addicts in exchange for the therapeutic promise of the sick role: mitigated culpability and moral sanction. However, as Whetstone and Gowan illustrate, in “strong-arm” rehabilitation the biopsychological addiction discourse neither exempts addicts from moral judgment nor lessens their blame. Instead, biomedicine works in the service of the state as structured inequalities distort therapeutic aims, infusing the medical model with the punitive register it attempts to replace. Finally, returning to themes with which Jutel began, McGann cautions scholars not to leave a core insight behind as the sociology of diagnosis emerges from medicalization studies. Although diagnoses are cultural constructs permeated with moral judgments, the institutionalization of diagnoses in medical texts and practice reifies and naturalizes them. These processes are reinforced by the diffusion of medical frameworks into the vernacular and the increasing presence of diagnosis in everyday life, making it easy to focus on the benefits of diagnosis in lieu of its social control potential. McGann reminds us that seemingly scientific entities are sociopolitical achievements marked by the conditions of their creation.

Diagnoses, and their attendant results, comprise important terrain for sociological study. While medical sociologists have not *ignored* the importance of diagnoses, they have not been systematically investigated either. The time has come to seriously consider the role of diagnosis, the

power of categories, nosological authority, and the meanings attached to the named conditions of health and illness. Indeed, as the research on diagnosis accumulates, this volume and concurrent work in the field has contributed to solidifying the nascent “diagnostic turn” in sociology and related realms (McGann, 2011). The work in this volume represents more than simply a starting point for discussions of diagnosis – it is also a means with which to organize the conceptual landscape of an emerging field. The editors and authors of this volume invite readers to explore the work within, and experience how diagnoses connect to a wide expanse of sociological topics. As more research critically considers diagnosis as both category and process (Blaxter, 1978), we believe that the field will continue to grow and develop in ways that enhance the overall project of sociology and medicine alike.

NOTE

1. Such as managed care, pharmaceutical companies, allied professionals, and even patient advocacy (Conrad, 2005; Furedi, 2006).

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PART I
FRAMEWORKS

SOCIOLOGY OF DIAGNOSIS: A PRELIMINARY REVIEW[☆]

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ABSTRACT

Purpose – This chapter presents a case for reframing medical sociology to focus on diagnosis as a pivotal category of analysis via an extended literature review of the diagnosis as a tool of medicine.

Methodology/approach – Conceptual overview.

Practical implications – By reviewing the range of social functions served by diagnosis, and the similarly wide assortment of social forces that shape diagnostic categories, this chapter pushes social scientists and theorists to consider diagnosis as a cornerstone to the understanding of health, illness, and disease.

Originality/value of paper – Building on Brown's earlier call for a sociology of diagnosis, this chapter sets forth potential parameters for this field. It defines how the study of diagnosis is dissipated across myriad areas of scholarship, including medicalization, disease theory, ethics, classification theory, and history of medicine. Extirpating diagnosis and

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Sociology of Diagnosis

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revealing it for specific discussion provides an opportunity to study topics such as illness experiences, health social movements, and disease recognition from a different and rich perspective.

Keywords: Sociology of diagnosis; medical sociology; medicalization; nosology; disease categories

Diagnoses are the classification tools of medicine, and are pivotal in the ways medicine exerts its role in society. Their sociological study is commonly subsumed under the rubrics of medicalization, history of medicine, and theory of disease. Diagnosis is, however, a powerful social tool, with unique features and impacts, which deserve their own specific analysis. The process of diagnosis provides the framework within which medicine operates, punctuates the values that medicine espouses, and underlines the authoritative role of both medicine and the doctor. Diagnosis takes place at a salient juncture between illness and disease, patient and doctor, complaint and explanation.

Despite calls for its establishment, more than a decade ago (Brown, 1995), there is not yet a clear sociology of diagnosis. This book draws together a number of threads of medical sociology that potentially contribute to the sociology of diagnosis, including the relationship between diagnoses and medicalization; the import of social context in diagnostic processes; issues of “turf” related to diagnostic tension and category contestation; links between diagnoses, diagnosis, and identity; the political nature of nosology; and issues of medical social control.

Even while diseases have actual biological and clinical existence, scholars of the sociology of diagnosis must consider them as more than just given, a priori entities. It is incumbent upon social and cultural thinkers to consider how and why particular diseases are framed as they are, why some conditions attract public and medical attention (and others don't), and why some diagnoses are seen as desirable and legitimizing, while others are shunned for their stigmatizing effects. The social framing and consequence of the diagnostic label play a significant role in how we understand and negotiate health, disease, and illness.

Diagnoses are the classification tools of medicine. They do what Bowker and Star refer to as “work”: segmenting and ordering physical, bodily states, valorizing some, disregarding others, and in any case, exerting an important material force (1999). A diagnosis is both the preexisting set of categories agreed upon by the medical profession to designate a specific condition it considers pathological, and the process, or deliberate judgment, by which such a label is applied (Blaxter, 1978). The diagnosis organizes the individual

illness: identifying treatment options, predicting outcomes, and providing an explanatory framework. Administratively, the diagnosis administers, enabling access to services and status from insurance reimbursement to restricted-access medication, sick leave, support group membership, and so on.

Once diagnosed, an individual has permission to be ill. What was previously a *complaint* is now a *disease*. Light duty, rest, sick leave, and disability payments are authorized as the individual becomes patient and (in some cases) pampered. Diagnosis provides what [Parsons \(1951\)](#) referred to as “a claim for exemption.” The individual who is ill finds him or herself treated, rather than blamed, for imputed deviance ([Freidson, 1972](#)). The diagnosis integrates the afflicted individual in ways previously not enabled, with the allowance for, or tools to palliate and explain what makes him or her different (deviant) from the norm.

One can read via diagnosis a cultural expression of what society is prepared to accept as normal and what it feels should be treated. Witchcraft, homosexuality, and the tendency of slaves to abscond (drapetomania) have all been diagnosed as diseases in the past ([Cartwright, 1981](#); [Gevitz, 2000](#); [Mendelson, 2003](#); [Metzl, 2009](#)). There are similar contemporary examples such as erectile dysfunction, excited delirium, and undoubtedly others that are likely to look as value-laden and as culturally fraught as witchcraft to future researchers once time has elapsed and some historical distance is available. I will touch on these specific examples later.

Diagnosis guides medical care. It organizes the clinical picture, determines intervention, and provides a framework for medical education. But diagnosis also defines professional medicine. The ability to construct a medical diagnosis from a complaint and physical or biological findings sets the doctor apart from the layperson and other professionals, confirming the medical practitioner’s greater knowledge and status, as well as medicine’s authority ([Freidson, 1972](#)). Diagnosis also structures relationships within the profession, defining who should assume responsibility for particular disorders ([Rosenberg, 2002](#)): this complaint to the general practitioner, that one to the immunologist, the hematologist, or the rheumatologist.

On the one hand, diagnosis is interpretive and organizational ([Balint, 1964](#)). It provides structure to a narrative of dysfunction, or a picture of disarray, and imposes official order, sorting out the real from the imagined, the valid from the feigned, and the significant from the insignificant. On the other, diagnosis is an important site of contest and compromise because it is a relational process with different parties confronting illness with different explanations, understandings, values, and beliefs. The misfit between patient

and medical explanatory models may result individually in unsatisfactory therapeutic values and goals (Kleinman, Eisenberg, & Good, 1978), or collectively generate politicization of illness, with social movements and disease advocacy groups battling for recognition, funding, and other forms of support (Brown & Zavestoski, 2004).

Brown (1987, 1990, 1995) is perhaps the only scholar to have made an explicit call for a sociology of diagnosis, arguing that understanding diagnosis provides an important insight into how we understand disease, health, illness, and the forces that shape our knowledge and practices. However, the sociology of diagnosis does not have a clear identity or literature, riding more on the coattails of medicalization, disease theory, and history of disease. It's not that diagnosis has been excluded from medical sociology; it's simply that it has been well buried in these and other areas of focus, and while pivotal, it hasn't been clearly isolated from these interests. Extirpating diagnosis and revealing it for specific discussion provides an opportunity to study an array of topics from a different perspective, for example, patient–doctor interaction, medicalization, illness experiences, health social movements, and disease recognition.

Volume 12 of the *Advances in Medical Sociology* series aims to display a range of works discussing diagnosis in order to encourage sociology to define and analyze the specific role of diagnosis in medical sociology. This introductory chapter takes a quick stroll around a range of publications that set the scene for this book, highlighting the work that diagnosis does in cultural and social settings, as well as the traces of social and cultural forces embedded in diagnostic labels.

MEDICINE AND DIAGNOSIS

The Naming of Diseases

Ancient Greek medicine did not have a medical terminology: “So long as medical knowledge was restricted, a narrative descriptive style was used to evoke a picture of a disease, where nowadays one word, a simple disease name, would suffice” (Veith, 1981). The lack of nomenclature reflected a lack of systematic knowledge of the nature of disease, which, according to Fischer-Homberger, a number of eighteenth century physicians threw themselves at correcting. Thomas Sydenham, who many, including Foucault (1975), see as the father of classificatory medicine, sought “the improvement of physick” (Sydenham, 1742, p. iv) by classification. It provided the doctor

with a tool to “distinguish [a disease] from all other distempers” (p. xvi). Sydenham followed a botanical model of classification, listing the characteristics of diseases as one might the petioles or the sepals of a flower. Fischer-Homberger (1970) explains that nosology served to further medicine as a science, providing a linguistic means to rein in its unintelligible and confused inconsistencies (p. 401).

Not all doctors felt that disease was ontological, or a natural entity waiting to be named, as assumed by Sydenham and many of his followers. Broussais (1828), for example, vehemently opposed such a conceptualization, and believed instead that organs transmitted stimuli from one part of the body to another, causing and propagating illness.

Regardless of the epistemological perspective that underpinned the various approaches to diagnosis, this classificatory project saw medicine shift its focus from individual symptoms to groups and patterns of symptoms that doctors could reliably recognize. Clinical medicine, according to Foucault (1963), removed the symptom from its previously supreme position, seeing it instead as simply one element in a symptom cluster that would constitute the disease.

Historian Lester King (1954) describes historical disease construction as pattern recognition that takes on new and different forms as knowledge changes:

What one epoch calls a disease is, to a later period, only a symptom. A pattern has reasonable stability only when its criteria are sharp, its elements cohere, and its utility in clarifying experience remains high. Let these factors become blurred, and the erstwhile disease, as a well-defined and useful class, will melt away. (p. 202)

King’s words reflect the fact that medicine is temporally situated, and makes its diagnoses on the basis of the technology and values available at a specific point in time. As an unidentified writer penned in the *British Medical Journal* in 1886 (Anon., 1886), “The imperfection of our medical vocabulary is not a matter for surprise. It is the measure and gauge of the imperfection of our medical knowledge, and only perfect knowledge admits of a perfect nomenclature” (p. 1116). Rosenberg describes a range of technological innovations that served to present objective images of disease, such as the ECG, the X-ray, and the manometer, and to “operationalize” diseases, providing a deeper texture and substance to their description (2002). Although this volume does not address it directly, technology continues to frame diagnostic classification as the human genome project, advanced imaging techniques, and prenatal screening highlight.

Diagnoses also emerge as individuals, professions, or society dynamically modify the boundaries of what they consider respectively normal and problematic. Aronowitz (2001) argues that “although biological and clinical factors have set boundaries for which symptoms might plausibly be linked in a disease concept, social influences have largely determined which symptom clusters have become diseases” (p. 803). The status of homosexuality in the *Diagnostic and Statistical Manual of Mental Disorders (DSM)* is one useful example. Kirk and Kutchins (1992) expose the degree to which political battles and controversies shaped the taxonomic project of modern psychiatry, using the status of homosexuality in the view of American psychiatry as one example among others. During the preparation of the *DSM-III*, gay activists adamantly objected to homosexuality’s then-categorization as mental illness. They sought public acknowledgment of their position via disruptive protests at the *American Psychiatric Association* conventions. The cumulative effect of their collective action was compounded by media attention and the personal ambition of the chair of the committee appointed to oversee the *DSM* revision process and resulted in the removal of homosexuality as a diagnostic category.

Seeking agreement about what conditions should be awarded diagnostic status serves a range of practical purposes. Bowker and Star (1999) write that classification “provide[s] a stabilizing force between the natural and the social worlds. [It holds] in place sets of arrangements that allow us to read the natural as stable and objective and the social as tightly linked to it” (p. 87). Diagnostic classification satisfies a range of needs, from health data collection, to the determination of treatment protocols, public planning, and marketing strategy (Bowker & Star, 1999). As a classification project, diagnosis captures and serves different ideologies. Hacking (2001) explains that “the idea of nature has served as a way to disguise ideology, to appear to be perfectly neutral. No study of classification can escape the obligation to examine the roots of this idea ... no study of the word ‘natural’ can fail to touch on that other great ideological word, ‘real’” (p. 7). Hacking’s discussion points to the fact that classification is seeking out the picture of an object, a “fixed target,” which is true to nature.

The *International Classification of Diseases (ICD)* is the diagnostic inventory that underpins medical practice in much of the world. Despite the range of uses which medicine makes of it today, its original purpose was to produce mortality statistics. Each revision of the *ICD* starts with a detailed historical exposé of its genesis and subsequent revisions, given the influence that the decisions taken at the time of each revision hold over its subsequent editions. Many of its contemporary categories are residual,

hearkening back to historical ways of clinical practice: symptom-focused, ontological, or anatomic-pathological medicine. Blaxter (1978) has written that contemporary diagnostic categories are best viewed “as a museum of past and present concepts of the nature of disease” (p. 10).

Blaxter (1978) also points out the complexity and fragmentation of diagnoses, which reflect a similarly disjointed body of knowledge in medicine, a point which Bowker and Star (1999) underline as well. A glance through the *ICD*, for example, reveals diagnoses assembled on the basis of cause, description, site or symptom, syndrome, variation from statistical norm (hyper and hypo, this or that, under or overweight) and even treatability. She captures the fractured nature of diagnostic categories by quoting Kendall, who charmingly writes:

In fact the diseases we currently recognise are rather like the furniture in an old house, in which each generation has acquired a few nice pieces of its own but has never disposed of those inherited from its predecessors, so that amongst the inflatable plastic settees and glass coffee tables are still scattered a few old Tudor stools, Jacobean dressers and Regency commodes, and a great deal of Victoriana. (Kendall as cited in Blaxter, 1978, p. 10)

This reference to the historicity of diagnostic categories provides a convenient introduction to the next section, in which I explore how specific diagnostic categories have emerged at particular junctures, stemming from political action, cultural context, and technological advancement.

“New” Diseases

The emergence of specific diagnostic labels provides a heuristic to the student of diagnosis. The process by which particular conditions become firstly described in medical terms, and secondly become incorporated as disease concepts, shows how social elements influence and frame diagnoses, and lead decision-makers to view a diagnosis as validating a reality that is simply waiting to be discovered (Goode, 1969), or which can be taken-for-granted (Scott, 1990). This speaks to Hacking’s comments on the intense interest in the classification of people. The focus is on “a picture of an object to be searched out, the right classification, the classification that is true to nature, a fixed target if only we can get there” (Hacking, 2001, p. 11).

Brown (1995) has described the stages of social construction of disease that are typically part of the disease discovery process. These include lay discovery, social movement, professional, and organizational factors. The histories of individual diseases illustrate this social construction quite usefully.

Wilbur Scott's account of Posttraumatic Stress Disorder's (PTSD) incorporation into the *DSM-III* provides a detailed account of the considerable individual and collective effort required to obtain acknowledgment that the psychological distress of numerous Vietnam veterans was something different from the psychosis, cowardice, or malingering to which it had previously been attributed (1990). The effort was political, involving negotiation, relationship management, and persuasion. Scott recounts this as an example of how diagnosis brings conditions forward as "always-already-there objects in the world" (p. 295), via a convincing display of objective evidence: "a discovery of what was present but previously unseen" (p. 295). The agents in this particular political process were cognizant of the fact that it did not suffice for the condition, as they saw it, to be a real-thing-in-the-world: those with control over classificatory processes needed to be brought to face the realness of the diagnosis by concerted and repeated efforts. Choosing how to speak of the disorder, with whom to discuss it, when to have said discussions, and how to use collective action was instrumental in its inclusion in the *DSM-III*.

Scott's (1990) description brings to the fore each step in Brown's (1995) model of social discovery. Lay discovery by individual veterans, buttressed by the social movement of veteran organizations were pivotal in the acceptance of PTSD in the *DSM-III*. As Brown has written is to be expected in lay-led discovery, the promotion of this particular label was also reliant upon professional backing of the lay movement, which in this case, came from a variety of sources, including the director of Manhattan State Hospital, psychiatrists Lifton and Shatan, and social worker Sarah Haley who played a pivotal role in reporting the traumatism of war veterans to the *American Psychiatric Association's* working group. Ultimately, institutional factors, that is to say, inclusion in the *DSM*, would solidify PTSD's disease status.

In contrast, Alzheimer's disease did not follow all of the stages that Brown (1995) has described. Not that this is problematic. Brown has clearly stated that not all disease discovery follows all of the stages, or necessarily in the same chronology as in his model. In the case of Alzheimer's disease, which was named in the early twentieth century, professional factors come to the fore, and lay participation played a much later role; one which is notable more for the promotion than for the creation of the diagnosis. The professional factors revolve both around scientific discovery (technology) and interprofessional relationships.

Two different neuropathological schools, respectively, in Munich, where Alzheimer worked in Kraepelin's laboratory, and in Prague, where Fischer worked under Pick, were involved in a range of discoveries that were to frame

Alzheimer's disease (Amaducci, Rocca, & Schoenberg, 1986). Previous medical literature described dementia in purely clinical terms and linked it with normal aging. The introduction of new staining and autopsy results enabled Alzheimer and his colleagues to identify "neurofibrillary tangles," while simultaneously, presumably using similar technology, Fischer described "senile plaques." Both lesions are considered characteristic of what we call Alzheimer's disease today. However, scientific rivalry between the schools at Munich and Prague, and between Alzheimer and Fischer resulted in a range of explanatory claims and descriptions for these disorders including Fischer's plaques, Fischer's presbyophenia, and of course, the now-assimilated Alzheimer's disease (Amaducci et al., 1986).

The nosological discussion was not resolved by technological advances, but by Kraepelin, the director of the department in which Alzheimer worked, a researcher whose own work was devoted to the classification of psychiatric disorders and disease categories. He assigned his junior's name to the diagnosis of presenile dementia. Amaducci et al. (1986) surmise that this action was taken to consolidate the position of both Kraepelin's school and of his researcher, and comments that Kraepelin's reputation and authority were of primary importance in the creation and perpetuation of this particular diagnosis. It also would likely be safe to presume that Kraepelin's particular focus on taxonomy (see Kahn, 1957) may have contributed to his interest and success in assigning the name to the condition.

Fox (1989) further maintains that the context of medicine at the time of these discoveries enabled the creation of this diagnosis. Alzheimer believed that the changes he saw in the brain tissue were due to more than just ageing. Fox writes: "The elimination of the age criterion was central because it contributed to the transformation of what had been generally considered "senility" into a specific disease with specific pathological characteristics and symptoms" (p. 59). Fox also describes lay social movements, including the push from family members of Alzheimer's patients, which, from the mid-twentieth century, rallied behind the Alzheimer's disease label to bring it forward in public consciousness, generate research interest, and promote its diagnostic status, as well as its characterization as a leading cause of death.

Diagnostic Authority and Medicalization

Medicine's authority is embodied in diagnosis at the institutional and individual levels. We will discuss later how other organizations and interests promote medicine's authority, above and beyond medicine itself. For the

profession, diagnoses and their classificatory systems exist as an important collective arrangement that both defines and enables medicine's promotion and influence. The authority of medicine, according to [de Swaan \(1989\)](#), resides in such professional accords about scientific medicine.

At an individual level, the ability to assign the diagnosis confers power to medicine and its agent, the doctor, as allocator of resources ([de Swaan, 1989](#)). As discussed previously, the diagnosis legitimizes sickness. When a doctor deems a patient's condition to be medical, the latter receives previously unauthorized privileges such as permission to be absent from work, priority parking, to be insurable, reimbursement for treatment, or access to services. The doctor certifies the medical nature of the complaint, and "medical advice" informs administrative and policy decisions.

[Freidson's \(1972\)](#) work on professional dominance focuses on the important role of diagnosis in reinforcing medical authority. It is, he postulates, "the ... foundation upon which the strength of a profession rests ... which establishes and supports the profession's claim to honor, income, and power. Where illness is the ubiquitous label for deviance in an age, the profession that is custodian of the label is ascendent" (p. 244). He continues, diagnosis is the mission of the doctor, whose task is "to authoritatively label as illness what a complainant suspects to be illness, and also to label as illness what was not previously labelled at all, or what was labelled in some other fashion, under some other institution's jurisdiction" (p. 261).

Authority in medicine comes from its ability to define and delimit behaviors, persons, and conditions write [Conrad and Schneider \(1980\)](#), but also from the organization and structure of the medical profession. Medicine has an officially approved monopoly over the right to define health and to treat illness, which results in its high public esteem ([Freidson, 1972](#)). The doctor, as the agent of medicine, is accorded a prominent position on the hierarchy of expertise, and a mandate to exercise his or her authority, over that of say, other health professionals, in addition to over lay people ([Freidson, 1972](#)).

The medical dominance articulated by [Freidson](#) is not, however, immutable. In 1988, [Light and Levine](#) argued that the power of the medical profession was already in decline as evidenced by the introduction of malpractice lawsuits, profit-driven administration of physician performance, and cost-management strategies in medicine. More recent evidence of change in the status of doctors is present, according to [Lupton](#), in increasing patient complaints, increasing use of alternative therapies, media portrayals of doctors, and lack of financial autonomy ([1997b](#)). Further, wider access to information has led to changes in the doctor-patient relationship, with

patients more willing to challenge their doctor, dispute findings, or seek advice outside of the doctor–patient relationship (Lupton, 1997a). The authority to diagnose some medical conditions has also been expanded to include other professional categories. In New Zealand, for example, a chiropractor or physiotherapist may diagnose certain conditions and grant access to Accident Compensation Corporation benefits and services.

This is not to say that medicine no longer has authority. The biomedical expertise of those trained to practice medicine still carries much weight (Lupton, 1997a). The practice of medicine, as well as its authority, is socially contingent, and is framed by broader socio-technological change (Nettleton, 2004). Nettleton discusses this change, and speaks of the “informatization” of medicine, where the body is seen as a system of information networks: the art of medicine gives way to evidence-based practice, the physical body defers to the CT scan, information once restricted to medicine is now available to the lay web-surfer, and the doctor–patient relationship becomes a meeting of experts. Medicine’s jurisdiction is shifting, incorporating new agents and social forces in its contemporary context. The theory of medicalization offers the explanatory framework to understand the changing yet persistent face of medical authority.

Zola coined the term medicalization in 1968 (1983). Zola’s work explores the historical and theoretical basis of the medicalization of society, as well as its political consequences (Zola, 1972). He looked at the consequences of medical authority for the individual, patient resistance, notions of power, compliance and submission (Zola, 1986), the distance between doctor and patient (Zola, 1973), and the breaking down of “distancing barriers” (Zola, 1991). Diagnosis played an important role in medicalizing, Zola (1972) contended. “If anything can be shown in some way to effect the workings of the body and to a lesser extent the mind, then it can be labelled an ‘illness’ itself or jurisdictionally ‘a medical problem’” (p. 495), he wrote, and he marveled at the increasing rate of clinical entities and disorders reported in surveys and studies.

Medicalization and diagnosis are clearly closely linked, but they are just as clearly *not* synonymous terms. Medicalization is a process, one that may be aided in its accomplishment by diagnosis as a classification tool. It may be that this close relationship is fundamentally the explanation for why a sociology of diagnosis has not had its own delineation: it has been enveloped in the folds of medicalization.

This broader literature of medicalization informs the sociology of diagnosis by the way in which it establishes the authoritative and pervasive position of medicine in Western society. While Conrad’s later definition points to role of

diagnosis in medicalization, indicating the place of illness and disorders in the assertion of medicine's professional territory, medicalization encompasses more than just diagnosis. Infant feeding and child rearing, for example, have historically been, and continue to be, medicalized as part of scientific motherhood (Apple, 1995). Seeking medical advice for matters of infant health, using medical endorsement for child nutrition and educational products, and reading doctor-authored columns or books on childrearing privileges medical authority over other forms of knowledge without any diagnosis or pathological condition. This is in contrast to, say, sadness or sexual problems, both arguably nonmedical in nature, but variably transformed by the diagnostic labels "depression" and "erectile dysfunction," both of which trigger an army of medicalized actions, therapies, and processes. In these cases, it is the diagnosis that is a specific step in, and an enabling factor of, medicalization.

Understanding medicalization requires us to look at the preceding work of other social scientists who were concerned with medicine's authority in contemporary society, and its role in legitimizing social concerns (Zola, 1983). Prior to the emergence of the concept of medicalization, Talcott Parsons (1951, 1958) and Eliot Freidson (1972) wrote about the roles of the various components of the social system. Freidson focused particularly on the professional role of the physician with regards to illness, while Parsons explored health and illness in terms of how they respectively affected participation in a social system. "Health and illness" he wrote "are not only 'conditions' or 'states' of the human individual ... they are also states evaluated and institutionally recognized in the culture and social structure of societies" (p. 126).

Zola acknowledged that one of the means by which medicalization functions is by affixing diagnostic labels to socially deviant behavior. Conrad (1975, 1979, 1992) and Conrad with Schneider (1980) explore this in greater depth, noticeably in the book *Deviance and Medicalization: From Badness to Sickness*. They note the role of medicine in reform – medical crusaders attempting to influence public morality and behavior – as well as the respect for medical advances. These authors propose a five-stage model by which a deviant behavior is medicalized through diagnoses: defining the behavior as deviant, discovering the behavior from within the medical community, making claims, challenging the existing designation to bring the behavior to medical turf, and finally, institutionalizing the behavior via diagnosis.

A number of scholars focus on the myriad of social conditions receiving medical attention and diagnostic labels. John Rosecrance (1985)

extends Conrad and Schneider's model to his work on compulsive gambling. Scholars have explored hyperactivity (Conrad, 1975), alcoholism (Blaxter, 1978), menstruation (Smith-Rosenberg & Rosenberg, 1973; Vertinsky, 1994), pregnancy (Barker, 1998), sexuality (Tiefer, 1996), obesity (Jutel, 2008), andropause (Conrad, 2007), adult ADHD (Conrad, 1979), and even compulsive buying (Lee & Mysyk, 2004) as examples of the transfer of life events, activities, and ways of being to the auspices of medical care.

The expansion of diagnostic categories is not without risk and can have severe iatrogenic results. The concordant treatment, which accompanies a diagnosis, may expose an individual to undesirable or unintended secondary effects. The medicalization of shyness that results in the diagnoses of Social Phobia, Social Anxiety Disorder, and Avoidant Personality Disorder, as one example, encourages patients to request and doctors to recommend the use of pharmaceutical remedies, use some of which have led to reports of devastating side-effects (Scott, 2006). As we will note further along in this chapter, this focus on diagnosis also provides a fertile ground for the commercial exploitation of patients and doctors alike.

Medicalization and diagnosis are clearly closely linked, but they are just as clearly *not* synonymous terms. Medicalization is a process, one that may be aided in its accomplishment by diagnosis as a classification tool. It may be that this close relationship is fundamentally the explanation for the absence of a sociology of diagnosis.

DIAGNOSTIC TENSION

Brown (2008) has penned that defining diseases is often like a turf war: individuals and groups with different interests scramble to establish the authenticity of their claims or of their expertise. These tensions can be present between lay person and medical representative, intra and interprofessional groups, policy-makers and doctors, doctors and administrators, and so on. In the section that follows, I describe areas of tension in diagnosis: the illness–disease distinction, the contested diagnosis, and nonmedical agents of medicalization.

Illness–Disease Distinction

The distinction between illness and disease is important to the sociology of diagnosis. This differentiation was not made clear in earlier sociological texts.

Freidson (1972), for example, used the terms interchangeably. However, today, the distinction contains important conceptual differences that frame discussions of diagnosis. Kleinman et al. wrote about illness as the personal experience of sickness, shaped by culture and influential for health outcomes (1978). Illness problems are those that result from undesirable changes in social or personal function. How an individual perceives these problems, explains or labels them, and seeks remedy originate from a cultural context, and in turn influences the response to, or decision to access, medical services. In any case, as Locker (1981) points out, to consider oneself ill is to presume a biological cause for a disvalued state of being.

Disease, in contrast, is framed by the biological, rather than the personal. Western medicine considers disease a biological or psychophysiological dysfunction or maladaptation (Kleinman et al., 1978). Disease is diagnosed, but illness is not; rather, it is presented to a clinician as *presumed* disease. The transformation from illness to disease takes place via the intermediary of the doctor and the diagnosis.

Someone who feels unwell describes their sense of disorder, and recounts what ails them, constructing a narrative that describes and contextualizes their complaint, but this description does not in itself constitute a diagnosis. This is what Balint (1964) refers to as the patient “proposing” one or many illnesses in an attempt to find one upon which patient and doctor will concur. Diagnosis is the medical reading of these symptoms: interpreting and organizing them according to models and patterns recognized by the profession. Leder describes this process as a “clinical hermeneutic” or interpretive project. The individual initiates an encounter with the doctor to obtain an explanatory position from which to approach the illness (Leder, 1990).

While not all illnesses can be diagnosed, their narratives are the starting point for diagnosis. Note that there is more than one narrative: both the patient and the doctor’s stories juxtapose and merge for a diagnosis to materialize. The patient’s stories, emerging from his or her own experience, culture, and consideration of the role of the doctor are transformed into medical accounts upon their telling. The doctor interrogates, interprets, and retells the story, establishing the “plot” and a diagnostic organization (Hunter, 1991). In Leder’s model, the patient has already determined that the explanation for his or her discomfort is medical in nature, and that it is a doctor (rather than a different social authority, say a rabbi or a lawyer) who will confer meaning to the narrative. Illness is the story which results when an individual sees the interpretation in terms of health and medicine. Alternatively, diagnosis is the story of medicine, told in the language of

disease. “In the narrow biological terms of the biomedical model,” says Kleinman (1988), “this means that disease is reconfigured *only* as an alteration in biological structure or functioning” (pp. 5–6).

Arthur Frank (1995) claims that a social expectation of being ill is not just seeking care, it is “a narrative surrender” in which the patient’s story is relinquished to the doctor’s, told through diagnosis, and “the one against which others are ultimately judged true or false, useful or not” (pp. 5–6). Kleinman maintains that doctors are taught to be skeptical of patients’ narratives about illness, a view shared by Foucault (1963), who wrote that clinical medicine sought to silence the patient’s story unequivocally. “In order to know the truth of the pathology, the doctor must abstract the patient ... who, by trying to show things, ends up concealing them” (p. 8, translation mine).

The diagnosis thus confers legitimacy to illness, yet does not necessarily align with the patient’s narrative for a number of reasons, not the least of which is the position from which the stories are recounted. Illness narratives “reveal what life is like for the narrator ... [including] the practical consequences of managing symptoms, reduced mobility, and so on. In telling their story, individuals also reveal, or indeed may assert, their self and social identity” (Nettleton, O’Malley, Watt, & Duffey, 2004, p. 49). Medical narratives come from an institutional position, which presumes the absence of the lived experience. It is the objectivity of scientific classification (in this case, the diagnosis), which confers authority to the label. Diagnosis is the fulcrum of the medical narrative. The judgment that this infers, as Frank has asserted above, may deny the self and social identity that the story of illness embodies.

Frank (1995) refers to illness as the experience of living through disease. It begins, he writes “when popular experience is overtaken by technical expertise, including complex organizations of treatment. Folk no longer go to bed and die, cared for by family members ... [they] go to paid professionals who reinterpret their pains as symptoms, using a specialized language that is unfamiliar and overwhelming” (p. 5).

Hunter (1991) encapsulates this disconnection between the languages of disease and illness when she writes that the “transformed and medicalized narrative may be alien to the patient: strange depersonalized, un-lived, and unlivable. Returned to the patient in this alien form, the medical narrative is all but unrecognizable as a version of the patient’s story – and all but useless as an explanation of the patient’s experience” (p. 13). This occurs when the medical model takes inadequate account of the illness problems, how the patient has actually lived, explained, and accounted for her dysfunction and is unable to incorporate this in its own narrative via the diagnostic label.

Medical and individual narratives can also align, and in so doing, provide positive outcomes. Lillrank (2003) reports the stories of women who suffered from chronic back pain. Finally, receiving a diagnosis was a relief to these women; their illness was validated – not imagined – despite the fact that the name referred to a chronic, and potentially disabling condition.

An individual narrative of disease is not, however, independent of the *regime* associated with a diagnosis, proposes Klawiter (2004). A disease regime is the cultural, spatial, and historical practices associated with a diagnosis and goes beyond the circumstances of the individual and the physiological nature of her illness. Klawiter demonstrates how the narrative of one individual altered over time as a result of different conditions in which she experienced her diagnosis. The agendas, identities, social relations, policies and emotional vocabularies embodied in different “regimes of practice” around breast cancer transformed public discourses and other forms of cultural production around breast cancer, and in turn transformed the personal narrative of this particular woman.

The diagnostic process is engaged upon with a positive end in mind, although, as above, positive does not necessarily imply a welcome pathology. As Engelhardt (1992) writes:

One invests labor in making a diagnosis not simply in order to know truly, but because one would hope to be able to avoid or mitigate some unpleasant state of affairs. In the case of prognosis, one wants at least to be able to plan for likely unpleasant future developments. (p. 73)

When the patient’s account and the doctor’s interpretation of symptoms enable the discovery of pathology, the treatment, or correction of the biological abnormality ideally results in the restoration of good health, or at the least, enables a sense of where the road ahead may lead.

Chiong (2001) points out another positive outcome of diagnosis. Diagnosis may also confer collective identity to patients, removing them from the isolation of their suffering, and providing them with new potential networks of support. In turn, this collective identity has political potential to shape, and in some cases, challenge, professional authority, political imperatives, and social identity (Brown & Zavestoski, 2004). The social health movement is driven in part by what these authors refer to as “embodied health movements”: groups constituted around particular diagnostic labels, illnesses, conditions, or by the perception of vulnerability to the same.

The collective identity may be virtual. A growing number of internet communities are diagnosis-focused. Web pages play a part in the social health movement: using the web to gather individuals around both existing

and emerging diseases. Dumit (2006) explains that internet communities offer a means of survival for sufferers of medically unexplained symptoms. They provide an alternative support structure when the absence of diagnosis impugns the medical legitimacy of the individual's complaint. These communities "create their own separate and distinct medical culture, a culture that gives primary importance to the role of subjective experience" (Goldstein, 2004, p. 127). An example of a virtual community serving to create an alternative culture are pro-anorexia sites that seek to redefine anorexia nervosa outside of medical discourse, instead casting it as a sanctuary, a "place where control and purity [can] be found" (Fox, Ward, & O'Rourke, 2005, p. 958). Conversely, internet communities are also launched by health providers who have identified web pages as a site at which patients can be transformed from consumers into a "community of practice" with potentially improved health outcomes (Winkelman & Choo, 2003).

In any case, the question of identity, which both diagnosis and its absence help to consolidate, has an important role to play in understanding the social context of health, illness, and disease. Klawiter's description of three distinct cultures which developed around breast cancer and the varying needs of its sufferers highlights different conceptions of the diagnosis which framed cultures of action. The discourses she described were as divergent as the ahistoric biological cancer for which medicine is salutatory to breast cancer as the product and source of profit of a predatory cancer industry (Klawiter, 1999).

Inadequate understanding of patient illness, disease frameworks, or cultural context by either party prevents therapeutic alliance and shared ownership of the explanatory narrative. The ownership of the narrative is at the heart of tension between patients and doctors, Hunter (1991) maintains. Ownership revolves around, she argues, the language used, the assignment of authorship, and prioritization of one version over another. In a medical retelling, the illness becomes diagnosis, the person patient, and "professional values are transferred from the practitioner to the 'case'" (Kleinman, 1988, p. 131).

In contrast, in some instances, medicine relinquishes willingly, and perhaps surprisingly, ownership of the diagnosis to the patient. For example, a subclassification of migraine in the *ICD* is "intractable migraine, so-stated" (*italics mine*). For this diagnosis to exist, the patient must speak (Bowker & Star, 1999). Medicine's occasional willingness to shift ownership depending on the condition is not evidence, write Bowker and Star, of oppression, rather of what kind of a tool the *ICD* is: "what work it does, and whose voice appears in its unfolding narrative" (p. 84).

Contest

Hadler (1996), in his discussion of fibromyalgia, describes diagnosis in confrontational terms: it is a battle in which a submissive patient agrees to participate only because of a tiny sliver of residual trust in the doctor–patient relationship resulting from generations of reverence, he pens. He underlines the vulnerability of the patient, the potentially flawed process of diagnosis, the inability of the profession to accept its limitations, and the imperfection of science. Hadler undoubtedly overstates many cases. But he does punctuate the degree to which contest or dispute is always potentially present in the diagnostic process, particularly, as he notes here, in the case of the disability determination (which unsurprisingly entails the allocation of resources) of someone with a disputed diagnosis.

Contest is accentuated by the latent dichotomy between illness and disease, the unequal power relationship between the patient and doctor, and the need for medical diagnosis for access to other services. Contest is present, notably in emerging illnesses such as Hadler’s example of fibromyalgia above, and assumes a particularly acute form when the absence of diagnosis denies the patient access to the sick role, and more importantly to institutional recognition of suffering. Many have written of the distress of patients who do not receive a diagnosis for their complaint. This distress typically focuses on disorder, confusion, fear of being stigmatized by a psychogenic explanation, and denial of services (Dumit, 2006; Malterud, 2001, 2005; Nettleton, 2006).

Dumit (2006) describes how conflict is shaped both in- and outside of the patient–doctor relationship. Clinicians are directed in their practice by the impositions of the health maintenance organization, the employer, and the insurer; bureaucracy determines who can provide care, and for what ailments. These organizations join in symbolic domination over the individual patient. But the key point, as Dumit makes clear in this chapter and others is “the intense interplay between diagnosis and legitimacy: without a diagnosis and other forms of acceptance into the medical system, sufferers are at risk of being denied social recognition of their very suffering and accused of simply faking it” (p. 578).

Contested diagnoses are typically those that cannot currently be explained by medicine or have explanations which are in dispute (Brown & Zavestoski, 2004). The contest focuses on debate around whether they are primarily social, psychiatric, or biological in nature (Dumit, 2006). These are illnesses that are “are not defined in terms of organic pathology, but on the base of their symptoms” (Nettleton et al., 2004). As I have written in a recent review

of medical literature dealing with medically unexplained symptoms (Jutel, 2010), these enigmatic symptoms are predominantly assembled discursively as synonymous with somatizing ailments and psychogenic in origin. The term “medically unexplained symptoms” is used interchangeably with psychiatric diagnostic terms such as somatoform disorder, somatizing, functional somatic syndrome, or other related terms implying an illness of psychogenic or sociogenic origin. Yet, the absence of the objective finding is prevalent in many debilitating disorders such as chronic fatigue syndrome, lower back pain, occupation overuse syndrome, and others. Nettleton (2006) also demonstrates that the difficulties of living with the uncertainty of non-diagnosis and of defending the legitimacy of their complaints results in significant distress and dissatisfaction with the medical encounter and profession.

Conflict may also arise conversely, when diagnosis achieves nonclinical ends, and stymies the rights of the patient, who does not believe him or herself to be ill. A powerful example of this is political psychiatry, where dissent is treated as mental illness. Robin Munro (2002) quotes a Chinese textbook which develops the notion of “political mania” as a form of paranoid psychosis:

Those afflicted do avid research into politics and put forward a whole set of original theories of their own, which they then try to peddle by every means possible ... such people are sometimes viewed [by others] as being political dissidents. (Sifa Jingshen Yixue Jianding Zixun Jieda, in Munro, 2002)

A less sinister example of the state’s utilization of diagnosis is captured in the simple naming of fetal death, miscarriage, spontaneous abortion, and stillbirth give access to different privileges and liabilities according to the label applied. An almost-arbitrary gestational limit determines whether a death certificate is issued, a burial permitted, a death benefit awarded, or charges pressed (Jutel, 2006).

Another diagnosis, which may go counter to the patient experience, is the contemporary diagnosis of obesity. Many patients and advocacy groups refute that obesity is a disease and maintain that the medicalization of obesity is evidence of size discrimination rather than of biophysical dysfunction (Campos, Saguy, Ernsberger, Olive, & Gaesser, 2006a, 2006b; Gard & Wright, 2005). Both individual and collective action in the case of other disputed diagnoses has resulted in reconsideration in some cases and removal, in others, of the disease label.

The women’s health movement has both advocated for and succeeded to a certain extent in the demedicalization of some aspects of female biology,

including menstruation and childbirth. While childbirth is still generally medically managed in the West, there has been a move toward its demedicalization. In New Zealand, for example, current policy enables midwives to be lead maternity carers and 78.1% of New Zealand women registered with a midwife rather than a general practitioner or obstetrician to manage their pregnancy (New Zealand Health Information Service, 2006).

Routine screening is another source of potentially disputed diagnoses. Screening seeks to find evidence of disease in a patient who is presenting for what may be unrelated, and possibly not even clinical, reasons. While there has been a rise in screening as part of health assessment, there is significant debate about its putative benefits. Black (2000) has written that detecting subclinical conditions which would have otherwise gone to the grave with the patient (while not being the cause of death) can result in anxiety, unnecessary treatment, complications, and even actual death. Screening for disease is practiced with religious fervor, according to Howard Brody (2006), but not always with the acquiescence of the patient. This reflects what Armsrong (1995) casts as “surveillance” medicine: a perception of human existence which sees everyone as normal, but no one as truly healthy. Disease potential thus drives a focus on multiple and interrelated risk factors and continual monitoring.

The disease potential is a salient means of social control and is amplified by the ever-expanding technical access to new screening tools. The potential to detect genetic predispositions for disease, for example, may result in a range of actions including discriminatory hiring and insurance practices, selective abortion and stigmatization of carriers (Raz & Vizner, 2009; Wertz, 1992). Screening programs, such as the Dor Yeshorim premarital genetic testing programme for potential spouses in ultraorthodox Jewish communities, results in the reinforcement of stigma of potential spouses who are presumed genetic carriers (Raz & Vizner, 2009).

Engines of Diagnosis

While medicine holds the power to diagnose, many other agents hold the ability to promote particular diagnoses, if not to create them. Conrad (2005, 2007) has made reference to “engines of medicalization” which maintain or cultivate a medical locus for the management of banal life activities. These include biotechnologies, consumers, and managed care. These engines bolster the flagging authority of medicine in the face of declining trust in the doctor. Conrad’s concern is with medicalization, and I have argued above

that this focus is more general than on diagnosis alone. While there is not the space to expand upon each of these drivers in the context of this chapter, I will focus predominantly on the example of the pharmaceutical and related industries, whose interests are specifically served by the creation or maintenance of specific diagnoses.

In 1992, Payer introduced the term “disease monger” and identified a medical-industrial complex which, she argued, has a great interest in promoting the notion that the greater population is either already sick or at risk of so becoming. Her focus was on the abuse of diagnosis as a mechanism for advancing political, social, and commercial interests. She identified a range of agents who stood to benefit from the proliferation of diagnostic labels – creating a need for their products and services – including medical researchers, medical writers, health educators/promoters, the pharmaceutical and diagnostics industry, doctors, lawyers, hospitals, the courts, and insurance companies (Payer, 1992).

There has since been wide-ranging critical discussion of the clinical and economic contexts of disease mongering (Dear & Webb, 2007; Healy, 2006; Moncrieff, Hopker, & Thomas, 2005; Moynihan & Cassels, 2005; Moynihan, Heath, & Henry, 2002; Payer, 1992; Tiefer, 2006; Wolinsky, 2005), with an array of definitions. Payer (1992) described mongering as “big business trying to convince essentially well people that they are sick, or slightly sick people that they are very ill.” Moynihan and colleagues refer to “widening the boundaries of treatable illness in order to expand markets for those who sell and deliver treatments” (2002). However, to date, sociologists have paid scant attention to the pharmaceutical industry, in great part due to the discipline’s focus on the experience of illness, the secretive nature of the industry, the inadequate scientific–technical knowledge of many sociologists, and the threat of legal challenge emanating from the pharmaceutical companies (Abraham, 2007; Busfield, 2006).

From within a sociology of diagnosis, however, it is useful to explore and, indeed, theorize the phenomenon referred to as disease mongering by its critics as diagnostic labels are at the fulcrum of its activities. To understand the way that diagnoses are promoted by nonmedical sources requires reflection which includes, but goes beyond the pharmaceutical industry, and notably includes other industries as well as the context in which diagnosis currently takes place.

The ability to promote diagnoses is facilitated by the diffusion of informational knowledge through e-scaped medicine as described by Nettleton above. In this context, control over medical information shifts from doctor to a variety of other loci with manifold motivations (in the case of the industry,

commercial). The patient becomes “consumer,” but not only in the commercial sense of the word. A proliferation of information and media sites is available for ingestion: direct-to-consumer advertising, online self-screening tests, patient advocacy organizations, and disease awareness campaigns. Many of these are covertly, if not overtly propped up by the industry standing to gain from expanding the number of individuals under a particular diagnostic umbrella (Herxheimer, 2003).

Leonore Tiefer (2006) argues it was a convergence of pharmaceutical companies, urologists closely associated with this industry, and media savvy sex therapists operating within the for-profit sector that resulted in the creation and promotion of a diagnosis of “female sexual dysfunction.” The acute interest in women’s sexuality, she maintains, is linked to uncritical definitions of what constitutes normal female sexuality. It is also part of the industry’s desire to expand the market for drugs like Viagra by promoting erectile dysfunction more widely than justified (Lexchin, 2006).

Commercial interests have an important stake in highlighting overweight as a medical diagnosis, rather than a statistical deviation from normative weight. These interests go beyond the pharmaceutical industry. Fitness centers – part of a \$15 billion per annum industry in the United States (US Census Bureau, 2004), in addition to the pharmaceutical and weight loss industries, and even some practicing physicians, rely heavily upon promoting public belief in overweight as disease. Identifying obesity as a disease against which gym-goers can battle, reminding them of the ever-present “threat” of disease with body mass index charts, scales for self-monitoring, and doomsday publications about the risks of corpulence are important marketing tools: both of the diagnosis of obesity and of vigilant exercise; the first justifying the second.

As Campos (2006a) has pointed out, many of the leading researchers in obesity research, including those who set the criteria to determine what constitutes obesity, have an economic interest in defining overweight as widely as possible, either by their partnership with the pharmaceutical industry or by their own private weight loss clinics. Their preoccupation with overweight as disease defies evidence of: lower mortality associated with overweight (Body Mass Index (BMI) 25–29) than with normal weight (BMI 18.5–24.9) (Romero-Corral et al., 2006), health benefits of subcutaneous fat on hips and thighs (Nevill, Stewart, Olds, & Holder, 2006), and an increase in noncancer mortality after weight loss (Nilsson, Nilsson, Hedblad, Berglund, & Lindgarde, 2002).

Commercial influences are not the only nonmedical forces to have an interest in promoting particular diagnoses. The diagnosis of “excited

delirium” has surfaced in coroners’ courts as explanation for deaths in custody following physical restraint, even though the criteria for such “deliria” are far from established (Milliken, 1998). Attributing these unexpected deaths to disease rather than to excessive force concords comfortably with the presumed ethical behavior of the police and the role one would hope to see them play in the community.

Ivan Illich (1976) wrote that “disease always intensifies stress, defines incapacity, imposes inactivity, and focuses apprehension on nonrecovery, on uncertainty, and on one’s dependence upon future medical findings.” He continues:

Once a society organizes for a preventative disease-hunt, it gives epidemic proportions to diagnosis. This ultimate triumph of therapeutic culture turns the independence of the average healthy person into an intolerable form of deviance. (p. 104)

Goode (1969) writes in a similar tone, pointing out that “by devising a linguistic category with specific connotations, one is designing the armaments for a battle; by having it accepted and used, one has scored a major victory” (p. 89). Bowker and Star (1999) explain the power of the diagnosis through its classificatory functions: the diagnosis, as classification, does the work of “making it appear that science describes nature (and nature alone) and that politics is about social power (and social power alone)” (p. 46). However, in any case, the work of the diagnosis is often invisible, “erased by [its] naturalization into the routines of life” concealing conflict and multiplicity beneath layers of obscure representation (p. 47).

CONCLUSION

Most readers of these pages will have, at some point, gone to see the doctor to “find out what’s wrong.” Some will go with trepidation, wondering if they’re wasting the doctor’s time – “It’s probably nothing” – while others will leave with even more unease than when they went in – “If nothing’s wrong with me, why do I feel this way?” Yet, a third group will leave a consultation with a clear sense of what is remiss, instructions about treatment, and with some luck, an anticipation of when and how the ailment will resolve. Diagnosis structures the reality of individuals, as it clarifies and sometimes explains what they experience. Interactions in the doctor’s rooms are strongly framed by what it means both to be a patient and a doctor. Subservience to medical authority is both reassuring and problematic. Good patients, show signs of “compliance” and “adherence” to doctor’s orders.

Informed self-advocates work hard with, and sometimes against the doctor, probing and questioning why their complaint is or isn't considered medical, and protesting if a psychogenic cause is proposed: less physical, less real.

In a contemporary world where information abounds, the diagnostic relationship between patient and doctor is different. Patients may, at odds with Balint's description, propose a diagnosis, rather than an ailment, when they consult. Or, they may circumvent the doctor altogether. They calculate their BMI, take depression self-tests, or use medical terminology to describe their idiosyncrasies and those of their friends. "Are you sure you don't have ADD?" they might quiz. Lay people are changing the shape of what diagnosis means in practice.

The "modern" patient is the ideal: an informed "consumer" who can sit on an equal platform with the doctor as a result of now-open access to information previously restricted to doctors. The idealized clinical encounter is a cooperative interaction that brings patient and doctor together in a kind of handshake agreement about what ails the former and what the latter can do in response. It is not always so simple, particularly as the encounter is about far more, as Hunter (1991) points out, than a simple classification of our malady; focusing on the diagnosis draws attention away from the care of person who is ill. Furthermore, the profession's acknowledgments of its limitations and as well as of the myriad of social influences on its classificatory practices needs attention from within.

Exploring the social forces that influence the clinical process of diagnosis provides a greater understanding of both the fluidity and the fallibility of the diagnosis. Diagnoses do not exist ontologically. They are concepts that bind the biological, the technological, the social, the political, and the lived. Thomas Laqueur wrote that "Believing is Seeing." Despite the advent of autopsy and a presumed clear vision of the ways in which structures were connected, Renaissance anatomists still depicted the vagina as inside-out penis, and menstrual flow as transformed into breast milk during lactation (Laqueur, 1990). Diagnosis similarly captures what the medical institution currently believes to be the "Way Things Are." Suffice it to say, the world of facts is not detachable from an a priori conceptual framework.

Sociology of diagnosis is an important avenue for understanding not only lay experience of illness and lay-professional discord as we have discussed above, but also patient compliance, disease control, public health, health education, and many other aspects of health and illness. Kleinman and his colleagues' claims of 30 years ago hold strong today: understanding social science is necessary to deal competently with essential, nonbiomedical, aspects of clinical practice. They maintain that medicine is both a biological

and a social science (Kleinman et al., 1978). Focusing on both social and biological aspects assists clinicians to treat patients as well as diseases, a sometimes neglected feature of contemporary medical practice (see Goldstein, 2007; Leder, 1990). Understanding the social frames within which diagnoses are generated, and grasping the impact of the label is clinically powerful. As Aronowitz (2001) cautions, there is an “essential continuity between persons who have symptoms that have been given a name and disease-like status and persons whose suffering remains unnamed and unrecognized” (p. 808).

Sociology of diagnosis has a salient role to play in understanding health, illness, and disease – unpacking and identifying the play of interests that enter into discussions of what priorities should be set and what goals attained. Diagnosis defines the field of medicine and its professional reach, serves as the nexus in which the clinical encounter takes place, arbitrates normality and difference, organizes a patient’s illness, and determines how resources are allocated. In this opening chapter, I have, with a broad brush, covered a range of considerations that contribute to a sociology of diagnosis: the place of naming in medicine and the tensions naming can engender. But there is more work to be done. A rich collection of structures, agents, and actions enter into the diagnostic arena and deserve consideration. Identifying, analyzing, and understanding these and their connections will ultimately contribute to a better understanding of the medicine’s role and how it achieves it as well as the relationship of medicine to culture and society. The chapters which follow attempt to achieve this goal.

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DIAGNOSIS AND MEDICALIZATION

Karl Bryant

ABSTRACT

Purpose – The purpose of this chapter is to theorize the relationship between diagnosis and medicalization through an examination of the medicalization of childhood gender variance and the Gender Identity Disorder of Childhood diagnosis.

Methodology/approach – The chapter examines textual data (published clinical and research literatures, and critiques of the diagnosis appearing in a range of venues) to track how childhood gender variance is medicalized over time and the role of diagnosis in that medicalization.

Findings – While diagnosis certainly plays a role in shoring up medicalization, this case study reveals the many ways in which diagnoses may also become key tools in attempts to curtail medicalization.

Research limitations/implications – As a case study, the findings are not generalizable to all diagnoses. As a study of an instance of the medicalization of deviance, these findings may be particularly applicable to analogous cases.

Social implications – These findings show the sometimes tenuous nature of medicalization processes, and the social uses of diagnoses in those processes.

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Originality/value of paper – *This chapter sheds light on a relationship that is often assumed to be unidirectional (e.g., that the formation of diagnosis results in increased medicalization), and answers calls for a more nuanced sociology of diagnosis, including greater attention to the relationship between diagnosis and medicalization.*

Keywords: Gender Identity Disorder; transsexuality; childhood; medicalization; deviance

INTRODUCTION

Although for some time sociologists have called for the elaboration of a sociology of diagnosis (Brown, 1990, 1995), scholars continue to point out that a coherent theoretical framework and sociological body of knowledge has yet to emerge (Jutel, 2009). Nonetheless, sociologists have studied diagnoses by examining, for example, how diagnostic nosologies are conceptualized and produced, the formation of specific diagnoses as well as contestations over their legitimacy, diagnoses and clinical decision making, diagnostic reliability and validity, and the role of diagnosis in shaping illness experiences, among others (Blaxter, 1978; Brown, 1987, 1990, 1995; Bryant, 2006; Conrad, 1975; Conrad & Potter, 2000; Conrad & Schneider, 1992; Dumit, 2006; Figert, 1995; Liu, King, & Bearman, 2010; Loring & Powell, 1988; Lutfey, Eva, Gerstenberger, Link, & McKinlay, 2010; Mayes & Horwitz, 2005; Mirowsky & Ross, 1989; Nettleton, 2006; S. Scott, 2006; W.J. Scott, 1990; Whooley, 2010). In a recent review of such work, Jutel (2009) suggested that, despite this body of sociological scholarship, a fully articulated sociology of diagnosis has not emerged in part because our understandings of diagnoses have often been subsumed within the rubric of medicalization. Jutel argues that

Medicalisation and diagnosis are clearly closely linked, but they are just as clearly *not* synonymous terms. Medicalisation is a process, one which may be aided in its accomplishment by diagnosis as a classification tool. It may be that this close relationship is fundamentally the explanation for why a sociology of diagnosis has not had its own delineation: it has been enveloped in the folds of medicalisation. (2009, p. 285)

Jutel goes on to suggest that “More attention to the actual role that diagnostic labels play in medicalisation is likely to provide further, fruitful insights into the processes medicalisation entails” (2009, p. 286). This chapter takes the case of one controversial psychiatric diagnosis – Gender Identity

Disorder in Children (GIDC) – and reviews it in order to characterize with more specificity the relationship between diagnosis and medicalization. What range of roles does this diagnosis play in medicalization processes? How do different stakeholder groups make use of diagnosis, and how do those uses affect medicalization? How do other diagnostic categories interact with this particular diagnosis and impinge on medicalization?

METHODS

For the analysis in this chapter, I chart the knowledge production and critiques of GIDC by examining several sets of textual data: the diagnostic texts themselves (from *Diagnostic and Statistical Manual of Mental Disorders (DSM)-III*, *DSM-III-R*, *DSM-IV*, and *DSM-IV-TR*); American Psychiatric Association (APA) archival materials that shed light on the behind the scenes work of creating the diagnosis (committee notes and reports, drafts of the diagnosis, correspondence, etc); the clinical and research literature on GIDC (including critiques of the diagnosis published in professional literatures); and lay critiques of the diagnosis (gathered primarily from print journalism and LGBTQ community publications). I mined these data looking for clues about the role of the diagnosis in medicalization processes, asking questions like: In what ways was childhood gender variance medicalized prior to the appearance of the diagnosis? How did these medicalization processes shift once the diagnosis appeared? What was the role of the diagnosis in critiques of this body of work, including ways that the diagnosis might be used to put brakes on medicalization processes?

MEDICALIZATION AND DIAGNOSIS

The concept of medicalization has been extremely influential in social analyses of health, illness, and health care. Focusing on the processes whereby nonmedical aspects of people and their lives are redefined in medical terms, medicalization models emphasize the ways that medical definitions are socially constructed instead of simply discovered. As such, they examine the constellation of interests, beliefs, and power relations that result in defining particular aspects of our bodies, psyches, and behaviors in medical terms (Conrad & Schneider, 1992). And whereas early medicalization models (Freidson, 1970; Illich, 1976; Zola, 1972) tended to emphasize the top-down, social control function of medicine (where, for instance,

doctors increased markets, legitimated their authority, and controlled patients), subsequent models have included a broader range of stakeholders in medicalization processes and a more nuanced set of medicalization's effects (Atkinson, 1995; de Swann, 1990; Riessman, 1983).

Much of the medicalization literature has thus emphasized the (expanding) social control function of medicine. Brown (1990) suggests that diagnosis plays a key role in this social control function. Referring specifically to psychiatry, he notes that “*diagnosis* has been a central component of ... social control. *Giving the name* has been the starting point for social labelers” (p. 388, italics in original). This suggests that diagnoses as categories (Blaxter, 1978), and their role in definitional processes, are at the heart of medicalization processes. As such, diagnoses are often seen as key in securing medicalization. In their classic work on the medicalization of deviance, Conrad and Schneider (1992) place the formation of a diagnosis as the final stage of their sequential model, where diagnoses act to codify or institutionalize medical designations. Diagnostic labels are thus sometimes interpreted as the sine qua non of a fully achieved medicalized state.¹ Yet, diagnoses are also sometimes challenged (Bayer, 1987), and may be the site for resistance against the encroachment or expansion of medicalization, or may be the site of pushes for demedicalization. As I show in this chapter, the case of GIDC suggests that the appearance of diagnostic categories themselves – in concert with other enabling conditions – may both formalize a phenomenon's medicalized status and may concurrently help call it into question. Diagnoses may simultaneously shore up medicalization and foment resistance to it. Ultimately, then, the history of GIDC suggests that diagnoses do “work,” and may best be thought of as tools (Bowker & Star, 1999). This instrumental (and somewhat malleable) function extends to their role in medicalization processes, where they are taken up in any number of ways by a range of interested stakeholders – including of course formal agents of medicine (e.g., doctors and psychiatrists), but also patients, consumers, activists, and others – who play divergent roles in medicalization processes.

MEDICALIZATION BEFORE DIAGNOSIS

Childhood gender variance, and especially boyhood femininity,² became increasingly medicalized across the course of the twentieth century. Influenced by the mental hygiene and parent education movements of the early twentieth century, psychologists increasingly weighed in on childhood,

with the result being that children's gender – including nonnormative manifestations – was increasingly subject to the scrutiny of experts. For example, in her review of parent advice literature and clinical case studies from the first half of the twentieth century, Grant (2004) demonstrates how experts prioritized producing “real boys” (i.e., preventing or curing sissy behaviors), partly motivated by the desire to avert later homosexuality. New theories of boyhood development located gender nonconformity largely in family psychodynamics, with an overbearing mother and an absent father. In the first half of the twentieth century, experts increasingly intervened – in popular media advice, in clinics, and in schools – in the arena of childhood gender, resulting in some initial level of medicalization of gender nonconformity. Grant documents an increasing expert advice literature that warned parents about the dangers of the “effeminate” boy, as well as clinical referrals related to boyhood effeminacy during the first half of the twentieth century. Yet, there was little concerted, collective work to create formal knowledge, to standardize treatment, or to create a diagnostic category. This began to change in the second half of the twentieth century, with a qualitative shift in the form and pace of medicalization, resulting eventually in the formalization of a diagnosis – Gender Identity Disorder of Childhood – which first appeared in the *DSM*, 3rd ed, in 1980.

Beginning in the 1950s and 1960s, largely in response to the increased visibility of the medicalized category of transsexuality, a small group of researcher-clinicians began to devote a significant amount of time and energy specifically toward defining, understanding, and treating gender-variant boys. Small specialized groups of professionals “discovered” a newly medicalized phenomenon – childhood gender nonconformity – through a series of claims-making activities that speculated about causes, developed (largely preventative or curative) treatments, and sought legitimacy by arguing for the potential seriousness of the phenomenon (linking it to the devalued adult outcomes of transsexuality, transvestism, and homosexuality). Ultimately, they carved out intellectual and institutional “turf,” establishing expertise through the work of defining, studying, and treating childhood gender variance (Bryant, 2006).

By the 1970s, when formal diagnostic work was underway but not yet completed (e.g., there was not yet a formal diagnostic category listed in the *DSM*), childhood gender variance had already gone through a significant process of medicalization. A set of professionals had established a subspecialty niche where some forms of childhood gender variance were no longer defined as a passing phase but rather had been redefined as a potentially serious form of pathology linked to already pathologized and

devalued adult psychosexual and gender identity outcomes. Through years of privately and publicly funded research, experts generated subjects to study who doubled as patients to treat. They described the parameters of the phenomenon of childhood gender variance in medicalized terms. In doing so, they made claims about the medicalized nature of childhood gender variance, equating it with an as yet undifferentiated disorder. Further, they established a set of treatments designed to intervene, in some sense to “cure,” the condition they now described as a pathology. To identify the children who merited such intervention, they developed a set of diagnostic techniques that allowed them to make diagnoses in practice. Thus, well before the appearance of a formal diagnostic category, a proto-diagnosis of sorts existed, given that diagnostic practices were clearly underway. However, although childhood gender variance researcher-clinicians engaged in diagnostic *practices*, they did not yet benefit from the legitimating functions that come with a formal diagnostic *category*.³

DIAGNOSIS SUPPORTING MEDICALIZATION

Thus, by the time the work to create a diagnosis got seriously underway in the mid-1970s, many aspects of childhood gender variance were already medicalized, even in the absence of a formal diagnostic category. Not surprisingly, the appearance of the diagnosis helped to shore up and extend that medicalization. As a leading childhood gender variance researcher and primary author of the *DSM-III* GIDC diagnosis, Richard Green signaled the ways that a diagnosis may serve a (perceived or real) legitimization function:

Prior to its inclusion in the American Psychiatric Association’s list of mental disorders in 1980, there was no official recognition of extensive cross-gender behavior as a psychiatric syndrome, and less official rationale for treatment. (1987, p. 259)

While there certainly were treatment rationales and recognition of a syndrome (at least among the subspecialty researchers themselves) that were proffered prior to 1980, Green highlights here the “official” forms of legitimization that a formal diagnosis can bring with it. In other words, with the move from a set of diagnostic practices to a full-blown diagnostic category, the medicalized status of childhood gender nonconformity shifted significantly. A formal diagnosis brought with it the legitimating functions of such categories, transforming childhood gender variance into GIDC, a “real” psychiatric entity.

Researcher-clinicians in the 1960s and 1970s often began publications on childhood gender variance by stating the rationale for the work that they engaged in (e.g., arguing that it was not “just a phase” and could lead to the already stigmatized adult outcomes of homosexuality, transvestism, and transsexuality). While these legitimation strategies did not disappear, the GIDC diagnosis could be used as another strategy that rationalized their work. For instance, a few years after the diagnosis appeared, [Rekers and Morey \(1990\)](#) noted that “Programmatic research on the psychodiagnosis of childhood gender disturbances ... had progressed sufficiently by 1980 that the third edition of the *DSM* listed for the first time the diagnosis of ‘gender identity disorder of childhood’” (p. 29). While this seems at first blush to be a simple descriptive statement of fact, [Rekers and Morey](#) use the appearance of the diagnosis as evidence of the progression of science, signaling a taken-for-granted level of consensus concerning the legitimately medicalized status of childhood gender variance.⁴

In addition to providing new official forms of legitimacy for the work that childhood gender variance researcher-clinicians had been doing for more than 20 years, the appearance of a diagnosis also may have resulted in an increase in children receiving treatment. While there are no epidemiological data on prevalence or incidence of GIDC, proxy or anecdotal measures are sometimes used to approximate these numbers (e.g., survey data on parental report of childhood gender nonconformity and clinic referral rates). [Zucker](#) and his colleagues note an increase in the childhood referral rate occurring at their Toronto clinic beginning in the late-1980s. It is impossible to know with certainty the source of this change. However, [Zucker](#) and his colleagues speculate that it may be linked to changes concerning the diagnosis itself – either that it had become more generally known, or that the publication of *DSM-III-R* ([APA, 1987](#)), where GIDC was moved to the “Usually First Diagnosed in Infancy, Childhood, or Adolescence” section of the manual, resulted in the diagnosis being more visible to referring clinicians and pediatricians ([Zucker & Lawrence, 2009](#)).

In addition to their clinical use, diagnoses are taken up in many contexts beyond the specific treatment sites where specialists use them ([Cooksey & Brown, 1998](#); [Kirk & Kutchins, 1992](#)). [Wakefield and First \(2003\)](#) suggest that the *DSM* (and the diagnostic categories it contains) are routinely used in “research sample selection, general medical practices, courtrooms, and epidemiological studies” (p. 32). Here they may underestimate the uses of *DSM*; the manual and the diagnoses within it have become broadly diffused. In the case of GIDC, for example, [Martin \(2005\)](#) shows how contemporary childcare advice books that have incorporated gender-neutral parenting practices still frame gender nonconformity as potentially problematic by

making reference to GIDC. While many advice books show a level of tolerance for childhood gender nonconformity, “They find gender nonconformity diagnosable and unhealthy only in its extreme or exclusive form, that is, when it meets the criteria of the *Diagnostic and Statistical Manual of Mental Disorders (DSM)* categorization of gender identity disorder” (2005, p. 470). Indeed, some of the advice books Martin analyzed included shortened versions of the diagnostic criteria themselves as a warning sign for parents to consult. Martin further noted that while GIDC is a controversial diagnosis with critiques clearly enumerated, the advice books “appear unaware of the problematic nature of GID” (2005, p. 474). This is but one pertinent example of the many ways in which *DSM* diagnoses have a life of their own, with uses that go far beyond the stated intentions of the *DSM* framers. Diagnoses’ widespread use – where they are routinely taken up in many and varied domains – functions to further legitimate the medicalized status of the phenomenon in question.

DIAGNOSIS CHALLENGING MEDICALIZATION

Diagnostic Formation as the Site of Challenges to Medicalization

However, along with concretizing the medicalized definitional work via a formal category of mental disorder, the appearance of the diagnosis stoked both internal disagreements within the subspecialty about what the diagnosis should consist in and external critiques of the medicalization of childhood gender variance writ large. Thus, along with formalizing medicalization, the GIDC diagnosis itself has played a key role in crystallizing and amplifying conflicts concerning medicalization. As such, the diagnosis has at least the potential of playing a key role in limiting childhood gender variance’s medicalized status; it may even entail a possible roll back on medicalization, including demedicalization itself. This case ultimately suggests that, while diagnoses are important factors in institutionalizing medicalization, they are also important factors in resistance to medicalization. In fact, diagnoses may in some cases serve as *engines* of such resistance – shining light on medicalization and thereby fomenting critique.

The creation of the GIDC diagnosis unleashed some of the earliest sustained critiques of the medicalization of childhood gender variance. While still in draft stages, Robert Spitzer (the psychiatrist in charge of coordinating the production of *DSM-III*) circulated draft diagnoses to interested parties for feedback. Via this process or through other means, the GIDC diagnosis

was circulated to the APA's Committee on Women, resulting in a series of letters from feminist mental health professionals critiquing the proposed diagnosis (Spitzer characterized the level of correspondence at the time as "voluminous" (Spitzer memo, July 11, 1977)). Their critiques focused on the inclusion of girls in the diagnostic criteria (which letter writers challenged, especially given the fact that the existing research and clinical evidence was based overwhelmingly on studies and treatment of boys), the ways that the diagnosis mixed together gender role and gender identity, and the use of "sex role stereotypes" to define children (primarily via their behavior) as healthy or pathological (this criticism of "stereotypes" was applied by some to boys as well as girls). Letter writers also made specific suggestions of ways to fix some of the problems. Some argued that the diagnosis should be done away with altogether. Others argued that it be designated only for boys. Finally, some suggested that separate criteria be developed for boys and girls, with girls having narrower criteria than boys thus making them more difficult to diagnose (Chappell, letter to Spitzer, June 29, 1977).

By the time the diagnosis did appear in print, the feminist letter writing campaign had had significant impact. Ann Chappell, an APA Committee on Women member who coordinated the letter writing efforts, was included in *DSM* Committee discussions of how to address the feminist concerns. In the end, the final GIDC diagnosis focused more specifically on questions of identity than was apparent in early drafts. It also included separate and different diagnostic criteria for boys and girls, as was suggested by feminist mental health professionals commenting on the GIDC draft they reviewed.

Thus, even before it was officially formalized, the diagnosis-in-information became the site of debates over the medicalized status of childhood gender variance. The prospect of a possible diagnosis animated a series of questions about the proper course of action concerning the relationship between psychiatry and childhood gender variance, including whether a relationship should exist at all, and if so, to what degree. Finally, these debates were actually incorporated into the official diagnosis, including limits on the scope of medicalization being operationalized as part of the diagnostic criteria themselves.

Diagnosis, Expertise, Consensus, and Debate

Prior to the creation of a formal diagnosis, several childhood gender variance researcher-clinicians had proposed their own versions of a proto-diagnosis.

For example, Stoller had developed the concept of “male childhood transsexualism” (1968), whereas a team based in UCLA’s Psychology Department developed a diagnostic formulation predicated on a distinction between “cross-gender identification” and “gender behavior disturbance” (Rosen, Rekers, & Friar, 1977). The diagnosis, developed primarily by Green, ended up formalizing *some* aspects of the broad literature on childhood gender variance while ignoring or negating others. For example, Stoller’s and Rosen and colleagues’ formulations each differed significantly from the GIDC diagnosis, which now officially represented the medicalized category of childhood gender variance. Thus, although the formation of a diagnosis may appear to reflect a form of shared consensus, in this case it was one among several diagnostic formulations that researcher-clinicians had proffered. Once the diagnosis appeared, there was not agreement among childhood gender variance researchers (a group with at least some shared stakes in the phenomenon’s medicalized status) that the new diagnosis fully and accurately captured the children who ought to be diagnosed as having a gender disorder. Instead of settling questions about the proper diagnostic course, GIDC’s appearance became a focal point for questions about what the diagnosis should consist in.

Along with these alternative diagnostic approaches that had circulated, there were other critiques of the diagnosis put forth by childhood gender variance experts. For instance, a group of researcher-clinicians working in Toronto took issue with the GIDC diagnosis as applied to girls, including the fact that the diagnostic criteria for girls were not parallel with those for boys (unbeknownst to these researchers, this aspect of the diagnosis was in part attributable to the letter writing campaign outlined above). Unlike boys, to receive the diagnosis girls were required to actively repudiate female anatomic structures. In addition, and again unlike for boys, there were no diagnostic criteria based on girls’ preference for masculine activities or behaviors (for a list of the diagnostic criteria, see [Table 1](#)). The Toronto group argued that with diagnostic blind spots like these in place, girls who rightly should be diagnosed with GIDC would be undiagnosable (Zucker, 1982). In other words, for some researcher-clinicians, the new diagnosis did not fully cover the terrain of childhood gender variance that, for them, merited medicalization.

Zucker (1982) also drew on evidence from studies of different aged children at the Toronto clinic to suggest that while the new GIDC diagnosis was perhaps accurate for children with “gender disturbances” at young ages, it became less accurate as they grew older and their presenting features changed. Earlier work had noted such “burnout” tendencies where children

Table 1. Diagnostic Criteria for GIDC in *DSM-III*.

For females:

- A. Strongly and persistently stated desire to be a boy, or insistence that she is a boy (not merely a desire for any perceived cultural advantages from being a boy).
- B. Persistent repudiation of female anatomic structures, as manifested by at least one of the following repeated assertions:
 - (1) that she will grow up to become a man (not merely in role)
 - (2) that she is biologically unable to become pregnant
 - (3) that she will not develop breasts
 - (4) that she has no vagina
 - (5) that she has, or will grow, a penis
- C. Onset of the disturbance before puberty. (For adults and adolescents, see Atypical Gender Identity Disorder.)

For males:

- A. Strongly and persistently stated desire to be a girl, or insistence that he is a girl.
 - B. Either (1) or (2):
 - (1) persistent repudiation of male anatomic structures, as manifested by at least one of the following repeated assertions:
 - (a) that he will grow up to become a woman (not merely in role)
 - (b) that his penis or testes are disgusting or will disappear
 - (c) that it would be better not to have a penis or testes
 - (2) preoccupation with female stereotypical activities as manifested by a preference for either cross-dressing or simulating female attire, or by a compelling desire to participate in the games and pastimes of girls
 - C. Onset of the disturbance before puberty. (For adults and adolescents, see Atypical Gender Identity Disorder.)
-

were less and less likely to verbalize cross-gender identifications as they aged (Green, 1975; Zuger, 1978). Yet, criterion A of the GIDC diagnosis required such verbal statements (see Table 1). Further, the diagnosis did not include any age-specific information that might mitigate this requirement. Thus, as the now-official definition of the phenomenon, GIDC came under scrutiny and was critiqued by researcher-clinicians, in this case for instituting what they deemed to be unwarranted limitations on their ability to make a proper diagnosis.

In sum, the diagnosis was, and remains, somewhat contested within the childhood gender variance subspecialty itself. Researchers proposed alternate diagnostic formulations and pointed out problems with the GIDC diagnosis itself. Thus, within the subspecialty, the diagnosis functioned both to institutionalize the medicalized status of childhood gender variance *and*

became a flashpoint for debates over what exactly that medicalized status should consist in. But it also became central in debates over how, to what degree, and whether childhood gender variance should be medicalized *at all*. These kinds of challenges have taken place largely as debates among GIDC clinician-researchers and their intraprofessional and extraprofessional (lay) critics.

Formal Diagnosis and the Challenge to Medicalization

As noted above, there was a small amount of external critique that took place before the diagnosis even appeared. Once GIDC made its debut in 1980, such critiques did *not* immediately ramp up. Thus, the appearance of a diagnosis alone was not a sufficient condition in this case to engender critique, even concerning a controversial phenomenon like childhood gender variance with its ties to marginalized and politicized collectivities (e.g., LGBTQ people, communities, and organizations). Yet when a set of conditions came together in the early 1990s, and critiques did increase, the diagnosis became a key target.

Whereas the 1970s critiques came in the wake of gay liberation and second wave feminist movements and drew explicitly on these bodies of thought, the more contemporary critiques that began to surface in the early- to mid-1990s responded to a different set of enabling conditions present then: new queer, transgender, and intersex activism; academic queer theory and transgender studies; increased cultural production by and about gender transgressors; the demedicalization of homosexuality via its removal from the *DSM*; and the institutionalization of both affirmative models of gay and lesbian mental health and of gay and lesbian mental health professional networks. Finally, and, importantly for the analysis here, were changes to the diagnostic codification of GIDC and transsexualism; in other words, along with the broad developments listed above, diagnostic changes themselves created conditions directing critical attention to the diagnosis.

The publication of *DSM-IV* (APA, 1994) was an important catalyst for renewed critique of the diagnosis. Since *DSM-III*, the *DSM* as a document has been in near constant revision. This has resulted in three revised documents since *DSM-III*: *DSM-III-R* in 1987, *DSM-IV* in 1994, and *DSM-IV-TR* in 2000 (*DSM-IV-TR* is a “text revision” of the *DSM-IV*, and includes no changes to GID diagnostic criteria). Revisions to GIDC in *DSM-IV* included at least two major changes that were important for

critique. First, the diagnosis arguably moved away from its earlier focus on identity, at least in the diagnostic criteria. Whereas both the *DSM-III* and *DSM-III-R* versions included a pillar of the diagnostic criteria (criterion A in each version) that required a cross-gender identity, the *DSM-IV* version operationalized this requirement in terms of cross-gender behavior (for the diagnostic criteria across these revisions, see Tables 1–3). Critics have seized on this change to argue that the diagnostic net in *DSM-IV* is too broad.

The second change, perhaps even more significant in terms of immediate response, was a retooling and combining of the categories of GIDC and adult transsexuality. When GIDC first entered *DSM-III* in 1980, it was listed separately but alongside transsexuality, which was also making its *DSM* debut. With the publication of *DSM-IV*, the two were collapsed into

Table 2. Diagnostic Criteria for GIDC in *DSM-III-R*.

For females:

- A. Persistent and intense distress about being a girl, and a stated desire to be a boy (not merely a desire for any perceived cultural advantages from being a boy), or insistence that she is a boy.
- B. Either (1) or (2):
 - (1) persistent marked aversion to normative feminine clothing and insistence on wearing stereotypical masculine clothing, e.g., boys' underwear and other accessories
 - (2) persistent repudiation of female anatomic structures, as evidenced by at least one of the following:
 - (a) an assertion that she has, or will grow, a penis
 - (b) rejection of urinating in a sitting position
 - (c) assertion that she does not want to grow breasts or menstruate
- C. The girl has not yet reached puberty.

For males:

- A. Persistent and intense distress about being a boy and an intense desire to be a girl, or more rarely, insistence that he is a girl.
 - B. Either (1) or (2):
 - (1) preoccupation with female stereotypical activities, as shown by a preference for either cross-dressing or simulating female attire, or by an intense desire to participate in the games and pastimes of girls and rejection of male stereotypical toys, games, and activities
 - (2) persistent repudiation of male anatomic structures, as indicated by at least one of the following repeated assertions:
 - (a) that he will grow up to become a woman (not merely in role)
 - (b) that his penis or testes are disgusting or will disappear
 - (c) that it would be better not to have a penis or testes
 - C. The boy has not yet reached puberty.
-

Table 3. Diagnostic Criteria for GID in *DSM-IV* and *DSM-IV-TR*.

-
- A. A strong and persistent cross-gender identification (not merely a desire for any perceived cultural advantages of being the other sex). In children, the disturbance is manifested by four (or more) of the following:
- (1) repeatedly stated desire to be, or insistence that he or she is, the other sex
 - (2) in boys, preference for cross-dressing or simulating female attire; in girls, insistence on wearing only stereotypical masculine clothing
 - (3) strong and persistent preferences for cross-sex roles in make-believe play or persistent fantasies of being the other sex
 - (4) intense desire to participate in the stereotypical games and pastimes of the other sex
 - (5) strong preference for playmates of the other sex.
- B. Persistent discomfort with his or her sex or sense of inappropriateness in the gender role of that sex. In children, the disturbance is manifested by any of the following:
- (1) in boys, assertion that his penis or testes are disgusting or will disappear or assertion that it would be better not to have a penis, or aversion toward rough-and-tumble play and rejection of male stereotypical toys, games, and activities;
 - (2) in girls, rejection of urinating in a sitting position, assertion that she has or will grow a penis, or assertion that she does not want to grow breasts or menstruate, or marked aversion toward normative feminine clothing.
- C. The disturbance is not concurrent with a physical intersex condition.
- D. The disturbance causes clinically significant distress or impairment in social, occupational, or other important areas of functioning.
-

one diagnosis, “Gender Identity Disorder,” which contained specifications for “In children” and “In adolescents and adults.” The stated rationale underlying the reclassification was somewhat contradictory. A published interim report from the *DSM-IV* Subcommittee on Gender Identity Disorders (Bradley et al., 1991) noted that “only a small minority of cross-gender-identified children followed prospectively go on to develop transsexualism” (p. 334), yet went on to propose an overarching diagnosis because “The subcommittee felt that a statement of the essential, common elements of gender identity disorder could be applied to patients at different phases of the lifecycle” (p. 341).

This redesignation, with “Disorder” as part of the diagnostic label prominently and starkly highlighting the pathologizing effects that a psychiatric diagnosis might carry (and with that particular diagnostic label now affixed to adults as well as children), came along just as newly radicalized transgender social movements were building steam. A key trans social movement claim was that gender nonconformity is not pathological.⁵ Thus, the GID diagnosis became a key target for many transgender activists.

The revised umbrella diagnosis, combining childhood and adolescent/adult variants, had the unintended consequence of directing adult trans activists toward a consideration of the *childhood* as well as the adult variant of the diagnosis.

Beginning in the mid-1990s, on the heels of the redesignation and combination of GIDC and transsexuality into a single “Gender Identity Disorder” diagnosis, there was a relatively short period of LGBTQ social movement attention to GID,⁶ including its application to children. By 1996, that activism reached what may have been its apex. Several organizations, including the National Gay and Lesbian Task Force, the International Conference on Transgender Law and Employment Policy, the National Center for Lesbian Rights, and GenderPAC issued statements critiquing the diagnosis and calling for reform. While transgender activists had picketed the APA before (e.g., at the 1993 APA meetings in San Francisco there were several days of demonstrations, with three members of Transgender Nation reportedly being arrested (*Transsexual News Telegraph* 1993, p. 4)), in 1996 activists *repeatedly* picketed the APA. They began with the annual convention in May 1996 where “over a dozen activists” from Transsexual Menace, Menace Men, Transgender Officers Protect & Serve, and ActUP called for “an end to diagnosing transpeople as mentally disordered” (*In Your Face!* 1996, p. 2). In addition, at least one new but short-lived organization was formed around the same time that was conceived to directly focus on GID. It was aptly named the National Coalition for GID Reform (NCGIDR).

Challenges to the childhood diagnosis were included in the activist work undertaken during this period. For instance, under the banner “Million in Tax \$ for ‘Treating’ Gender-Variant Kids,” an activist newsletter reported that “‘research’ and ‘treatment’ continues today with children as young as 3 or 4 years of age. Often, their only ‘disorder’ is running afoul of the APA’s traditional fear of sexual or gender difference” (*In Your Face!* 1997, p. 2).

On one hand, then, the diagnosis (and diagnostic changes) directed external, social movement attention to the medicalization of childhood gender variance. At the same time, *intraprofessional* debates about the legitimacy of the diagnosis also posed challenges to medicalization. In the most general sense, these critics argued that GIDC hurts the children it purports to help. They covered several overlapping areas, and suggested that GIDC (or some aspects of it) should not be considered a psychiatric disorder, and that instead it describes some form of normal (albeit rare) variation. They argued that GIDC reinforces cultural notions of masculinity and femininity, and in conjunction with the differential application of

GIDC to boys versus girls, they charged that the diagnosis is sexist. Critics also drew on GIDC researchers' own findings indicating that GIDC boys disproportionately grow up to be homosexual or bisexual⁷ and argued that GIDC is a ruse for the continued pathologization (and sometimes prevention) of homosexuality. In the most general sense, then, in line with classic critiques of the dangers of medicalization (Conrad & Schneider, 1992), critics have argued that GIDC renders a social problem (homophobia, transphobia, and/or intolerance for gender nonconformity) as individual pathology.

In mounting such critiques, some critics have drawn on the general definition of mental disorder in order to question GIDC's status as a disorder. For example, Bartlett, Vasey, and Bukowski's (2000) published critique, which evaluates the diagnostic criteria for GIDC against the *DSM* definition of mental disorder, is forthrightly titled "Is Gender Identity Disorder in Children a Mental Disorder?" Wilson, Griffin, and Wren (2002) adopted a similar strategy in their analysis titled "The Validity of the Diagnosis of Gender Identity Disorder (Childhood and Adolescent Criteria)." Adopting such an approach for analyzing and critiquing GIDC has meant that the concept of "mental disorder," which serves as a conceptual scaffolding for all diagnoses listed in the *DSM*, is itself an important point of reference and a resource that critics strategically deploy (Horwitz, 2002).

Although *DSM* editors note the necessary fuzziness of any definition of mental disorder, and that, "like many other concepts in medicine and science, [the concept of mental disorder] lacks a consistent operational definition that covers all situations" (APA, 2000, p. xxx), they nonetheless have included a working definition (virtually unchanged in all editions since *DSM-III*⁸) as follows:

In *DSM-IV*, each of the mental disorders is conceptualized as a clinically significant behavioral or psychological syndrome or pattern that occurs in an individual and that is associated with present distress (e.g., a painful symptom) or disability (i.e., impairment in one or more important areas of functioning) or with a significantly increased risk of suffering death, pain, disability, or an important loss of freedom. In addition, this syndrome or pattern must not be merely an expectable and culturally sanctioned response to a particular event, for example, the death of a loved one. Whatever its original cause, it must currently be considered a manifestation of a behavioral, psychological, or biological dysfunction in the individual. Neither deviant behavior (e.g., political, religious, or sexual) nor conflicts primarily between the individual and society are mental disorders unless the deviance or conflict is a symptom of a dysfunction in the individual, as described above. (APA, 2000, p. xxxi)

Critics have scrutinized the GIDC diagnosis, measuring it against the standard set by the *DSM* definition, and argue that it does not meet several criteria. The most important aspects where critics cast doubt include questions of “distress,” “disability,” “deviance,” “dysfunction,” and “conflicts between the individual and society.”

In the actual text of the GIDC diagnosis, the general features of mental disorder have been further operationalized and specified for the GIDC case. For example, in terms of distress, criterion D of the GID diagnostic criteria requires that “The disturbance causes clinically significant distress or impairment in social, occupational, or other important areas of functioning” (APA, 2000, p. 581). In addition, there is a full paragraph that is pertinent under “Differential Diagnosis:”

Gender Identity Disorder can be distinguished from simple nonconformity to stereotypical sex-role behavior by the extent and pervasiveness of the cross-gender wishes, interests, and activities. This disorder is not meant to describe a child’s nonconformity to stereotypic sex-role behavior as, for example, in “tomboyishness” in girls or “sissyish” behavior in boys. Rather, it represents profound disturbance of the individual’s sense of identity with regard to maleness and femaleness. Behavior in children that merely does not fit the cultural stereotype of masculinity or femininity should not be given the diagnosis unless the full syndrome is present, including marked distress and impairment. (APA, 2000, p. 580)

This portion of the text purports to make a distinction between children with GID and children exhibiting milder forms of gender nonconformity, and in doing so suggests that while children with gender nonconformity may be cases “primarily of conflicts between the individual and society” (to quote from the general definition of mental disorder), such is not the case for GIDC. This portion of the text supports such a suggestion by pointing to GIDC as a “profound disturbance” that includes “marked distress and impairment.” The question of “distress” and “impairment,” however, and especially their relationship to “disturbance,” is highly contested.

Some critics argue that there is nothing inherently pathological about children who are diagnosed with GIDC (or some subset of children diagnosed with GIDC), and that instead their “distress” is a reaction to the kinds of social disapproval to which they are subjected. For example, Haldeman (2000) argues that

Researchers studying and treating gender atypical children have consistently assumed that anxiety, social withdrawal, rage, and other emotional reactions are intrinsic features of gender atypicality, either due to the child’s frustration at being restricted from preferred cross-gender activities, or to personal or systemic psychopathology in the family. Researchers have not considered the possibility that these emotional factors may

be normative responses to disapproving families and hostile peer groups. Further, researchers in this area have not considered the possibility that gender atypical behavior may, in some cases, be of benefit to the individual by expanding her or his behavioral repertoire. (p. 293)

Similarly, [Langer and Martin \(2004\)](#) argued that cross-gender identification is a “normal variant of human experience” (p. 11), and assert that “there is simply no evidence that ... distress or functional impairment are caused by the supposed disorder” (p. 11). Instead, they explain gender-variant children’s distress in terms of social isolation and victimization, which they liken to the experiences of gay, lesbian, and bisexual youth, a population that has been studied concerning the relationship between social disapproval and psychosocial adjustment. In these cases, then, critics draw on the language and criteria of mental disorder writ large to question the GIDC diagnosis, and in the process to challenge the medicalization of childhood gender variance.

Many critics have focused specifically on the diagnostic criteria in order to challenge the medicalization of childhood gender variance in general, or to suggest that this group is overly medicalized, arguing that some children caught up in the diagnostic net should not be. Although the *DSM* editors’ warn against using diagnoses in boilerplate, recipe-like fashion (see [APA, 2000, p. xxxii](#)), these criteria are actually presented as quasi formulas where calculations can be done to make a diagnosis. Given the potentially broad impact of *DSM* diagnoses combined with the way diagnostic criteria are often seen as shorthand for the full diagnosis, it is not surprising that *DSM* diagnoses, and specifically diagnostic criteria, become central in debates over categories of mental disorder, and are highly scrutinized when questions of the legitimacy of a diagnosis are raised. Such has certainly been the case in contemporary debates over the medicalization of childhood gender variance.

For example, significant critical attention has focused on diagnostic criterion A, which requires that four of five of the following be present to make a diagnosis:

- (1) repeatedly stated desire to be, or insistence that he or she is, the other sex
- (2) in boys, preference for cross-dressing or simulating female attire; in girls, insistence on wearing only stereotypical masculine clothing
- (3) strong and persistent preferences for cross-sex roles in make-believe play or persistent fantasies of being the other sex
- (4) intense desire to participate in the stereotypical games and pastimes of the other sex
- (5) strong preference for playmates of the other sex ([APA, 2000, p. 581](#)).

Critics (Bartlett et al., 2000; Bockting & Ehrbar, 2005; Corbett, 1996, 1998; Haldeman, 2000; Richardson, 1996, 1999; Wilson et al., 2002) argue that only item (1) concerns cross-gender identification, and that each of the other four items tap instead into cross-gender activities, interests, or other behaviors. With only four items required here to make the diagnosis, cross-gender identification need not be present to make the diagnosis (e.g., a child could exhibit items 2-5 but not item 1 and still receive a GIDC diagnosis). Some critics point out the internal inconsistency present when criterion A is examined in concert with other sections of the diagnostic text:

In regard to Criterion A, the diagnostic significance of widely disparate items is treated as if it were equivalent for each. In this way, having a preference for other-sex playmates is equated with a stated desire to be a member of the other sex. Moreover, because it is necessary to meet only four of the five criteria, Criterion A can be met without the child stating he or she wishes to be the other sex. Importantly though, as specified in the Diagnostic Features of GID subsection in the *DSM-IV*, to make a diagnosis of GID, “There must be evidence of a strong and persistent cross-gender identification, which is the desire to be, or the insistence that one is, of the other sex” (p. 532). That a mental disorder can be diagnosed when a core feature of that disorder is absent is alarming, as well as scientifically invalid. (Barlett et al., 2000, p. 757)

Previous versions of GIDC (from *DSM-III* and *DSM-III-R*) required some form of cross-gender identity statement or desire as part of the diagnostic criteria; [Burke \(1996\)](#) has put this critique in historical context, pointing out that “Today, a girl or boy can be diagnosed with GID without ever having stated the desire to be, or that he or she is or will be, the opposite sex. What had been the primary feature of the diagnosis when it first appeared in 1980 is now not even necessary” (p. 63).

Further, as noted earlier in this chapter, the diagnostic specifications for cross-gender desire or identification were not parallel for boys and girls in previous *DSM* versions. Some have noted the way that revisions of GIDC over time, including those concerning identity versus behavior ([McGann, 2006](#)), have resulted in diagnostic expansion, with GIDC potentially applicable to more and more children. McGann notes that “Since 1994 (*DSM-IV*) it has been possible to diagnose a child as gender disordered based *only* on cultural criteria – that is, based only on the child’s violations of social standards of traditional masculinity and femininity in the absence of demonstrated impairment of cognitive function... In effect, the diagnostic net has widened; a tomboy considered normal under *DSM-III-R* became abnormal in *DSM-IV*” ([McGann, 2006](#), p. 373). Some ([Burke, 1996](#); [Feder, 1999](#)) note the way domain expansion has been achieved

through changing diagnostic criteria so that it is increasingly possible especially for girls to be diagnosed.

These are but some examples of the way that specific features of the diagnosis are marshaled to question the medicalization of childhood gender variance in general, or the scope of that medicalization.

CONCLUSION

Diagnoses clearly play an important role in medicalization processes. However, their role is varied and, most likely, difficult to predict. While diagnoses are in a sense folded into medicalization, diagnosis and medicalization are certainly not reducible to one another. The ways in which they are related vary considerably. The history of Gender Identity Disorder as applied to children shows that diagnoses can both shore up and challenge medicalization. It comes as little surprise that diagnoses function to support and secure medicalization. In the case of childhood gender variance, for example, the formation of GIDC lent legitimacy to this mental health subspecialty, may have increased the number of children treated, and became evidence cited in nonmedical domains for the putatively pathological nature of this condition. However, the diagnosis has also been a crucial resource used in challenges to the medicalized status of childhood gender variance. In fact, the history of GIDC indicates that diagnoses are not merely tools that are taken up strategically to challenge medicalization (although they are that as well), but rather that diagnoses themselves may help to engender such critiques by drawing attention to the degree of medicalization that they represent. In this sense, they are not merely “terrains of struggle” (Cooksey & Brown, 1998), but instead they help *define* the terrain and *animate* the struggle, defining not merely phenomena that have been medicalized, but also marking out for all to see (and critique) medicalization processes themselves.

The history of GIDC further illustrates the ways in which medicalization exists prior to diagnosis. This is not surprising, especially given that diagnosis has often been posited as one of the later steps in the chain of events leading to a fully medicalized status (Conrad & Schneider, 1992). However, attention to the *ways* in which medicalization shifted in conjunction with the appearance of a diagnosis lends greater insight into their relationship. The appearance of GIDC helped to shore up medicalization, especially by acting as a legitimating force. However, the diagnosis also functioned to constrain medicalization, not merely by animating debate and critique (as noted above) but also by narrowly specifying what the diagnosable phenomenon consisted

in. In the absence of a formal diagnostic category, several (competing or complementary) proto-diagnoses could coexist, allowing for diagnosis-in-practice applied to a relatively varied range of children. With the advent of the diagnosis, some researcher-clinicians charged that children who should be diagnosed no longer could be – for instance, girls and older children. The diagnosis thus increased medicalization in some areas (legitimation), while it limited medicalization in others (patient range).

Finally, the general category that diagnoses tap into (in this case, mental disorder) becomes an important resource in challenging medicalization. Wakefield and First (2003) argue that even though the existing definition of mental disorder is limited, it nonetheless “can help explain ... why there are disputes about some conditions” (p. 24). Debates over GIDC, however, indicate that the definition of mental disorder, itself intimately tied to the construction of diagnoses, does not merely *explain* disputes, but can become an important tool and resource within the context of dispute. Instead of necessarily resolving disputes, a definition of mental disorder may help to animate them. Once a formal diagnosis has been put into place, it can be measured against the broader category of which it is a member – in this case, mental disorder. This suggests that it is not merely the diagnosis itself that becomes a tool used to either short up or challenge medicalization. Instead, a full range of conceptual and institutional “scaffolding” surrounding and supporting diagnoses (e.g., the definition of mental disorder and the *DSM* itself) are implicated in and drawn on in struggles over medicalization.

As some commentators have noted (Jutel, 2009), the largely unexamined or taken-for-granted relationship between diagnosis and medicalization has been a barrier to developing a fully articulated sociology of diagnosis. The analysis presented in this chapter suggests while diagnosis and medicalization are intimately intertwined, their relationship is complex and bidirectional, with diagnosis functioning both to support and challenge medicalization.

NOTES

1. To be clear, Conrad and Schneider remind us that medicalization is an ongoing and cyclical process, wherein what may seem like fully medicalized categories may move “back” in their model, and occupy less fully medicalized statuses. Thus, for Conrad and Schneider, the appearance of a diagnosis does not necessarily or for all times indicate an achieved and static medicalized status.

2. Research, treatment, and even formal diagnostic criteria for gender-variant children have historically focused more on boys than girls. This disproportionate focus on boys has been noted by critics (e.g., Feder 1999; Sedgwick, 1991) as evidence

that the interest in gender nonconforming children is driven by cultural anxieties. The ratio of prepubertal boys to girls seen at gender clinics today remains skewed toward boys, with Cohen-Kettenis & Pfäfflin (2003) reporting the ratios as 5.75:1 in Canada, 2.93:1 in the Netherlands, and 3.81:1 in the United Kingdom.

3. This case points to the ways in which Blaxter's (1978) important distinction between diagnosis-as-process and diagnosis-as-category might be rethought in terms of the ways they are interimplicated. In the case of childhood gender variance, a protodiagnosis (and an implied diagnostic category) existed via practices that were underway even in the absence of a formal category. And, of course, it was these diagnostic practices that partly laid the groundwork for the eventual formation of the formal diagnosis-as-category in the form of GIDC. This begs a larger question: When is a diagnosis truly a diagnosis? When an implied category exists via practices? Or only once a formal category has emerged? This points to the possible utility of thinking about "diagnosis" not in a categorical sense, but as a continuum of sorts. Thanks to PJ McGann for pointing me toward this question.

4. Along with linguistically producing a consensus that might not exist, such a statement also ignores the ways that diagnoses are *socially* produced.

5. Although trans activists typically argue that gender nonconformity is not a sign of pathology, there is less consensus about whether or not it should be medicalized. While some argue that medicalization, especially in the form of a diagnosis, should be challenged because of its stigmatizing effects, others have argued that gains in terms of access to desired medical services make the diagnosis necessary if not ideal (see, e.g., Burke, 2011).

6. Calls for reform of GID, and social movement activity directed toward that effort, have continued up to the present (see, e.g., www.gidreform.org). However, especially during the mid-1990s there was a flurry of such activity.

7. Prospective studies that followed feminine boys from childhood into adulthood, begun in the 1960s, began to report such findings in the 1970s and 1980s. For the most widely cited of such studies, see Green (1987).

8. The definition of mental disorder that was developed for and included in *DSM-III*, and that has remained in place up to the present, was itself largely a product of the early 1970s controversy over the *DSM* homosexuality diagnosis, and was created partly as a means of avoiding any similar debacle in the future (see Bayer, 1987).

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DEFINING SOCIAL ILLNESS IN A DIAGNOSTIC WORLD: TRAUMA AND THE CULTURAL LOGIC OF POSTTRAUMATIC STRESS DISORDER

Thomas DeGloma

ABSTRACT

Purpose – In this chapter, I examine the ways that various trauma carriers, including social movements, self-identified survivors, professional organizations, and advocates make public claims about trauma and the PTSD diagnosis as they work to define moral and political issues.

Methodology/approach – Employing the method of social pattern analysis, I analyze a variety of narrative data pertaining to issues such as child sexual abuse, war, slavery, and genocide.

Findings – Trauma carriers engage in significant social memory work and collective identity work, define social problems, and practice social activism as they address the causes and consequences of psychological suffering. Within the context of modern diagnostic psychiatry, the PTSD diagnosis stands out as a unique narrative of social illness. The PTSD diagnosis is a powerful cultural script that various individuals and interest

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groups use to interpret mental health symptoms while attributing psychological consequences to social causes as opposed to problems rooted in the individual's psyche (as with psychoanalysis) or neurophysiology (as with modern diagnostic psychiatry). By implication, the social world must be "cured" for the individual to be healthy.

Originality/value of paper – I detail the unique sociocognitive implications of the PTSD diagnosis, highlighting its impact on our collective understanding of particular traumatic experiences and the shared nature of posttraumatic affect. I show the relevance of social memory studies, the more broadly conceived sociology of culture and cognition – especially as it pertains to collective identity and classification norms, the sociology of health-focused social movements, and the analysis of social problems claims-making to an emerging sociology of diagnosis.

Keywords: PTSD; trauma; memory; identity; narrative; diagnostic work

THE UNIQUE SOCIAL LOGIC OF POSTTRAUMATIC STRESS DISORDER

I would wake up suddenly, soaked in sweat and afraid. I couldn't forgive myself for having taken other people's lives and for being naive enough to believe the US government's lies and winding up in the war zone to begin with. I thought that if others knew my story, they would shun me as a murderer. Sometimes when I was alone I would cry and I never talked to anyone about what was going on inside my head. I heard about Post-Vietnam Syndrome (now called Post-Traumatic Stress Disorder, or PTSD) but didn't understand that I was experiencing it.

David Cline, Vietnam veteran and anti-war activist

In the above epigraph, Vietnam veteran David Cline, long-time anti-war activist and member of Vietnam Veterans Against the War, gives a moving depiction of his psychological distress. In just a few words, Cline conveys his overwhelming fear, difficulty sleeping, guilt, shame, sadness, and sense of isolation. Beyond a stirring depiction of personal suffering, Cline presents us with a powerful, retrospective diagnostic claim. He describes a profound personal discovery – an awakening (DeGloma, 2010) in which he deems his adverse psychological affect to be the consequence of his experiences at war. Although Cline previously “didn't understand [what he] was experiencing,” he now knows that it was posttraumatic stress disorder (PTSD).

Consequently, as he tells his personal story he engages in diagnostic work of moral, political, and cultural significance, establishing an implicit psychological connection to others who share in the trauma of war.¹

Stories about trauma are increasingly common in the modern world (see Alexander, 2004a, 2004b; Davis, 2005; DeGloma, 2009; Plummer, 1995). The PTSD diagnosis is a narrative of trauma told with a modern psychiatric vocabulary. Of all the official diagnoses listed in the Diagnostic and Statistical Manual of Mental Disorders (DSM), PTSD is unique in that it involves locating the cause of adverse psychological symptoms in worldly experience (APA, 1994, pp. 424–429; see also Young, 1995). It requires establishing a causal link between an experience held in common by a group of individuals and the psychological symptoms they share as a result of that experience, socializing both the causes and manifestations of mental disorder in a unique way. In this chapter, I explore the cultural logic of PTSD, distinguishing this particular way of thinking about mental illness from other psychiatric illness models and detailing the sociocognitive implications of this unique diagnostic category.

The PTSD diagnosis was established due to the impact of a broader cultural “trauma process” (Alexander, 2004a) on the institution of clinical psychiatry. It is both the result of cultural and political activism and a discursive tool that various interested parties use to define social problems and make claims for social change. Typically, their claims are controversial. Due to the efforts of Vietnam Veterans Against the War and their allies, PTSD first appeared in the third revision of the DSM in 1980. These “diverse champions of this new diagnosis” (Scott, 1990, pp. 294–295), including movement participants working in the mental health professions (e.g., Lifton, 1973), worked to transform previous notions of war-related stress such as “shell-shock” (WWI) and “war neurosis” (WWII) into an official and diagnosable psychiatric illness (see also Shephard, 2000; Young, 1995). Simultaneously, the North American feminist movement began to publicly call attention to the trauma of child sexual abuse (Davis, 2005; Herman, [1981] 2000). Meanwhile, Holocaust survivors were publishing memoirs and redefining the Holocaust as trauma, shifting the predominant cultural understanding of that event away from its initial definition as a war crime (Alexander, 2004b) and “taking center stage in the growing number of public and private commemorative practices” (Kidron, 2004, p. 517). Recently, PTSD has been linked to a wide variety of social experiences, including crime, terrorism, natural disasters, and the multigenerational legacy of events such as the Holocaust (Danieli, 1998; Kidron, 2004), American slavery (Hicks-Ray, 2004; Leary, 2005), and the historic treatment

of Native Americans (Duran, Duran, *Yellow Horse Brave Heart, & Yellow Horse-Davis, 1998*; Gagné, 1998). As public activism focusing on various traumatic events proliferated, several professional mental health organizations and advocates also took a particular interest in the question of trauma and began making public claims about PTSD.

Social movements, professional mental health organizations, and individual advocates that do this cultural and political work are trauma carriers (Alexander, 2004a) – interested parties that work to shape our broad cultural understanding of trauma in general and PTSD in particular. According to Jeffrey Alexander (2004a, p. 11), such trauma carriers

have both ideal and material interests, they are situated in particular places in the social structure, and they have particular discursive talents for articulating their claims – for what might be called “meaning making” – in the public sphere.

As trauma carriers, including self-identified survivors, link adverse psychological, interpersonal, and community-based symptoms to worldly experiences they deem “traumatic,” they also function as “health social movements” (Brown & Zavestoski, 2004; see also Jutel, 2009; Stein, 2011) and advocates who use diagnostic language to advance a strong moral and political critique of such experiences. Using a clinical vocabulary, they define various social problems in the world and thus advance a collective moral impetus to redress and reparation. Given their commitment to identifying the social causes of psychological distress such trauma carriers present a challenge to “the biopsychiatric medical model” (Cooksey & Brown, 1998, p. 526) of diagnosis that has dominated the field of psychiatry for the past three decades.

PTSD AND THE PSYCHIATRIC FIELD

The 1980 publication of the DSM-III signaled a fundamental paradigm shift (Kuhn, [1962] 1996) from “dynamic” to “diagnostic” models of psychiatric thought (Horwitz, 2002; Smith, 2010). The PTSD diagnosis, introduced in the midst of this transition, is distinguishable from each of these psychiatric paradigms while incorporating and transforming foundational tenets of both. The dynamic model of psychiatry, largely defined by Freudian psychoanalytic thinking, characterized mainstream psychiatry for the greater part of the twentieth century. Mental disorders, from this perspective, are seen to be continuous with normal behavior and explainable by exploring the inherently personal unconscious (Zaretsky, 2004),

particularly in order to reveal deeply repressed memories of painful psychic experiences. The PTSD framework incorporates and revamps three interrelated premises of dynamic psychiatry and psychoanalytic theory. The first is the view that adverse psychological symptoms are the consequence of some cause rooted in the past (Freud, [1899] 1938; Young, 1995, pp. 119–121). The second, inherent in Freud's theory of the unconscious (Freud, [1899] 1938, [1901] 1938, [1905] 1963), is the idea that psychological symptoms must be decoded in order to understand their meaning. The third is an emphasis on an interactive therapeutic dialogue.

Alternatively, the newer diagnostic model of psychiatry involves a classificatory biomedical approach to mental illness (Brown, 1990). With the advent of this paradigm, psychiatric authorities "imported a medicalized framework organized around specific disease entities to formulate the basic nature, causes, and treatment of disturbed behavior," classifying "mental illness into discrete diagnostic entities" (Horwitz, 2002, p. 2). This revolution in the psychiatric field was in part motivated by pressure from governmental agencies, private insurance providers, and pharmaceutical companies (Mayes & Horwitz, 2005). The new diagnostic model of mental illness replaced dynamic psychiatry's emphasis on the personal unconscious with an emphasis on "underlying organic pathologies" (Horwitz, 2002, p. 3), one that "precludes a consideration of the importance of social and institutional contexts in identifying and reacting to mental disorders" (Cooksey & Brown, 1998, p. 526). Mental illness thus became firmly rooted within the individual's neurophysiology and/or genetic makeup at the expense of their mind or psyche. This biomedical worldview shapes mainstream diagnostic practices today. In some ways, the PTSD diagnosis conforms to this newer medicalized model of psychiatry. Diagnosing PTSD requires modern psychiatric assessment practices such as measuring the degree of a patient's correlation with symptom set lists. Further, PTSD is commonly associated with physiological changes in the body or brain (van der Kolk, Hopper, & Osterman, 2001) and treated with pharmaceuticals (Duffy, Craig, Moscicki, West, & Fochtman, 2009, p. 189). Although some are critical of the medicalization of PTSD (Becker, 2000), it is a discrete diagnostic entity defined by a discrete symptom set with which a medical diagnosis can be made.

Dynamic and diagnostic psychiatric paradigms are appropriately contrasted given these distinctions. However, despite their differences, both models locate the root of mental disorder in the individual. Each of these frameworks represents a different *narrative of individual illness* (on illness narratives, see Frank, 1993; Kleinman, 1988). In contrast, PTSD is a

discursive frame (Kidron, 2004, p. 514) that interested parties use to locate the origins of mental disorder in an “extreme” and “abnormal” social experience. Thus, PTSD stands out as a unique *narrative of social illness* within a field of psychiatry dominated by theories that ground mental illness within the individual (Fig. 1). Deliberately downplaying the differences between dynamic and diagnostic models, I stress their shared commitment to an individualistic worldview in order to emphasize the unique social logic of PTSD. Fig. 1 highlights an under-explored etiological tension between two contradictory ways of understanding mental disorder and, consequently, the conditions necessary for psychological well-being. Using the PTSD diagnostic paradigm, trauma carriers seek underlying social causes of psychological distress. Challenging mainstream diagnostic practices that individualize and internalize mental disorder, they (re)define particular past experiences as morally problematic and link such experiences to the psychological distress of a posttraumatic community of sufferers. Engaging in such culturally relevant diagnostic work, individuals cooperate to transform “personal troubles” into “public issues” (Mills, [1959] 2000, p. 8).

Today, the official diagnostic criteria of PTSD include a multifaceted set of symptoms that must be linked to any one of a diverse range of “credible” traumatic experiences. The requisite past traumatic experience is broadly defined to include a wide variety of life-threatening or otherwise serious experiences, the witnessing of (or being “confronted with”) such events, and/or the learning that a socially significant other has had such an experience. Posttraumatic symptomatology involves the criteria that “the traumatic event is persistently reexperienced” (e.g., via intrusive thoughts, nightmares, and “dissociative flashback episodes”), the “persistent

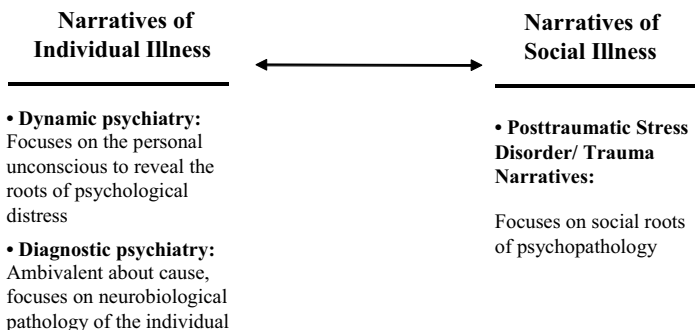


Fig. 1. A Two-Dimensional Classification of Psychiatric Paradigms.

avoidance of stimuli associated with the trauma,” and “persistent symptoms of increased arousal,” including difficulty sleeping and concentrating, irritability, “outbursts of anger,” and “exaggerated startle response” (APA, 1994, p. 424). More, physical symptoms such as “headaches, gastrointestinal complaints, immune system problems, dizziness, chest pain, or discomfort in other parts of the body” have also been attributed to PTSD (Mental Health America, 2010a), as have anti-social behavior, aggression or violence towards others, feelings of intense guilt, high-risk behaviors, drug and alcohol abuse or dependency, depression, anxiety, obsessive and compulsive behavior, delusions, defiance of authority, and social phobias. Using the PTSD diagnostic framework, trauma carriers prompt individuals to look to their past experiences to explain such behaviors and feeling states in the present. They thereby ground individual consciousness and well-being in a broader social environment and subvert the biopsychiatric push to “minimize psychiatric attention to social context” (Cooksey & Brown, 1998, p. 548). By implication, the social world must be cured in order for individuals to be healthy.

METHODS AND DATA

The data in this chapter stems from my analysis of over 500 documents of different types and sizes (including published books, webs pages, organizational pamphlets and articles, video documentaries, and public message board posts) pertaining to the consequences of trauma and the PTSD diagnosis. I analyzed professional psychiatric narratives from several sources. These include the American Psychiatric Association, The National Center for PTSD, The PTSD Alliance, Mental Health America (formerly the National Mental Health Association), The American Psychological Association, and the National Institute of Mental Health. In addition, I studied the narratives of various social movements and advocates concerned with PTSD and trauma more generally. These include veterans’ groups such as Vietnam Veterans Against the War and Iraq Veterans Against the War, groups and activists concerned with the enduring legacy of American slavery, including the National Coalition of Blacks for Reparations in America (NCOBRA) and Dr. Joy DeGruy Leary (2005) – a social worker and moral entrepreneur (Becker, [1963] 1997) who coined the concept of posttraumatic slave syndrome, as well as notable advocates and self-identified survivors linked to the more diffuse cultural movement focused on

the consequences of child sexual abuse (Bass & Davis, 1988; Davis, 1990, 1991; Farmer, 1989; Herman, [1981] 2000, 1992; Whitfield, 1995).

Intentionally drawing from a diverse range of cases, I show how such interested parties work to make and expand the trauma paradigm. Following Wagner-Pacifici and Schwartz, (1991, p. 383), I contend that “specific worldviews inhere in the specialized discourses of social organizations” and interest groups and “these worldviews involve ideas of what it is to be a human being in society and how human beings ought to be represented.” As they work to define particular social problems, all of these various trauma carriers use the logic and language of PTSD to advance their various causes and concerns. In the process, they reinforce a broad cultural framework for understanding traumatic experience and its consequences for psychological well-being. Deliberately disregarding the significant differences among these parties, I highlight general sociocultural patterns (Zerubavel, 2007) that reveal their commitment to a common “thought style” (Fleck, [1935] 1979, p. 28) – a shared way of thinking about the world. These sociocognitive similarities exemplify the fundamental tenets of an even broader, culturally engrained narrative of social illness that manifests in a variety of “institutional arenas” (Alexander, 2004a, pp. 15–21) beyond the field of psychiatry and throughout popular discourse. With this approach, I show how the sociology of culture and cognition (particularly, a sociological view of memory and identity) can apply to a sociology of diagnosis in order to elucidate important features of our broad cultural understanding of PTSD in particular and the social logic of trauma in general.

TRAUMA AND MEMORY WORK

Reparations will allow United States residents to make peace with a significant part of this country’s shameful past and end the intergenerational trauma of its current effects.

~ National Coalition of Blacks for Reparations in America

As they engage in diagnostic work, trauma carriers treat both individual and community-based troubles as evidence of the morally problematic character of a past event or experience (Kidron, 2004; Young, 1995, pp. 159–162). Subverting the biopsychiatric model of diagnosis, they emphasize the need to discover the cause of contemporary symptoms. Their diagnostic work is inherently retrospective in orientation. However, instead of stressing the personal and idiosyncratic character of an individual’s memory, such mnemonic agents emphasize the social character and widespread

implications of the past. Thus, trauma carrier groups are also “mnemonic communities” (Zerubavel, 1997) where individuals are united in their collective concern with understanding the past. Despite many differences among them, all are committed to a common memory genre (Olick, 1999a) or “memory style” (Pillemer, 1998, p. 179) that stresses the process of “recovering” memories or reclaiming lost history and thereby discovering a previously suppressed “truth” about the past. Thus, they often work to reinterpret past events, publicly questioning the official record of the experience at issue by highlighting new details or stressing previously under-acknowledged characteristics of the particular event at hand. While defining the past as traumatic, they advance a vocabulary of motive (Burke [1945] 1969; Mills 1940) and assign blame, consequently providing a socially determined foundation for claims of redress and restitution. When such trauma carriers do diagnostic work in the public sphere, they use both autobiographical and collective narratives to shape broader mnemonic conventions and recounting norms (see also DeGloma, 2007, 2010; Eyerman, 2001). They work to shape the collective mnemonic record of particular events and establish a social framework for individuals to reconstruct their autobiographies with attention to the impact that such events had on their lives.

Some trauma carriers work to define past wars, for example, by filtering the memory of war through a present-day lens of its psychological consequences for veterans. In the process, they characterize war as an extreme, disturbing, and morally problematic experience with serious implications for the health and well-being of the participating forces. For example, Bill Leary (2003), a member of Vietnam Veterans Against the War, writes

When you realize that you just shot and killed an old man, woman or child, you must put it out of your mind to be able to continue functioning, but you can only do so for a short while. Sooner or later you have to deal with the guilt you must feel if you are human at all. This is where the PTSD comes in and the violence or depression it can trigger. That leads to the classic example of the vet in the bell tower with a rifle picking off people on the street, or the seemingly-incurable alcoholic or drug addict that spends the rest of his life on the edge of society or in a jail or hospital.

By offering this public account of the veteran’s experience, Leary also advances a retrospective indictment of the activities of war (specifically killing) by linking these activities to psychological consequences. Further, he claims that the impact of these psychological consequences spreads beyond the individual to become a social problem (in the form of public killing sprees, public health issues, and incarceration). By telling this story, Leary

retrospectively defines the Vietnam War through the lens of its eventual consequences, countering those who define the war as an honorable, heroic, and progressive patriotic venture. Similarly, Ethan McCord (2010), an Iraq war veteran, attributes meaning to the Iraq war when he describes the posttraumatic consequences of his experiences at war. McCord, who can be seen rescuing two severely wounded children from a van in the controversial Wikileaks “Collateral Murder” video of an American Apache helicopter attack in an Iraqi suburb, later describes this incident to an audience at the 2010 United National Peace Conference in Albany, New York. He follows his depiction of these events by commenting

My mind was reeling, the thoughts controlling every ounce of me [...] I hated myself for what I was a part of [...] Ever since that day, I live with this. It’s burned into my head [...] I see it every day. I hear the cries of the children when I close my eyes. I smell the smells. When it’s quiet, I see the carnage like a slideshow. I’m hoping one day I can sleep a full night without memories coming to haunt me.

By accounting for the haunting torment that continues to mark his life, McCord defines the Iraq war through the lens of its psychological consequences. As such trauma carriers seek the meaning of psychological symptoms in past experience, they simultaneously use their stories to transform the meaning of the past by attributing consequences to it in retrospect. Moving beyond the psychoanalytic focus on decoding conflict within the individual, they focus on discovering and interpreting problems within the social world.

Other trauma carriers work to define American slavery by filtering the memory of slavery through the lens of its psychological and social consequences for African-Americans who are said to be suffering in its wake. Thus, Joy DeGruy (2009) interprets psychological phenomena including “vacant esteem” (involving “feelings of hopelessness, depression, and general self destructive outlook”), “a marked propensity for anger and violence,” and “internalized racism” to be a

condition that exists as a consequence of multigenerational oppression of Africans and their descendants resulting from centuries of chattel slavery [...] then followed by institutionalized racism which continues to perpetuate injury.

Consequently, DeGruy and other proponents of posttraumatic slave syndrome work to define the moral character of an event that officially ended over 150 years ago by describing its contemporary implications. Further, they determine American slavery to have a persistent power to traumatize. By interpreting “cultural dissonance” (Leary, 2004a) and “violence against self, property and others” (DeGruy, 2009) within

contemporary African-American communities, including one case of murder (Arrieta-Walden, 2004), to be symptoms of a traumatic past, proponents of posttraumatic slave syndrome ground the pathological character of such violence and other social problems in that past event. They thereby attribute meaning to American slavery and “the destruction of African culture” (Crawford, Nobles, & Leary, 2003, p. 251) that occurred several generations ago. By doing this diagnostic work in the public sphere, such trauma carriers promote social rules of remembering slavery. They provide a mnemonic framework that others can use to ascribe meaning to this past event while simultaneously articulating an unmistakable *presence* of the past in their own lives.

When other trauma carriers work to call public attention to rape, they are often redefining various experiences that were once defined as “sex” in the public sphere (Kelly, 1988, pp. 138–158) or calling public attention to what they claim to be previously *unseen* interpersonal and domestic sexual violence (Herman, [1981] 2000). Such trauma carriers often work to define sexual experience during childhood by publicly portraying its enduring consequences for those who experience it. In the following testimony, printed in the popular survivor manual *The Courage to Heal*, a self-identified victim locates the origins of her various troubles in her past abuse experience. Without such an experience (“If I had a comfortable childhood”), she claims, her life would have been much different (“I could be anything today”). She writes

People have said to me, “Why are you dragging this up now?” Why? *WHY?* Because it has controlled every facet of my life. It has damaged me in every possible way. It has destroyed everything in my life that has been of value. It has prevented me from living a comfortable emotional life. It’s prevented me from being able to love clearly. It took my children away from me. I haven’t been able to succeed in the world. If I had a comfortable childhood, I could be anything today [...] I don’t care if it happened 500 years ago! It’s influenced me all that time, and it does matter. It matters very much. (Bass & Davis, 1988, p. 33, emphasis in original)

In line with the recounting conventions of her autobiographical community, this individual defines a particular childhood phenomenon as a traumatic turning point (Gergen & Gergen 1997) in her life. By telling her story, she retrospectively defines such experiences through the lens of their painful, destructive, and debilitating consequences. In the process, she provides an autobiographical model that others can use to account for suffering in their own lives. Further, she advances a mnemonic framework with which a broad audience can understand the moral character of adult-child sexual contact.

In each of these otherwise different cases, trauma carriers work to define past events as traumatic by filtering them through the lens of adverse psychological and social consequences. As they do diagnostic work, such interested parties promote mnemonic conventions and recounting norms that pertain to particular events and relationships. Professional organizations and advocates often reiterate, institutionalize, and generalize these mnemonic conventions. When *Mental Health America* (2010b) publishes a guide to “understanding your mental health in times of war and terrorism,” this organization encourages the general population to attribute their psychological distress to the prominent political events of the recent past. When child protection advocates define a variety of experiences including receiving inappropriate love letters, ridicule, kissing, and sexual penetration (Bass & Davis, 1988, p. 21) as traumatic abuse, or assert that sexual abuse, beatings, teasing, and belittling can each lead to PTSD (Farmer, 1989, pp. 47–49), they are providing a mnemonic framework for others to interpret present-day suffering as caused by such childhood experiences. Subverting both the psychoanalytic and biopsychiatric drives to internalize and individualize mental disorder, they use a clinical vocabulary to locate the root of psychological suffering in the social world. By diagnosing the consequences of such experiences as a disorder, they deem the experience itself to be a social problem. Engaging in public diagnostic memory work, they use a common mnemonic framework to illuminate the past for various populations and audiences in the present.

TRAUMA AND IDENTITY WORK

There were tremendous similarities in the stories. The Black ex-nun from Boston and the ambassador’s daughter from Manila described the stages of their healing process the same way. A pattern started to emerge. What I was going through started to make sense.

Laura Davis, Personal Statement in the Preface to *The Courage to Heal*

With the rise of the PTSD diagnosis, trauma carriers expanded therapeutic interaction beyond the dyadic relationship characteristic of psychoanalysis to a broader social dynamic. Shifting the psychoanalytic focus on *looking within* the individual to include a simultaneous process of *looking among* group members for commonality, trauma carriers grounded therapeutic work in settings where reciprocal story-sharing and collective authority is emphasized. In these collective settings, psychological symptoms and life situations become the properties of an emergent community as, trauma carriers argue, “group discussion can help people to realize that

other individuals *in the same circumstances* often have *similar reactions* and emotions” (American Psychological Association, 2010, emphasis added). Thus, PTSD sufferers can “discuss traumatic memories, PTSD symptoms, and functional deficits with *others who have had similar experiences*” as well as “discuss and *share how they cope* with trauma-related shame, guilt, rage, fear, doubt, and self-condemnation” (NCPTSD, 2000, emphasis added). As expressed by Laura Davis in the earlier epigraph, such an interactive dynamic is inseparably linked to the process of making sense of trauma and its consequences and comprehending a healing process.

As trauma carriers do diagnostic work, they lump together of a “constellation of complaints” (Jutel, 2009) providing a sociomental basis for a collective identity. They emphasize similarities in the *consequences* of war, slavery, child sexual abuse, or another traumatic event at the expense of the variations that exist among otherwise disparate individuals. Thus, various individuals come to be grouped as “survivors of” any of the myriad experiences that are deemed traumatic and seen as “special populations” that “share certain characteristics associated with their own sets of vulnerabilities” (Ursano & Norwood, 1995, p. 10). These groups further come to be defined in relation to diagnostic lists of “common reactions after trauma” (NCPTSD, 1999) or “predictable patterns of behavior” (DeGruy, 2009) that provide for a psychosocial cohesion and further explain the rationale behind discussion groups where “group members help one another realize that many people” experience “the same emotions” (APA, 2010). Such symptom set lists, detailed by “workbooks” and “checklists” (see Bass & Davis, 1988; Davis, 1990) or “respect scales” (Leary, Eileen, & Briggs, 2005), provide a diagnostic mechanism that trauma carriers use to stress their shared identity attributes and shared present-day suffering at the expense of the differences among them. However, whereas other diagnoses also provide a social foundation for the emergence of collective identity and social activism (Klawiter, 2008; Gould, 2009), the PTSD diagnosis requires shared identities to be grounded in specific, etiologically situated events and experiences. Consequently, trauma carriers build biographical and etiological, rather than simply circumstantial, homogeneity as they articulate a shared life course among group members. Their diagnostic work becomes especially political because the posttraumatic identity, expressed as a shared symptom array linked to a common cause, stands as an indictment of specific worldly events.

By establishing a shared connection to adverse psychological *consequences*, trauma carriers provide a framework for individuals to harmonize their identities using the storytelling conventions and story models of the posttraumatic community. Undermining the biopsychiatric aversion to

cause, their storied identities also serve as politically charged testimonies. For example, Vietnam Veterans Against the War member Raymond Parrish (2002) provides a graphic depiction of intrusion, avoidance, and increased arousal – the three main PTSD symptom clusters – while describing the plight of a community of individuals who share in the consequences of war. In the process, he provides a generic biographical model of the Vietnam Veteran as a suffering social type. He states

When you see a veteran with the so-called “thousand-yard stare,” try to remember that he is seeing the faces of the dead [*intrusion*] and try not to laugh at those who duck when a car backfires [*increased arousal*]. Many veterans turn vegetarian or avoid barbecues because the smell of burning flesh reminds them of a horrific experience with napalm or phosphorous weapons [*avoidance*]. Similar reasons may cause them to avoid any Asian food or recoil at Asian faces or language [*avoidance*]. Those who have seen needless deaths because of the mistakes of others have a hard time trusting anyone in authority.

Using the psychosocial logic of trauma and PTSD, Parrish provides a narrative framework with which Vietnam veterans can build posttraumatic solidarity and link their selves to a moral and political standpoint in the world.

Structurally speaking, trauma carriers construct and circulate autobiographical and collective stories that advance a fundamentally psychosocial conception of “historical continuity” (Zerubavel, 2003, p. 37) from traumatic past to posttraumatic present. They give meaning to posttraumatic identity by strategically regarding “the present as a continuation of the past” (*ibid.*) and thus relating “fragmentary occurrences across temporal boundaries” (Gergen & Gergen, 1997, p. 162). Using such a psychosocial sense of historical continuity, one member of Vietnam Veterans Against the War asserts that “For some, the war is never over” (Parrish, 2002), directly grounding the shared psychological state of his community in a war that reaches across decades to characterize veterans in the present. Such an active temporal link can span several years of each community member’s life course or even stretch across multiple generations, as is evident in modern notions of the “multigenerational legacies of trauma” (Danieli, 1998), “Posttraumatic Slave Syndrome,” and “Second-Generation Holocaust Survivors” (Auerhahn & Laub, 1998; Bar-On, 1989). When reparations advocates in the United States refer to their progeny as “African children” (NCOBRA, 2010), or advocates of posttraumatic slave syndrome refer to African-Americans as “slavery’s children” (Leary, 2005, pp. 144–182), they are simultaneously highlighting their common descent from slavery and their shared identity in the present.

Using the temporal implications inherent in the socio-diagnostic logic of PTSD, trauma carriers advance moral and political arguments about a series of events that continue to impact a group of people at different points in historical time (see also DeGloma, 2009, p. 112). Such a temporal continuity is quite clear when proponents of posttraumatic slave syndrome argue that

Recurring racist incidents like, [sic] the 1955 brutal killing of Emmitt Till, the 1989 beating death of Mulugeta Seraw [...] in Portland, the 1991 police assault of Rodney King, and the recent dragging death of James Byrd, in Jasper Texas in 1999, serve as *fresh reminders* that the *trauma continues*. (Leary, 2004b, emphasis added)

By linking such modern violent crimes to slavery, proponents of PTSS argue that they are directed at individuals because of their historically entrenched community affiliations and socially grounded identities. In a similar fashion, the children of Holocaust survivors link their current identities to the traumatic experiences of their parents (Kidron, 2004, p. 521; Stein, 2009). As with war veterans and victims of child sexual abuse, the problem, while rooted in the past, continues to influence the present. Such a strategic attribution of cause and consequence serves as a culturally sanctioned “recipe for structuring experience” (Bruner, 1987, p. 31) and sharing identity, binding communities together based on common interests and shared threats to their well-being.

By building such “mental bridges” (Zerubavel, 2003, p. 40) between past experiences and present identities, self-identified victims and survivors of trauma stand as *living monuments* to a past atrocity (Fig. 2). By publicly embodying the legacies of the past, they shrink the distance between past and present. Their storytelling selves stand “as living sites of [...] traumatic memory” (Kidron, 2004, p. 527), as “both the *site of narration* and also the normal *site of ascription*” (Kerby, 1997, p. 132, emphasis in original) – both speaker and object to which the public can refer in order to empathize with the continuing consequences of traumatic experience. Such living monuments invite us to comprehend their posttraumatic affect. They offer their self-identities as public evidence of the harm caused by a traumatic past. Such a social mobilization of identity occurs when self-identified survivors of child sexual abuse share stories about their abuse on public websites (DeGloma, 2007) or at “Take Back the Night” rallies. Such an active presence of the past is also evident when trauma carriers use the psychological concept “regression” to liken the behavior of adult victims of child sexual abuse to the behavior of victimized children (e.g., Davis, 1991, p. 103). Self-identified survivors actively reinforce this striking

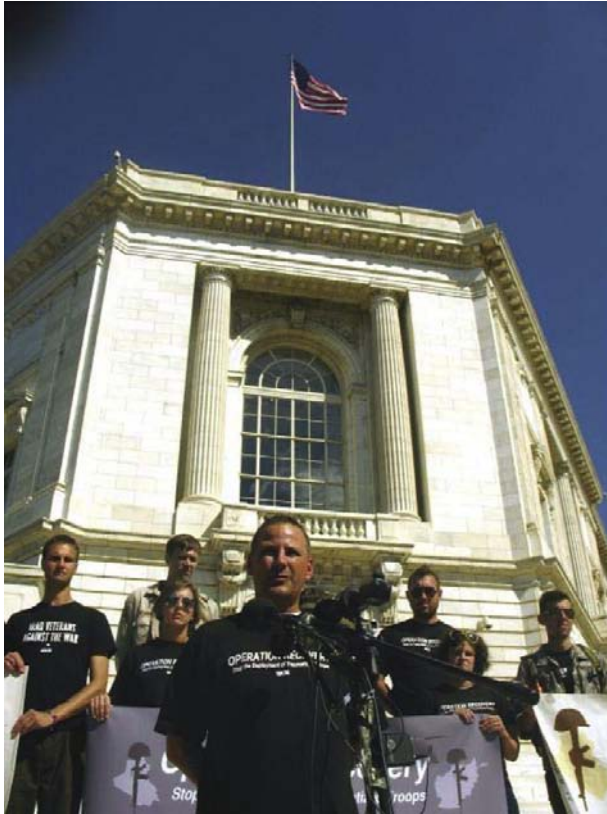


Fig. 2. Living Monuments to a Past Atrocity.

Iraq War Veteran Ethan McCord Speaks about His Struggles with Posttraumatic Stress Disorder as a Part of the “Operation Recovery” Campaign Organized by Iraq Veterans Against the War. Photo by Maria Saenz-Luna © 2010 Iraq Veterans Against the War. Image Retrieved October 2010 (<http://www.ivaw.org/gallery/operation-recovery>).

presence of the past when they use a child-like voice or perspective to recount their abuse experiences in the present. For example, reflecting on her childhood, Sylvia Fraser writes

I cry when my mother puts me to bed. I didn't used to be afraid of the dark but now I know that demons and monsters hide in the cubbyholes of my bed. I am afraid one will

jump out at me, and rub dirty dirty up against me with his wet-ums sticking out. (Fraser, 1987, p. 7)

Standing as living and embodied evidence of the consequences of the past experience at hand, trauma carriers do diagnostic work with unique moral and political implications. They define the “nature of the victim” (Alexander 2004a, pp. 13–14) while simultaneously constructing and performing the identities of “survivors” in the present.

PTSD AND THE DIAGNOSTIC STRATEGIES OF TRAUMA CARRIERS

To the children yet unborn with the hope that we leave them with a better world in which to grow.

Inscription, *International Handbook of Multigenerational Legacies of Trauma*

On October 7, 2010, Iraq Veterans Against the War announced the initiation of the “Operation Recovery Campaign to Stop the Deployment of Traumatized Troops” (IVAW, 2010). As part of this effort, the organization is spotlighting the personal stories of veterans and active duty military personnel who are suffering from PTSD and organizing various events that highlight the traumatic impact of war on everyday life. Beyond their demand that suffering soldiers and veterans be provided the resources they need to heal, IVAW offers the stories of posttraumatic individuals as evidence of the immoral and atrocious character of war. They use their claims about PTSD to strengthen their demands to end the wars in Iraq and Afghanistan.

When trauma carriers circulate their stories in the public sphere, they challenge the internalizing and individualizing logic of mainstream psychoanalytic and biopsychiatric models of diagnosis. They use the PTSD diagnostic framework to make moral and political claims as they work to define various social problems and articulate the need for social change. Just as a support group facilitator can serve as a “figure of epistemological authority” (Kidron, 2004, p. 523) in small group settings, trauma carriers work to establish cognitive and diagnostic authority in more open, public venues. Like other moral and cultural entrepreneurs, they “seek to insert themselves, individually and collectively, into an extant narrative (the status quo story) to bring about change, to create a new narrative” (Benford, 2002, pp. 54–55). As trauma carriers do diagnostic work, they invite us to experience sociomental and emotional empathy with the victims of the particular traumatic event of concern. They promote formulaic “feeling

rules” (Hochschild, 1979, 1983) and advance social “structures of feeling” (Saito, 2006) that public audiences can use to comprehend the psychosocial consequences of trauma and the plight of posttraumatic individuals and communities. These public narratives, each to a greater or lesser degree, become “a point of reference for future remembering as well as future perception, influencing down the road how new experiences will be coded” (Olick, 1999b, p. 347). Further, as is evident in the earlier epigraph, trauma carriers work to shape the future by defining what ought to be done to prevent further injury.

The case of trauma carriers and the PTSD diagnosis suggests the relevance of social memory studies, the more broadly conceived sociology of culture and cognition – especially as it pertains to collective identity and classification norms (Zerubavel, 1991), the sociology of health-focused social movements (Brown & Zavestoski, 2004), and the analysis of social problems claims-making to an emerging sociology of diagnosis. Trauma carriers are cultural agents who advance an alternative “discourse of the past” (Vinitzky-Seroussi, 2002) and define social problems in a fragmented cultural arena. The case of trauma and the PTSD paradigm specifically highlights the ways individuals and communities wield life stories and do diagnostic work to set a moral and political agenda. Their claims are often contested by reactive *trauma disputers* who work to undermine the logic of the PTSD diagnostic paradigm and thereby dispute the trauma carrier’s claim of social illness. Examples of such parties include the False Memory Syndrome Foundation (an organization that formed to dispute individuals’ recovered memories of child sexual abuse) and David Horowitz (who actively disputes claims for reparations and undermines the notion that American slavery was a trauma). Institutions can also act to undermine the efforts of trauma carriers, as when key players in the Veterans Administration and the American Psychiatric Association once opposed the inclusion of PTSD in the DSM-III (Scott, 1990). Despite the differences among them, each of these trauma disputers actively opposes the cultural work of trauma carriers by advancing alternative ways of defining a particular past experience and/or its relevance to the present. In the process, these trauma disputers often accuse trauma carriers of making unfounded claims or even victimizing others with unwarranted accusations. Such a tension between opposing cultural genres (see also Wagner-Pacifici & Schwartz, 1991) broadens the notion of “diagnosis as an arena of struggle” (Brown, 1990, pp. 402–403; see also Jutel, 2009) to suggest how certain diagnostic agents work to affect broader cultural and sociomental norms and set widely relevant and controversial moral and political agendas.

Although the twentieth century did not see a war fought on American soil, the PTSD diagnosis brought the Vietnam War and the Iraq War home – into the neighborhoods of the American public, carried in the minds and expressed in the behaviors of veterans. Similarly, the PTSD narrative brings child sexual abuse out of the home or church, extends the Holocaust beyond the death camps, and slavery beyond the antebellum plantation. Psychological “intrusion” thus has a distinctly social correlate. Using the logic of PTSD, trauma carriers work to make each of these experiences an unavoidable and pressing concern of contemporary communities. Using the discourse of trauma and PTSD, they advance moral and political claims while linking troubled selves to social problems.

NOTE

1. Cooksey and Brown (1998, p. 538) introduce the term “diagnostic work” to refer to “the process by which clinicians concretely proceed with their evaluation and therapeutic tasks.” In this chapter, I broaden the relevance of this concept to describe the ways various individuals and groups use the PTSD diagnostic framework to account for their psychological suffering.

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PART II
CONTEXT

RESISTING AMERICAN PSYCHIATRY: FRENCH OPPOSITION TO DSM-III, BIOLOGICAL REDUCTIONISM, AND THE PHARMACEUTICAL ETHOS

Manuel Vallée

ABSTRACT

Purpose – This chapter has two central purposes. The first is to suggest that western, as well as non-western, illness categories are culture bound. The second is to elucidate the diagnostic and treatment implications associated with adopting a reductionistic diagnostic approach, including for psychiatric as well as nonpsychiatric illnesses.

Approach – A comparative approach is used to highlight the differences between American psychiatry's diagnostic system (i.e., DSM) and French child psychiatry's diagnostic system (CFTMEA). The analysis begins by identifying the overarching differences between the systems, then analyzes the differences between their respective versions of the Attention Deficit/Hyperactivity Disorder diagnostic category, and ends by tracing the diagnostic and treatment implications of those differences.

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Findings – This analysis reveals that the systems differ in three significant ways: (1) theoretical orientation (biological vs. psychodynamic), (2) the view that symptoms should be counted as opposed to understood, and (3) the presence of symptom checklists versus their absence. Additionally, these differences encourage American clinicians to both administer the ADHD diagnosis to a greater number of symptomatic children and to treat these children with psychiatric medications.

Contributions to the field – The analysis makes three contributions to the field: (1) the comparative analysis highlights the limitations of the DSM's ADHD definition; (2) it strengthens the case for seeing western diagnostic categories in general, and the DSM categories in particular, as cultural artifacts; (3) it elucidates the profound relationship between diagnostic systems and both diagnostic rates and treatment practices.

Keywords: DSM; CFTMEA; diagnostic reference manuals; ADHD; culture-bound syndromes

Diagnostic reference manuals are fundamental to medical practice, for their diagnostic categories define what is and is not disease, which subsequently influences: (1) illness prevalence rates, (2) who qualifies for a medical diagnosis, and (3) who will get access to medical care resources. Additionally, each diagnostic manual is built upon a theoretical edifice (about what contributes to health and illness) that orients what we attribute the illness to, and how we should try to address it. Thus, such systems have profound social implications and should be analyzed carefully, particularly when there is temporal or cross-national variation.

Previous scholarship has analyzed different types of variation, including the expansion of diagnostic categories over time (Conrad, 2007; Fox, 1989), changes to theoretical orientation (Healy, 2002; Horwitz, 2007; Kirk & Kutchins, 1992), and cross-national differences in the definition of disease (Kleinman, 1988; Lakoff, 2005). Studying the latter variation is particularly useful for studying the extent to which disease categories, and the diagnostic manuals more generally, are cultural artifacts. However, while much scholarship (Kleinman, 1988; Lakoff, 2005; Watters, 2010) has analyzed the differences between disease definitions used in “developed” and “developing” countries, little has been said about the extant differences between “developed” countries. This is an important lacuna because those with a western bias could interpret the differences with “developing” countries as simply being an incomplete diffusion of “superior” technology, with the

non-western perspectives seen as the vestiges of a more “naïve” civilization. However, such a perspective loses its footing when the analyzed differences are between two former colonizing powers, each of whom adheres to western medicine and can lay claim to being a founding member of the discipline.

To address this lacuna, I compare American psychiatry’s *Diagnostic and Statistical Manual (DSM)* to French child psychiatry’s *French Classification of Child and Adolescent Mental Disorders (Classification Française de Troubles Mentaux d’Enfants et d’Adolescent (CFTMEA))*. Beyond identifying the overarching differences between these classification systems, I elucidate the differences between their definitions for Attention Deficit/Hyperactivity Disorder (ADHD), and draw out the implications of those differences for diagnosis and treatment. Pursuing this approach provides analytical leverage for better understanding the limitations of the *DSM* and for mapping the implications of those differences.

I argue that the *DSM* and *CFTMEA* differ in three significant ways: (1) theoretical orientation (biological vs. a psychodynamic), (2) the view that symptoms should be counted as opposed to understood, and (3) the presence of symptom checklists versus their absence. These differences have significant implications for the clinical encounter because they lead to very different conceptualizations of mental illness. In particular, where French clinicians tend to see mental problems as being caused by psychological and social problems, American clinicians are encouraged to assume the problem lies at the biological level. As well, I argue that these differences lead to corresponding psychosocial and biological interpretations of ADHD, which have important diagnostic and treatment implications. Specifically, the American system encourages clinicians to give the ADHD diagnosis to a much larger number of symptomatic children, while also encouraging them to treat those children with pharmaceuticals.

Beyond illuminating the specific case of ADHD, this comparative analysis yields three benefits. First, spotlighting differences between “developed” countries strengthens the case for viewing even western illnesses as “culture-bound syndromes” (Kleinman, 1988). Second, the analysis provides comparative depth to the critique against the *DSM*, as it suggests that the symptom-focused classificatory approach is but one cultural approach to dealing with mental illness symptoms. In turn, this helps to relativize the *DSM* and to underscore that it is a socially constructed cultural artifact. Third, the analysis draws attention to the role that *DSM-III* (and its subsequent versions) have played in fuelling America’s consumption of

psychiatric drugs, including those consumed by children as well as the public in general.

In what follows I begin by articulating my conceptual framework. Then I briefly summarize American psychiatry's history since WWII and highlight the profession's migration toward a reductionistic checklist approach. Additionally, I articulate French child psychiatry's opposition to *DSM-III* and describe the alternative classification system it developed in response. The analysis then shifts toward illuminating overarching differences between the two systems, differences between their definitions of ADHD, and the implications of those differences. Finally, I conclude by discussing the contributions of this chapter and avenues for future research.

CONCEPTUAL FRAMEWORK

How a society defines illness is fundamental to medical practice, for how illness is defined will influence: (1) illness prevalence rates, (2) who will be diagnosed as having a medical condition, and (3) who will get access to medical care resources. For these reasons, in recent decades sociologists have paid great attention to the processes by which life conditions come to be defined as medical problems (Brown, 1995; Conrad 1976, 1992; Zola, 1972), and to the social construction of illness definitions. Historically, sociologists have taken a constructionist approach vis-a-vis illness categories in general and mental illness categories in particular. The latter are viewed as the products of cultural and social processes, which problematize some symptoms and behavior at particular points in time and place, but not at others. Importantly, constructionists believe that "mental illnesses do not arise in nature but are constituted by social systems of meaning" (Horwitz, 2002, p. 6). In this approach, the mentally ill are not defined by anything they do, but rather by the cultural rules that define what is normal and abnormal behavior.

In turn, diagnostic categories play a critical role in the medicalization process because they guide physicians in identifying who does and does not qualify for a diagnosis, which strongly influences the number of people diagnosed with and treated for the conditions. The significance of the categories, for the medicalization process, is further enhanced by three factors. First, "medical diagnostic categories, perhaps especially psychiatric categories, are often fluid and subject to expansion and contraction" (Conrad, 2007, p. 47). Second, researchers have found that the slightest

change to a diagnostic concept¹ can have a profound impact on disease prevalence rates:

by slightly altering the wording of a [diagnostic] criterion, the duration for which a symptom must be experienced in order to satisfy a criterion, or the number of criteria used to establish a diagnosis, the prevalence rates in the United States will rise and fall as erratically as the stock market. (Kutchins & Kirk, 1997, p. 244)

And third, while diagnostic expansion can significantly expand the realm of medicalization, the changes often occur “almost unnoticed as part of regular medical practice” (Conrad, 2007, p. 47).

These points are exemplified by the case of Alzheimer’s, which went from being an obscure disorder prior to 1980, to being among the top five causes of death in the United States. Fox (1989) attributes the change to a shift in the conceptualization of Alzheimer’s. Specifically, the age criterion was removed from the diagnostic concept, which helped transform what was previously considered senility “into a specific disease with specific pathological characteristics and symptoms” (p. 59). Fox (1989) argues that this shift in conceptualization allowed a greater number of symptomatic people to be diagnosed with Alzheimer’s, which greatly expanded the number of deaths attributed to that condition. Similarly, Peter Conrad (2007) argues that American medicine expanded the ADHD concept by dropping the age limit, which enabled clinicians to administer the diagnosis to adults as well as children.

Beyond the expansiveness of diagnostic categories, researchers should also consider the theoretical orientation (about what causes health and illness) of reference manuals, as theoretical differences can impact what an illness is attributed to and how it will be addressed. This is exemplified by the transformation that occurred to American psychiatry’s diagnostic reference manual. Prior to 1980 the *DSM* reflected a psychodynamic diagnostic approach, which encouraged clinicians to consider the psychological and social causes of mental illnesses (Mayes & Horwitz, 2005). However, after 1980 clinicians began to bracket concerns about psychological and social causes, focusing instead on accurately describing and classifying psychiatric symptoms (Mayes & Horwitz, 2005). In turn, the latter approach led clinicians to attribute mental disorders to biological causes and to treat them with psychiatric medications (Kirk & Kutchins, 1992).

The problem with simply tracking change over time is that it falls prey to the evolutionary fallacy, whereby changes are perceived as steps in the linear progression of “science.” Science did play a role in the transformation that occurred to the *DSM*, for researchers (Abbott, 1988; Healy, 2002; Kirk &

Kutchins, 1992) have shown that the transition was partially directed by American psychiatry's loss of scientific credibility in the 1960s and 1970s, which prompted them to develop a more reductionistic approach. However, Brown (1990) argues that the search for credibility was very much tied to larger professional ambitions, which included fostering greater professional unity in order to legitimize the field as a "hard" science and to secure third-party health-care resources. Moreover, Abbott (1988) emphasized that the transformation to biopsychiatry and pharmacotherapy was also driven by the field's desire to distinguish and elevate itself from an increasingly crowded and competitive mental health field. Importantly, other researchers (Cooksey & Brown, 1998; Kirk & Kutchins, 1992) have emphasized that the biopsychiatric project wasn't pursued by psychiatry in general, but rather by biological psychiatrists. Thus, the transformation wasn't just a step in the linear progression of "science," but rather a politically and economically motivated professional project, which underscores that diagnostic instruments are politically and economically motivated cultural artifacts.

Beyond the historical approach, cross-national comparative research (Kleinman, 1988; Lakoff, 2005; Watters, 2010) has also exposed the socially constructed nature of diagnostic systems. For example, Kleinman's research (1988) in China revealed the presence of Chinese and western models of mental illness, which led to very different interpretations of the same symptoms. In one case, a woman's symptoms would have been interpreted as depression by western-trained clinicians, whereas clinicians trained under the Chinese system would have diagnosed her with neurasthenia. Studying the latter variation is particularly useful for studying the extent to which disease categories, and the diagnostic manuals more generally, are cultural artifacts. As previously mentioned, although the anthropological literature has analyzed differences between reference systems from "developed" and "developing" countries, little has been said about the extant differences between "developed" countries.

To address this lacuna, I compare American psychiatry's *DSM* to French child psychiatry's *French Classification of Child and Adolescent Mental Disorders (CFTMEA)*. If psychiatry is the "hard" science it claims to be, then we would expect the American situation to have parallels in France. However, this chapter shows the opposite. Beyond simply dismissing or criticizing the American "advance" in psychiatry, French child psychiatry responded by developing a competing diagnostic reference system, which emphasizes a psychosocial understanding of mental illness and encourages clinicians to identify and address the psychological and social factors contributing to the onset of mental illness.

AMERICAN PSYCHIATRY: THE SHIFT TOWARD A DESCRIPTIVE DIAGNOSTIC APPROACH

From the late 1940s to the early 1970s, psychoanalysts dominated American psychiatry. In 1948, psychoanalysts held 75% of the committee posts in the American Psychiatric Association (APA) (Healy, 2002). As well, by 1962, most psychiatric departments were headed by dynamically oriented psychiatrists, 13 of the 17 most used psychiatry textbooks had a psychoanalytical orientation, and all psychiatry graduate programs but one were based on analytic principles (Healy, 2002, p. 141). Along these lines, a former director of the National Institute of Mental Health (NIMH) stated “from 1945 to 1955, it was nearly impossible for a non-psychoanalyst to become the chair of a department or professor of psychiatry” (Brown, 1976, p. 492).

A consequence of the psychoanalysts' dominance is that American psychiatry strongly adhered to the psychoanalysts' psychodynamic diagnostic approach (Healy, 2002; Kirk & Kutchins, 1992). This approach is founded on a psychosocial model of mental illness, which attributes psychiatric symptoms to the interaction between the patient's psychological biography and their surrounding social context. This approach stands in stark contrast to the reductionist approach recently popularized by the *DSM-III* (and reinforced by its successors: *DSM-III-R*, *DSM-IV*, and *DSM-IV-TR*), which implicitly attributes mental illness to biological malfunction. In the psychodynamic approach, psychiatrists were relatively unconcerned about diagnostic accuracy, as diagnoses were not used to classify patients to one condition or another. Rather, diagnoses were used as heuristic tools to help patients uncover and address the underlying social and psychological etiology of their ailments (Healy, 2002; Menninger, 1963). This approach was the general guiding principle for the first and second editions of the *Diagnostic and Statistical Manual* (i.e., *DSM-I* and *DSM-II*), both of which provided general descriptions of psychiatric disorders that implicitly supported a psychosocial model of mental illness (Kutchins & Kirk, 1997; Wilson, 1993).

While American psychiatry enjoyed tremendous success in the 1950s, in the early 1960s it came under increasing attack from sociologists, disillusioned psychiatrists, and other social critics (Goffman, 1961; Healy, 2002; Laing, 1960; Szasz, 1960). This antipsychiatry movement highlighted the low interclinician reliability² of psychiatric diagnoses, criticized the validity³ of psychiatric diagnostic categories, and undermined psychiatry's scientific legitimacy and their place within medicine (Healy, 2002).⁴ The reliability problem was one professional leaders had been aware of since

1949, when researchers observed there was little more than a random chance that two psychiatrists would agree on the diagnosis of a given patient (Ash, 1949). However, while psychiatry's leadership acknowledged the problem, they did little to address it because, under the dynamic approach, their focus was on clinical practice, and classification problems (such as the reliability and/or validity of diagnostic definitions) seemed "irrelevant to good clinical work" (Wilson, 1993, p. 403).

However, the lack of concern about reliability was problematic, as explained by Kirk and Kutchins (1992): "if diagnoses cannot be reliably made, it is nearly impossible to conduct research or make progress on etiology and treatment effectiveness or to engage in research across geographically different settings" (p. 31). Moreover, a major problem with low reliability was that it made it difficult to develop a coherent research agenda, which contributed to the field's loss of government research funding over the course of the 1960s. Between 1963 and 1972, there was a 16% decline in the number of grants awarded by the NIMH to psychiatry (Brodie & Sabshin, 1973, p. 1310). Additionally, Brodie & Sabshin calculated that NIMH funding decreased by an annual rate of 5% between 1969 and 1972 (Brodie & Sabshin, 1973, p. 1309).

Importantly, the loss of funding eventually undermined the profession's claim as a "medical science," for such sciences were expected to produce verifiable studies demonstrating the accuracy of its diagnostic and treatment practices. Moreover, the loss of funding alienated research psychiatrists, who criticized the profession's adherence to the psychosocial model and increasingly clamored for a return to the medical model of psychiatry, with its emphasis on disease classification (Wilson, 1993, p. 402).

Economic pressures also emerged on the clinical front as medical inflation, spurred by Medicare, led medical organizations to pursue cost-cutting measures. For example, medical institutions began hiring mental health professionals who were not psychiatrists and would command lower salaries (Cooksey & Brown, 1998). Additionally, the low reliability of psychiatric diagnosis led insurance companies to curtail reimbursements for mental health services. For example, while Aetna and Blue Cross fully reimbursed psychiatric care in the 1960s, by the mid-1970s they had reduced their coverage to 20 outpatient visits and 40 inpatient hospital days per year (Wilson, 1993, p. 403). This development was largely driven by the low standardization of psychiatric diagnostic practices, which led to low diagnostic reliability and thus, for insurance companies, no accountability (Wilson, 1993). The situation was such that government and private insurance companies came to see psychiatry as a "bottomless pit" – voraciously consuming resources without providing any accountability (Sabshin, 1990,

p. 1270; Wilson, 1993). Importantly, the loss of insurance reimbursement financially impacted clinicians, further damaged psychiatry's place within medicine, and undermined the psychoanalysts' hold over psychiatry.

In the late 1960s, dissatisfaction with the situation led biological psychiatrists from Washington University to develop a classificatory diagnostic approach, which they believed would address psychiatry's "reliability problem" and strengthen its scientific credibility (Decker, 2007; Wilson, 1993). This approach consciously ignored both social context and psychological etiology, and led clinicians to focus instead on classifying clusters of symptoms, a profound shift that implicitly promoted a biological understanding of mental illness (Kirk & Kutchins, 1992). This classificatory approach represented a radical paradigm shift from the psychodynamic focus on etiology, and the Washington group believed that simplifying the diagnostic task in this way would improve interclinician reliability, thereby addressing one of the main criticisms against psychiatry (Cooksey & Brown, 1998; Decker, 2007). Notably, in 1974 one of their members (Robert Spitzer) was named to head the revision committee for the *DSM*, a position he used to transform the *DSM* from its psychodynamic orientation to a classificatory orientation. The revamped *DSM* made its debut in 1980 with the *DSM-III*, which provided specific symptom checklists for each psychiatric diagnosis, and intentionally eliminated concerns about social and psychological etiology (Kutchins & Kirk, 1997). Beyond the *DSM-III*, the developers used the same classificatory model for *DSM-III-R*, *DSM-IV*, and *DSM-IV-TR*,⁵ which served to further institutionalize the biomedical revolution in American psychiatry (Kutchins & Kirk, 1997).

THE SHIFT IN CHILD PSYCHIATRY

During the 1970s, two major developments in American child psychiatry⁶ influenced the evolution of diagnostic concepts for child mental illnesses. First, following adult psychiatry, American child psychiatry also migrated away from a focus on context to an approach that essentialized and biologized mental illness. This manifested itself by the subdiscipline's greater receptiveness to the work of Stella Chase and Alexander Thomas, which suggested that "behavior styles" were consistent from infancy to adolescence, and unaltered by social environment (Lakoff, 2000). The shift also manifested itself by a deliberate change within *The Journal of the American Academy of Child Psychiatry*, the discipline's flagship journal. While the journal previously emphasized case studies that stressed the importance of social and psychological biography, in 1976 the journal's new editor opened

the journal to biological researchers and required that articles be based on “scientific methods” that would allow for replicability (Lakoff, 2000).

The second development that influenced American child psychiatry was the increased use of scales for evaluating and monitoring pathological behavior. These usually took the form of questionnaires, given to parents and teachers to track a child’s daily behavior. Examples include the Achenbach Child Behavior Checklist (used to rate a child’s competencies and problem behaviors), the Wechsler Intelligence Scale for children (used to detect intellectual impairment or other cognitive problems), and the Conner Rating Scales (used for diagnosing hyperactivity). The use of scales enabled clinicians to move away from subjective diagnostic practices and toward a more structured evaluation process, where results could be quantified (Barkley, 2005). They also further reinforced psychiatry’s adoption of a descriptive diagnostic approach, where identifying symptoms and classifying children into diagnostic categories was the focus. By adopting these processes, clinicians turned away from trying to understand etiological causes of symptoms and focused instead on managing them.

As this pertains to ADHD, the 1970s witnessed the growing use of the Conners standardized behavior rating scales for diagnosing hyperactivity (Barkley, 2005). These rating scales provided lists of symptoms, and required parents and teachers to indicate whether they were “not at all present,” “just a little,” “pretty much,” or “very much present” (Conners, 1969, p. 154). The results were then converted to numbers to provide a total score, which facilitated quantitative comparison and statistical analysis (Nefsky, 2004). They also helped clinicians assess symptoms of hyperactivity, particularly during trials of psychostimulant medications (Barkley, 2005; Nefsky, 2004). Additionally, they gave clinicians a more structured, objective, and quantifiable approach to evaluating children for hyperactivity. Consequently, during the 1970s and 1980s, the Conners scales became the predominant method for evaluating children for hyperactivity (Barkley, 2005) – a development that dovetailed with American psychiatry’s migration toward both descriptive psychiatry and a biological conception of mental illness.

FRENCH PSYCHIATRY – THE CONTINUING INFLUENCE OF PSYCHOANALYSIS

Where psychoanalysis, and the psychodynamic perspective more generally, were marginalized in America (Plakun, 2006), the opposite is true for France where psychoanalysis has continued to enjoy significant professional power.

Specifically, out of 13,600 French psychiatrists, 50% of them practice psychoanalysis (Roudinesco, 2004). Psychoanalysis is also deeply embedded in the rest of the mental health field as 80% of the 22,000 clinical psychologists are trained in psychoanalysis, and there are over 6,000 practitioners of either Classical Freudisme or Lacanisme (Roudinesco, 2004).

That isn't to say that French psychiatry has rejected a biological approach. After all, the French are among the largest consumers of psychiatric medication in general, and are the largest European consumers of antidepressants in particular (Dorozynski, 1996). However, rather than imitating the biological reductionism found in the United States, French psychiatry evolved toward an eclectic approach, which draws from psychoanalysis, phenomenology, and psychopharmacology, and where clinicians "are not interested in mental illness per se, but rather in the sick, who have to be approached in their entirety, in their singularity, and in their history" (Ohayon, 2006, p. 424). Moreover, the role of the psychosocial perspective was and continues to be even more predominant in French child psychiatry, which adheres to a psychosocial model of mental illness and a psychodynamic diagnostic approach. This difference is well illustrated by French child psychiatry's reaction to the *DSM-III*. While some French child psychiatrists realized the *DSM-III*'s classificatory approach offered potential benefits for epidemiological research, leaders within the profession believed the *DSM-III* was wholly inappropriate for the French setting, as the classification was overly reductionistic and at odds with French child psychiatry's developmental approach to mental disorders (Interview with child psychiatrist: November 11, 2006).

Their overarching concern was that *DSM-III*'s descriptive approach diverged too significantly from the dynamic diagnostic process used by most French psychiatrists (Misès et al., 2002), and "could drastically change clinical practices by focusing all of the clinical and therapeutic attention on isolated symptoms, rather than taking into account structural psychopathological configurations" (Misès et al., 2002, p. 176). In response to the release and growing influence of America's *DSM-III*, and out of a desire to "offer French child psychiatrists an alternative to *DSM-III*," the French Federation of Psychiatry (Fédération Française de Psychiatrie (FFP)) commissioned a task force to develop an alternative classification system for French clinicians (Misès et al., 2002, p. 176). In turn, the task force developed the French classification system for child and adolescent mental illnesses (*CFTMEA*), which they released in 1983, and updated in 1988 and 2000.

The *CFTMEA* is the primary diagnostic reference manual used in France for children's mental disorders.⁷ It focuses strictly on psychiatric conditions (as opposed to the ICD-10, which also addresses nonpsychiatric illnesses), was first published in 1983, and was updated in 1988 and 2000 (Misès et al., 2002). The *CFTMEA* is a classification system that has definitions and criteria that better fit with French child psychiatry's psychopathological clinical orientation. While the *CFTMEA* relies on a dynamic approach, it is used by child psychiatrists from various theoretical orientations and was validated through a broad study that included professionals from most French public child psychiatric facilities (Misès et al., 2002). Moreover, it is the system of reference for French child psychiatrists (Misès et al., 2002). To better highlight the differences, I now turn to contrasting the *CFTMEA* and *DSM*.

CONTRASTING *CFTMEA* AND *DSM*

The *CFTMEA* differs from the *DSM* (hereafter used instead of the cumbersome *DSM-III*, *DSM-III-R*, *DSM-IV*, and/or *DSM-IV-TR*) in three ways: its theoretical orientation, its approach toward symptoms, and the use of diagnostic criteria. Regarding the first, where the *CFTMEA* is openly informed by psychodynamic theory (Misès et al., 2002), the *DSM* developers explicitly rejected psychodynamic theory and sought to create an "atheoretical" and purely descriptive reference manual (Kirk & Kutchins, 1992). This difference is significant because it represents different approaches toward symptoms. In the psychodynamic approach, symptoms are seen as the manifestation of a dysfunctional psychological process. They are seen as being infused with psychological meaning, as needing to be unraveled and understood in order to identify root causes (Decker, 2007; Wilson, 1993). Notably, suppressing symptoms is not the therapeutic focus. Rather, the focus is on identifying and addressing the underlying psychosocial causes of symptoms (Horwitz, 2002). By contrast, the *DSM*'s purely descriptive approach brackets the potential meanings of symptoms, as well as concerns with their underlying causes (Kirk & Kutchins, 1992). Instead, symptoms are treated as discrete elements of a disease process, to be observed and counted toward a diagnosis, and ultimately suppressed through the use of pharmaceuticals.

The difference manifests itself by the fact *DSM* provides explicit symptom criteria (e.g., Appendix A) for all mental illnesses, where the *CFTMEA* does not (e.g., Appendix B). The *DSM*'s symptom checklist emphasize a checklist

approach, where clinicians focus on identifying whether or not children have the requisite number of behavioral symptoms to qualify for a given diagnosis. While this approach has marginally increased diagnostic agreement among clinicians, it has been criticized for decontextualizing symptoms (Cooksey & Brown, 1998; Horwitz, 2007; Kirk & Kutchins, 1992). Horwitz (2007), in particular, has argued that a classificatory approach fails to distinguish between symptoms that are a normal response to a stressful social situation, and those that result from an underlying psychological disorder. The *CFTMEA*, by contrast, “emphasizes a global psychopathological diagnosis that does not rely on symptom checklists,” but rather “takes into account how these symptoms relate to one another and to the structural organization of the whole disorder in which they are included” (Misès et al., 2002, pp. 178–179). Moreover, “this psychopathological diagnosis includes personality characteristics” (Misès et al., 2002, p. 179), leads clinicians to consider etiological factors (including organic and social context), and “takes into consideration a psychodynamically oriented psychopathology” (Misès et al., 2002, p. 179). In sum, where the *CFTMEA* encourages a contextualizing approach to diagnosis, the *DSM* encourages a decontextualizing and reductionist approach.

COMPARING ADHD DEFINITIONS

In what follows I compare the ADHD definitions from the *DSM-IV-TR* (APA, 2000) and the third edition of the *CFTMEA* (FFP, 2000). Both were published in 2000 and are the most current versions. Comparing the latest versions permits me to control for any convergence that may have taken place. As I show, despite any convergence that may have occurred between the two systems, they still differ in significant ways.

There are three major differences between the *DSM* and *CFTMEA* ADHD definitions. First, the *CFTMEA* definition is narrower. Where *DSM* allows clinicians to give the diagnosis to children who exhibit attention deficits without hyperactivity (see Appendix A), the *CFTMEA* explicitly discourages it, stating that the ADHD diagnosis should be excluded for “attention problems that are not accompanied by hyperactive behavior” (see Appendix B). Moreover, the *CFTMEA* definition requires the hyperactive behavior be of sustained duration, as it stipulates that the diagnosis should be excluded for “hyperactive behavior of limited duration” (see Appendix B).

Second, where the *DSM* version has a symptom criteria list (see [Appendix A](#)), the *CFTMEA* version does not. Specifically, the *DSM* provides two lists of nine symptoms (option A and option B), and if a child exhibits six of the symptoms from option A, or six from option B, then he/she qualifies for an ADHD diagnosis (provided criteria II, III, IV, and V are also met). By contrast, while the *CTMEA* describes the physical and psychological symptoms normally associated with the ADHD syndrome, it does not require that a specific number of symptoms be present for the diagnosis to be made. In turn, the lack of symptom criteria orients clinicians away from taking a checklist approach and encourages instead a psychopathological approach, where a child's inattention and hyperactivity symptoms are understood in a broader psychological and social context, which clinicians are responsible for unraveling, understanding, and addressing.

Third, while the *DSM's* symptom criteria are designed to bracket concerns about causes, the second axis of the *CFTMEA* (see [Appendix B](#)) explicitly encourages clinicians to consider etiology and to identify "factors relating to the environment," such as "emotional, educational, social and cultural deficiencies, as well as bad treatments and negligence" (see [Appendix B](#)).

These differences have three important implications for the assessment and treatment of ADHD. First, the narrower *CFTMEA* definition means that fewer French children qualify for the ADHD diagnosis, as well as its corresponding psychostimulant treatment. Second, the *CFTMEA's* psychodynamic orientation also reduces the number of children who will qualify for an ADHD diagnosis. Specifically, by encouraging clinicians to consider the etiology of symptoms, the *CFTMEA* increases the likelihood that clinicians will consider and address the contributing psychosocial factors. To the extent clinicians are successful in remediating those factors, fewer children qualify for the ADHD diagnosis. By contrast, the *DSM's* descriptive approach brackets concerns about etiology, which means underlying psychosocial problems are less likely to be addressed, thereby artificially inflating the number of children who qualify for an ADHD diagnosis and psychostimulant treatments. Third, by inspiring a more comprehensive understanding of ADHD, the *CFTMEA* promotes a multidisciplinary treatment approach, where psychostimulants are but one treatment option, and are regarded as the option of last resort ([Bursztejn & Golse, 2006](#); [Le Heuzey, 2006](#); [Raynaud, 1999](#)). Conversely, by supporting a reductionist understanding of ADHD, the *DSM* discourages clinicians from addressing the child's social context and instead encourages them to treat the symptoms with pharmaceuticals.

Both approaches have strengths and weaknesses. The French approach could lead clinicians to underappreciate the biological dimension of psychiatric disorders, while the American approach could lead to over-reliance. Having said that, the American approach is concerning because it encourages a reductionistic understanding of children’s needs, which means treatment interventions are unlikely to address emotional and psychological concerns and are more likely to use pharmaceuticals as the main, and oftentimes only, treatment intervention. Indeed, since the release of the *DSM-III*, there has been a significant increase in the number of American children medicated with psychiatric medications. For example, Safer and Krager (1994) found that between 1981 and 1995, there was a doubling in the number of Maryland primary school students who were medicated with psychostimulants, with a fivefold growth among middle and high school students (see Fig. 1). Similarly, for the period between 1987 and 1996, Zito et al. (2003) found a two to threefold increase in the psychotropic prevalence rate for youths. While pharmaceutical companies have profited tremendously from

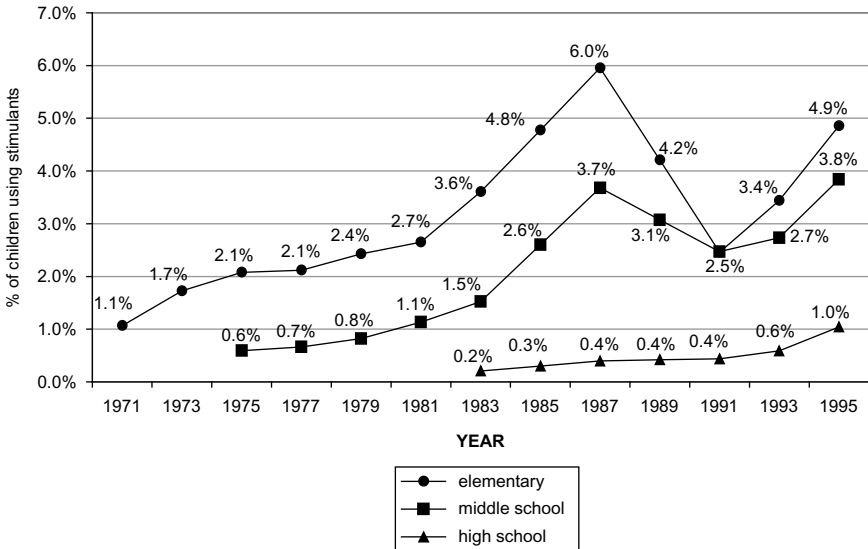


Fig. 1. The Expansion of the U.S. ADHD Meds Market.

Source: Krager, Safer, and Earhart (1979), Safer and Krager (1985, 1994), and Safer, Zito, and Fine (1996).

this development, it remains to be seen whether children have benefited from it as much as has been claimed.

Importantly, while this chapter focuses on the *DSM*'s bracketing of psychological and social causes, the *DSM*'s classificatory approach also overlooks the potential role played by nutrition and exposures to environmental neurotoxins. This point is salient for mental illnesses, as a growing number have been linked to nutritional deficiencies,⁸ including ADHD (Boris & Mandel, 1994; Conners, 1990; Egger, Carter, Graham, Gumley, & Soothill, 1985; Feingold, 1976). In the 1980s and 1990s, the diet-hyperactivity link was clouded by industry-sponsored research and propaganda (Jacobson & Schardt, 1999). However, in 1999 the Center for Science in the Public Interest (CSPI)⁹ reviewed 23 controlled studies, and concluded that 17 supported the diet-hyperactivity link (*ibid.*). Specifically, the studies showed that the behavior of some children is significantly worsened after consuming artificial colors, certain preservatives, and/or allergen-containing foods (such as wheat, eggs, and soy) (Jacobson & Schardt, 1999). More recent studies have further substantiated the causal role of food additives (McCann et al., 2007), and have also related ADHD symptoms to deficiencies in iron (Konofal et al., 2008) and Omega-3 essential fatty acids (Johnson, Ostlund, Fransson, Kadesjö, & Gillberg, 2009). However, the nutritional link is unlikely to be addressed in a checklist diagnostic approach. In turn, because the public, and to a large degree the medical establishment, remains uninformed about the role of nutrition, the situation suggests that children who could be helped with dietary interventions will continue exhibiting symptoms that will qualify them for an ADHD diagnosis and its corresponding psychostimulant treatment.

This is not to suggest that French clinicians are much more likely to consider nutritional factors, as one can safely assume that French child psychiatrists are as unlikely as American physicians to undergo much nutritional training. However, having an approach that considers etiology will make clinicians more likely to at least consider the role of nutrition. Moreover, one could easily argue that a failure to consider dietary causes is more salient in the United States, where an impoverished relationship to food has been associated with the federal government's approval of, and food manufacturers' use of, a greater range of food colorants and preservatives (Schapiro, 2007). One could also argue that the American situation privileges the "manufacturers of disease" (McKinlay, 2009) by shielding the food manufacturers who use detrimental ingredients in their food products, which artificially increases the ADHD prevalence rate and rewards the producers of psychostimulants.

CONCLUSION

In 1980, American psychiatry introduced *DSM-III* and the arrival of this classification system had a revolutionary effect on American psychiatry and society. In order to better historicize the social event and its implications, this chapter contrasted the *DSM* to France's *CFTMEA*. I began my analysis by tracing the rise of *DSM-III* and its successors to the ascendancy of biological psychiatry in America. Then I argued that *DSM-III* was rebuffed in France because French child psychiatry was still dominated by psychoanalysts and they believed the *DSM-III* was overly reductionistic and inappropriate for the French context. As well, the French child psychiatrists responded by developing a classification system that fundamentally differed from *DSM-III*. Specifically, these systems differ in their theoretical orientation, their approach toward symptoms, and their use of symptom checklists. These differences have significant implications for the clinical encounter because they lead to very different conceptualizations of mental illness. In particular, where French clinicians are encouraged to see mental problems as being caused by psychological and social problems, American clinicians are encouraged to blame the problems on a biological malfunction. Moreover, to illustrate the social ramifications of the divergence, I focused on the case of ADHD, analyzing the way each diagnostic system defined the syndrome, and the diagnostic and treatment implications that flowed from those diverging definitions.

This analysis makes three contributions to a sociology of diagnosis. First, it shows that what counts for illness can vary greatly from country to country. While a rich anthropological literature (Beiser, 1985; Kleinman, 1988) has demonstrated this to be the case between “developed” and “developing” countries, this analysis underscores that it can also be the case between fully industrialized countries. This undermines the notion that diagnostic categories are derived solely from objective, empirical science, and suggests that illnesses are far more culture-bound than is usually acknowledged (Kleinman, 1988).

Additionally, while previous analyses (Conrad, 2007; Fox, 1989) have suggested that diagnostic definitions can vary in breadth (i.e., narrowness or broadness), this analysis demonstrates that diagnostic definitions can reflect and encourage very different diagnostic approaches. The *DSM* discourages physicians from considering etiology and instead encourages a symptomatic diagnostic approach, which views symptoms as elements to be counted toward a diagnosis. By contrast, France's *CFTMEA* suggests a dynamic approach (where symptoms are seen as the manifestation of underlying

problems, to be unraveled and understood). This divergence is surprising when we consider that both systems were developed by psychiatrists (as opposed to competing medical subdisciplines, such as neurology and pediatrics). Moreover, beyond “culture-bound syndromes” (Kleinman, 1988), the analysis suggests classification systems should also be considered “culture-bound.”

Third, the analysis showed that differences in diagnostic approach also matter for the treatment of illness. If clinicians employ a checklist diagnostic approach, they focus on symptoms, ignore the underlying causes of disease, and are predisposed to treat the condition with symptom-suppressing treatments, such as pharmaceuticals. On the other hand, a more comprehensive approach tries to understand and address the underlying cause of symptoms. Moreover, while the analysis focused on psychiatric disorders, the findings also have implications for nonpsychiatric illnesses.

Beyond tracking the social ramifications of classification differences, future sociological research should consider two related issues. First, sociologists should analyze how the impact of classification differences is mediated by institutional structures, such as health-care systems. For instance, the French classification system supports labor and resource-intensive diagnostic and treatment practices, and such an approach is well-suited for a country with a universal health-care system, which covers the majority of medical costs. Conversely, such a labor-intensive approach would not find the same support in America’s managed care system, which deliberately seeks to curtail access to medical resources in general, and labor-intensive practices in particular.

Second, given the social ramifications of diverging classification systems, sociologists should study the causes of such differences. This chapter sketches the outline of an answer by tracing the classification differences to a divergence between American and French child psychiatry. The next step is to study the social forces and institutional structures that contributed to the divergence. Regarding social forces, sociologists should analyze the developers of each country’s classification system, focusing particularly on the developers’ institutional affiliations, such as associations with governmental agencies and financial relationships with pharmaceutical companies. The latter point is underscored by the recent work of Cosgrove, Krimsky, Vijayaraghavan, and Schneider (2006), which found that 56% of *DSM-IV* developers had financial relationships with one or more pharmaceutical companies. Relatedly, while researchers have tracked the way pharmaceutical companies drive demand for diagnoses (Carpiano, 2001; Conrad, 2005; Conrad & Leiter, 2008; Conrad & Potter, 2000; Tiefer, 1994), sociologists

should also track the way those marketing activities relate to diagnostic changes. While the acceptance of a new diagnostic category is likely to be followed by marketing activities, we can surmise that marketing activity will also increase following the expansion of a diagnostic category or a country's acceptance of a reductionistic diagnostic system.

Beyond developers and pharmaceutical companies, sociologists should also analyze the role of culture. In *Medicine and Culture*, Lynn Payer (1996) identified the way French and American treatment practices diverge for a number of different conditions, and traced those differences to cultural biases. For example, while American medicine typically addresses uterine cancer with complete hysterectomies, French medicine invariably opts for myomectomies, which preserve the uterus and the woman's ability to bear children. Moreover, Payer (1996) attributed the difference to the greater cultural value that the French place on women's ability to reproduce. Relating this to child psychiatry, it could be that the divergence between American and French classification systems can be traced to differences in the way each country conceptualizes childhood, and/or the amount of value each country places on children's psychological health and development. Further research should explore these lines of inquiry, as well as other ways that culture can impact the development of a medical subdiscipline.

Lastly, given the *DSM's* reductionistic tendencies, future research should study the dissemination of the *DSM* system to other countries, focusing particularly on developing countries. While French child psychiatry was able to resist this form of American cultural imperialism, they are likely to have benefited from numerous institutional resources (such as long tradition as a hegemonic cultural power), and medical disciplines in developing countries are unlikely to have benefited from the same resources. It is particularly worthwhile to identify which agents are playing a role in the globalizing process, and the institutional factors that have enabled them to succeed in some contexts. Given that a reductionistic diagnostic approach favors the interests of pharmaceutical companies, one should expect that they have played a role in the dissemination process, and so particular attention should be cast on their activities.

NOTES

1. For the purposes of this chapter, I use "diagnostic concept" and "diagnostic category" interchangeably.

2. Diagnostic reliability refers to the extent to which practitioners agree in their diagnosis of a specific set of symptoms (Kirk, 2004).

3. Diagnostic validity refers to the degree to which the psychiatric concepts accurately distinguish between different disorders (Kirk, 2004).

4. The mounting professional crisis reached a peak in the mid-1970s, following the Rosenhan experiment and the controversy surrounding the profession's listing of homosexuality as a psychiatric disorder (Kirk & Kutchins, 1992).

5. Additionally, the additional diagnostic categories added to *DSM-III-R* and *DSM-IV* served to further expand American psychiatry's reach (Kutchins & Kirk, 1997).

6. I specify "American" child psychiatry because in other countries, such as France, the subdiscipline resisted the biological approach and has continued to adhere to a psychosocial model of illness.

7. While some French clinicians use the *International Classification of Disease* (ICD) and this classification system has an entry for ADHD, I chose to analyze the *CFTMEA* because it is the classification of reference for French child psychiatry and it better represents French psychiatric thought. The *CFTMEA* is a French product whereas the ICD is a British product.

8. For instance, the onset of schizophrenia has been linked to omega-3 deficiencies (Emsley, Myburgh, Oosthuizen, & Van Rensburg, 2002); Peet, 2003; Yao et al., 2004), depression has been linked to Folate/Vitamin B deficiencies (Bell et al., 1990; Young, 2007), with Bipolar Disorder also linked to omega-3 (Frangou, Lewis, & McCrone, 2006; Stoll et al., 1999) and Vitamin B deficiencies (Bell et al., 1990; Hasanah, Khan, Musalmah, & Razali, 1997).

9. CSPI is an award-winning public-interest nonprofit watchdog based in Washington DC, which advocates for nutrition and health, food safety, alcohol policy, and sound science. Available at <http://www.cspinet.org/about/index.html>.

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APPENDIX A: ADHD CRITERIA FROM *DSM-IV-TR* (2000) (Source: APA, 2000)

The following are the criteria for year 2000 *Diagnostic and Statistical Manual (DSM-IV-TR)* ADHD diagnosis.

I. Either A or B

(A) Inattention

For the ADHD diagnosis to be made, six or more of the following symptoms of inattention have been present for at least six months to a point that is disruptive and inappropriate for developmental level:

- (1) The child often does not give close attention to details or makes careless mistakes in schoolwork, work, or other activities.
- (2) The child often has trouble keeping attention on tasks or play activities.
- (3) The child often does not seem to listen when spoken to directly.
- (4) The child often does not follow instructions and fails to finish schoolwork, chores, or duties in the workplace (not due to oppositional behavior or failure to understand instructions).
- (5) The child often has trouble organizing activities.
- (6) The child often avoids, dislikes, or doesn't want to do things that take a lot of mental effort for a long period of time (such as schoolwork or homework).
- (7) The child often loses things needed for tasks and activities (e.g. toys, school assignments, pencils, books, or tools).
- (8) The child is easily distracted.
- (9) The child is often forgetful in daily activities.

(B) Hyperactivity/Impulsivity

For the ADHD diagnosis to be made six or more of the following have been present for at least six months to an extent that is disruptive and inappropriate for developmental level.

Hyperactivity

- (1) The child often fidgets with hands or feet, or squirms in seat.
- (2) The child often gets up from seat when remaining in seat is expected.
- (3) The child often runs about or climbs when and where it is not appropriate (adolescents or adults may feel very restless).

- (4) The child often has trouble playing or enjoying leisure activities quietly.
- (5) The child is often “on the go” or often acts as if “driven by a motor.”
- (6) The child often talks excessively.

Impulsivity

- (1) The child often blurts out answers before questions have been finished.
 - (2) The child often has trouble waiting one’s turn.
 - (3) The child often interrupts or intrudes on others (e.g., butts into conversations or games).
- II. Some symptoms that cause impairment were present before age seven years.
 - III. Some impairment from the symptoms is present in two or more settings (e.g., at schoolwork and at home).
 - IV. There must be clear evidence of significant impairment in social, school, or work functioning.

APPENDIX B: ADHD CRITERIA FROM *CFTMEA* (2000)

(Source: FFP, 2000)

Axis I: Clinical category

Axis II: Psychological factors. Organic factors. Factors relating to the environment, such as “emotional, educational, social and cultural deficiencies, as well as bad treatments and negligence.”

7.00 – Hyperkinesis with attention problems

- From a symptomatic perspective, this syndrome is characterized by the following:
 - On the psychological plane: difficulty to focus, a lack of continuity in activities that require an intellectual effort, a tendency toward disorganized, uncoordinated and excessive activities, and a certain degree of impulsivity.
 - On the physical plane: hyperactivity or an incessant physical agitation.

- The interaction between these children and adults is often marked by a lack of reserve and social inhibition.
 - These troubles are often accompanied by a deterioration in cognitive functions and a specific linguistic and motoricity delay. They can lead to antisocial behavior or a loss of self-esteem.
 - These troubles, which clearly depart from the standard of behavior that are appropriate for the child's age and mental development, are more significant in situations that require application, such as in school. They can temporarily disappear in certain situations, such as in one-on-one interaction or in a new social situation.
-

Include:

- Attention deficit with hyperactivity.

Exclude:

- Attention deficits without hyperactivity
- Excessive behavior that is age appropriate (particularly among young children)
- Manifestation of maniacal excitation (which should be classed, depending on the case, in category 1 or 3)
- Hyperactive reaction of limited duration.

LABELING, LOOPING, AND SOCIAL CONTROL: CONTEXTUALIZING DIAGNOSIS IN MENTAL HEALTH CARE

Kerry Dobransky

ABSTRACT

Purpose – To assess labeling and social control of clients in contemporary mental health care organizations.

Methodology/approach – Fifteen months of observation in two multi-service mental health care organizations, interviews with workers and clients, and analysis of organizational documents.

Findings – The organizations used a variety of organizational labels, both official and informal, which served distinct purposes in organizational life and which did not always agree in their construction of the client. Official mental illness diagnosis was a bureaucratic label, while informal labels determined the types of social control to which clients were subjected. Clients who were informally labeled severely mentally ill were subject to integrative social control, while exclusionary social control was applied to those informally seen as not being severely mentally ill. Unlike in classic studies of mental health care, looping processes, in which client behaviors are viewed as symptoms, do not reliably predict the types of labels or social control applied to clients.

Sociology of Diagnosis

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Implications – It is important for a sociology of diagnosis to contextualize official diagnosis in the repertoire of organizational labels applied to clients in mental health care, recognizing that it plays a limited but important role in organizational life. Informal labels, which at times conflict with official diagnosis, play a more prominent role in the management of everyday organizational life.

Keywords: Mental illness; diagnosis; labeling; social control; health policy

INTRODUCTION

Classic studies of mental health care such as Goffman (1961) and Rosenhan (1973) revealed a world in which mental patients are viewed and interacted with through the “master status” (Hughes, 1945) of their official diagnosis and are stripped of a sense of personhood. All actions patients take are subject to interpretation as symptoms of mental illness, a process that Goffman referred to as “looping.” Much has changed in mental health care since these classic studies were written, both in terms of the settings in which care takes place and the relations between mental health care providers and those they treat. This study investigates provider labeling of clients in the contemporary setting, demonstrating that there is more complexity than these studies show in both the types of labels applied to clients and the social control to which clients are subjected. A sociology of diagnosis must direct attention to this variation to gain a fuller understanding of both the context within which official diagnoses are applied and the effects of those diagnoses.

THE LABELING AND SOCIAL CONTROL OF MENTAL ILLNESS

The drawing of boundaries is a fundamental human practice, though how we carve up reality varies across time, place, and social context (Zerubavel, 1991, 1997). Professions serve as “thought communities,” each having distinct ways of dividing up the world. Which profession we take our problem to can thus result in a drastically different type of resolution. For example, a physician may have different concerns from an attorney if your child has been bitten by your neighbor’s dog. Professional socialization

involves not only learning the trade's particular skills, but also more fundamentally its way of perceiving and dividing up the world (Haas & Shaffir, 1987). As Abbott (1988) argues, when a professional approaches a problem, his or her first major task is to "diagnose" the problem, so that through professional "inference" the appropriate "treatment" for the problem may be determined and carried out. This process is not limited solely to the medical field; it is common to all professions.

The same could be said for different types of organizations. Though "people processing" organizations share the broad goals of applying technologies to human beings to solve personal and societal problems, each type does so with distinct combinations of priorities and technologies. This leads to a juvenile court and a youth residential treatment facility, for example, to routinely apply different official labels to their clients (e.g., "delinquent" vs. "child with oppositional defiant disorder"). The differences in the official labels point to distinct conceptions of clients, their problems, and what should be done to address those problems. In both cases, however, those labels lead to social control.

Within the contemporary medical and mental health fields, a key component of professional and organizational social control is collecting constellations of bodily complaints or psychological/emotional/behavioral issues and labeling them disorders. Brown (1995) explains this process as beginning primarily on the macro and meso levels with the "social discovery" of the disease category, with laypersons, social movements, professionals, and organizations advocating and resisting the construction of new diagnostic categories of disease. These diagnostic categories may either dovetail or contrast with people's own interpretation of their issues (their "illness experience"). As Brown explains,

... [P]eople do not always experience disease as illness. Conversely, not all experienced illness is the result of a particular disease. Some people manage to avoid active symptoms, or to attribute them to other sources, or to accommodate to them. At the other side of the equation, certain people experience symptoms that are not traceable to a known cause, and some spend much time fearing they will catch any number of diseases. (1995, p. 46)

Thus another set of (possibly contentious) negotiations can play out at the micro-level (which may be directly or indirectly connected to the above-mentioned macro-level processes) between treatment professionals and patients (in Brown's "treatment" stage) regarding the application of an existing diagnostic disease label in a particular instance.

While the reconceptualization of human problems as medical entities with diagnoses can bring more humane and flexible treatment (Parsons, 1951), it

replaces one form of social control with another, elevating medicine and biotechnology to institutions of social control alongside the criminal justice system (Conrad, 2005; Conrad & Schneider, 1992; Zola, 1972). So, for example, rather being disciplined for “acting out” in school, a child might now be diagnosed with ADD/ADHD (“hyperkinesis”) and be forced to take medication (see Conrad, 1975). More broadly, patients’ “voice” and their experience (or lack of experience) of illness may be drowned out by the “voice of medicine” (Brown, 1995; Mishler, 1984).

What is most relevant for the present study is research dealing with the role of diagnoses of mental illness in social control in the *actual treatment setting*. Classic studies of mental health care focused on mental hospitals, the primary site of treatment of severe mental illness at the time they were written. Goffman (1961) outlines one process involved with official diagnosis in mental health services: “looping.” The mental patient’s resistance to treatment, his or her disruption of the treatment process, is viewed as a symptom of mental illness itself. Goffman describes it as follows: “the inmate’s reaction to his situation is collapsed back into this situation itself, and he is not allowed to retain the usual segregation of these phases of action” (p. 37). So, a patient’s claims of repeated mistreatment by workers may be seen as paranoia, or as Goffman (1961) explains,

a mental patient’s effort to present himself in a well-oriented, unantagonistic manner during a diagnostic or treatment conference may be directly embarrassed by evidence introduced concerning his apathy during recreation or the bitter comments he made in a letter to a sibling – a letter which the recipient has forwarded to the hospital administrator, to be added to the patient’s dossier and brought along to the conference. (p. 37)

Further, when mental patients offer “apologias” to workers or to other patients, attempting to explain away the circumstances that brought them to the hospital and to show they’re not *really* all that bad after all, the workers can call upon their knowledge (and official documentation) of the patients’ lives to tear down the patients’ attempts to save face. Underlying these interactions is the idea that, from the viewpoint of mental health professionals, all aspects of a patient’s life, both past and present, are relevant for therapeutic evaluation. The patient’s history is framed to show the now-inevitable pathway to the hospital, and all thoughts, behaviors, and interactions are potential fodder for social control and the onslaught against the patient’s self.

Goffman argues that patients are also subject to child-like treatment, wherein all mental health workers have power over all patients. Privileges and punishment are at the discretion of workers. Good behavior lands a

patient on a less restrictive ward. Especially important for the present study, bad behavior does not lead to one being kicked out of the hospital, but instead leads to movement to a more restrictive ward (Belknap, 1956). Rosenhan (1973) seems to agree with Goffman's assessment, arguing that the bar is relatively low for admittance to the mental hospital, and that once admitted, the patient is viewed through a frame that sees all behavior as evidence of psychopathology. Moreover, according to Rosenhan, being a patient subjects one to powerlessness and abuse by workers, especially if any initiative is taken by patients. There is little variation described in these processes; once the official label of mental illness is applied to patients, the effects are rather uniform.

In the wake of deinstitutionalization, the mental hospital is no longer the monolithic provider for people with severe, chronic mental illness. Instead, community-based mental health care organizations provide many of these services (Dowdall, 1999). Much of the research that has examined life in these organizations argues that the reduction of people with mental illness to their diagnoses and the concomitant subversion of patient autonomy and self continue. For example, in her study of occupational therapists in a range of mental health services organizations in Canada, Townsend (1998) finds that mental health workers tend to "objectify" the clients, using their diagnosis of severe mental illness to construct and interact with them as passive "patients." This objectification plays a major part in creating social relations in which true empowerment of clients is impossible, despite any efforts to include clients in decision-making. "... [C]lient participation is a veneer," Townsend argues. "Clients rarely participate in the underlying organization of services" (p. 39). While acknowledging there is variation in the treatment ideologies to which community mental health providers subscribe, Scheid (2004) finds that some espouse a "coercive" orientation, seeing their role as custodial and the ultimate goal of mental health treatment as controlling the client.

These studies do much to help us understand official diagnosis and social control of clients in mental health care settings. However, in their tendency to focus on official diagnosis, they ignore the range of factors impacting day-to-day organizational life in mental health care, and the resulting variety of ways that clients are categorized and responded to. Attending to these issues reveals much more variety in social control processes than existing research presumes. A sociology of diagnosis in mental health care needs to direct attention to the range of social control processes tied to both official and informal organizational labels of clients. In what follows, I discuss another body of research that can help us to understand these issues.

ORGANIZATIONAL LABELING

Mental health care organizations, like all health and human services organizations, have a set of core tasks they regularly need to accomplish: to ensure resource flows to keep the organization running in an uncertain environment, to channel resources to workers and clients, to follow laws and regulations, to document activities, and to take care of many routine activities in the face of regular crises (Hasenfeld, 2010a). Those who study mental health services have characterized it as a highly “institutionalized” environment, meaning that it is very difficult to judge the technical work that is done (i.e., mental health treatment) in terms of clear outcomes. Thus, organizations are more often judged on how well their structure and processes meet the norms and rules within that sector (such as adopting a hierarchical, bureaucratic structure rather than a decentralized, informal one) (Meyer, 1986; Scheid & Greenberg, 2007; Schlesinger & Gray, 1999; Scott & Meyer, 1991). In environments like this, the actual everyday practices within the organization can become “loosely coupled” with (i.e., not strongly entwined with or affected by) the organization’s actions in the pursuit of legitimacy within the environment.

Loose coupling leaves health care and human services workers with discretion in carrying out their daily work (Hasenfeld, 2010b; Lipsky, 1980; Watkins-Hayes, 2009). They use this discretion to apply a range of official and informal *organizational labels* to clients in order to both meet bureaucratic requirements and manage the flow of organizational life (Belknap, 1956; Dobransky, 2009; Emerson & Pollner, 1978; Floersch, 2000; Hasenfeld, 2010b; Heimer & Staffen, 1995, 1998; Light, 1980; Peyrot, 1982; Roth, 1972; Timmermans, 1998). For mental health care organizations, official diagnoses are often tied to resource flows from third-party payers and to certain treatment protocols, and so are a key component of health care and human services work, regardless of how “accurate” workers think they are (Brown, 1987; Kirk & Kutchins, 1988, 1992). However, they are not adequate tools to manage all aspects of organizational life. Not only are they often applied in problematic circumstances with insufficient information, but they also are limited in their ability to guide workers in negotiating competing demands with insufficient resources (Brown, 1987; Dobransky, 2009). Thus, official, “clinical” labels, such as official diagnosis, are only a portion of the labels workers apply.

Though they cannot completely ignore government mandates or organizational policies and procedures, workers can and do develop their own informal rules and routines to make their jobs more manageable and to

make decisions in their work, while also applying official labels and categorizations. For example, [Belknap \(1956\)](#) observes that, in addition to the diagnostic classification of mental illness, mental hospital workers classify clients based on “their manageability and occupational utility on the ward and in the hospital work” (p. 128). This classification, and not their psychiatric diagnosis, is most significant in structuring patient treatment. [Floersch \(2000\)](#) finds that the community mental health-care managers use the “situated” but ultimately nonclinical terms “low functioning,” “high functioning,” “low need,” and “high need” in order to determine how best to direct their limited resources in working with clients.

Each organizational label can have implications for how social control is carried out in health care and human services settings. For example, [Heimer and Staffen \(1995, 1998\)](#) describe how workers in neonatal intensive care units label parents of children on the unit based on the more official “clinical” issue of their ability to provide adequate care for their child’s medical condition and also based on more informal labels regarding how disruptive they are of routines of the units and on their race, gender, and age. In general, because they are “stuck with” working with the patients’ parents, they must seriously attempt to integrate the parents into organizational rules and routines. However, depending on the combinations of labels applied to them, parents are subject to different types of social control. For instance, if a parent repeatedly demonstrates a lack of knowledge regarding how to care for their fragile child, they are labeled “inadequate,” are subject to increased surveillance and documentation, and can lose custody of their child. Yet, it takes more for African American parents to be given such a label, because workers expect them to have less knowledge. We need this type of nuanced attention to how a variety of organizational labels are connected to social control processes in mental health care.

Existing literature addresses how mental health care workers use official diagnoses – and looping – to control clients within the hospital. I demonstrate that contemporary community mental health care workers use a number of official and informal organizational labels, each with distinct connections to social control processes. These labels include both official and informal labels regarding client mental illness – labels that at times conflict regarding whether clients are severely mentally ill. This study illustrates the importance of conceptualizing mental health diagnosis in the organizational context in which it is officially and informally applied. Official diagnosis plays a particular, bureaucratic function in organizational life that is distinct from that played by informal labels of mental illness. The latter are key in social control processes in mental health care.

DATA, METHODS, AND FIELD SITES

Data and Methods

The data for this chapter come from a 15-month ethnographic study conducted in 2006 and 2007 of two multiservice mental health care organizations for the chronically mentally ill in the Midwestern US. Semi-structured interviews with 42 clients and 49 workers supplemented the ethnographic observational data. I attended meetings and treatment groups, counseling sessions and periods of idle time, and I had informal conversations and played games with workers and clients. During my time in the organizations, one of my ground rules was never to engage in behaviors that only workers would do (such as running treatment groups, for example), so as to minimize power and not to become identified as a worker myself (by either workers or clients). I also spent time with clients outside of the organizational context, both in idle times immediately outside the buildings' walls, and at other times at their places of residence. Organizational documents were another source of data. In addition to documents produced by and for the organizations I was also granted access to the complete clinical files of 39 clients. Data were collected and analyzed using a grounded theory approach (Glaser & Strauss, 1967; Strauss, 1987). Key to this process is continuous interplay between data collection and analysis. Early coding and memoing regarding processes in the field (in this case, labeling clients) led to more focused data collection and further coding and memoing, etc. For the component of the analysis focused on in this chapter, I analyzed the way workers label clients, and what the consequences of those labels are for mental health care work and for clients' lives. I analyzed data using the qualitative data analysis program ATLAS.ti. The institutional review boards of the author's university at the time data were collected and those of both organizations studied provided ethical approval for the research protocols. Subjects provided verbal consent for observations and written consent for semiformal interviews. Both organizations studied and clients themselves provided written consent for clinical file access. In order to protect respondents' identities, all names used are pseudonyms, and identifying information has been altered or omitted.

Field Sites

Both field sites were divisions of large not-for-profit organizations that provided community mental health services to people determined to be severely, persistently mentally ill. One site, which I refer to as "Urban," was

the mental health and addiction services programs of an organization located in a gentrifying neighborhood. Urban prided itself on serving those other organizations would not, most notably people labeled mentally ill who were also classified as homeless substance users. The organization served a couple hundred clients; most were African American and most were men. Some clients came to the organization for a day program, where there were psychosocial rehabilitation groups, medical and psychiatric care, and free lunch. Some of the approximately 40 workers, a little over a half of whom were white and who were split evenly along gender lines, visited some clients in their homes through the Assertive Community Treatment program. Many clients were eventually housed through programs Urban provided. The most common official psychiatric diagnoses assigned to clients here were psychotic disorders, such as schizophrenia, or severe mood disorders, such as bipolar disorder or major depression.

The other site, which I refer to as “Suburban,” was located outside the same city in the midst of a neighborhood that interspersed small industrial and residential property. Constituting one program in a larger organization, Suburban included a sheltered workshop, where clients had flexible employment. The vast majority of clients served by Suburban had to come to the building for services, which included psychosocial rehabilitation, job services, case management, and psychiatric services. Lunch here cost \$1.50 unless clients worked either making it or cleaning it up. Suburban also had a group home, though many clients lived in other residential mental health services organizations or with their parents. Most of the approximately 90 clients were white, as were most workers. While half of the clients were men, women made up the majority of the approximately 12 workers.

ORGANIZATIONAL LABELING, LOOPING, AND SOCIAL CONTROL

Hospital versus Community Care

The community organizations I studied differ from hospitals like the one in which Goffman conducted his classic research, and these differences were consequential for looping and social control processes. One major difference was discretion the organizations had in serving clients. Whereas public mental hospitals have somewhat limited control over the clients they admit (given their mandates), independent nonprofit community organizations

such as those I studied have more of an ability to refuse admittance to clients and to stop serving them when they see fit. Those patients leaving the organization can be referred to a hospital, another community organization, or the street. Further, they can be forced to leave the organizations or could leave voluntarily (at times with encouragement from workers). Another distinction was that the share of clients' lives subject to the direct control of the organizations was very limited relative to that in hospitals. Unlike the mental hospitals, these organizations were not "total institutions" (Goffman, 1961). There were significant amounts of clients' time, and large portions of clients' lives, were not subject to organizational surveillance. Many clients lived independently and spent minimal time in the organization or in the presence of organizational workers.

Looping and Social Control in the Community

Organizational Labels and Looping

Urban and Suburban applied both official and informal organizational labels to clients, each serving distinct purposes in the organization (Dobransky, 2009). Official diagnoses were rather uniform and mainly served bureaucratic purposes. Informal labels of client mental illness, which at times differed from official labels, were much more varied. As we will see in the next section, they also were more important in determining the type of social control applied to clients. Research that focused only on official medical diagnosis would overlook major determinants of patterns of mental health treatment.

Official psychiatric diagnoses had a couple of purposes. Ideally, they gave workers a sort of roadmap for treatment, such as pointing to which medications would be most effective. More commonly, however, the labels served bureaucratic functions. Official diagnoses were part of the process through which the organization would prove "medical necessity," a condition of continued government reimbursement for providing services. In order to ensure compliance with requirements of governmental and accrediting organizations – and, in turn, ensure funding – workers at both Suburban and Urban experienced the constant pressure to translate the stream of everyday organizational life into documentation. This documentation was grounded in looping, translating all interactions – including disruption – into "symptoms." As a documentation "best practices" manual from Suburban explained, "'medical necessity' is derived from the medical model," which is based on "defining the problems a person is experiencing

in the form of symptoms, behaviors, and impairments.” Elsewhere the manual made explicit that workers should regularly remind themselves, “NOTHING I have done today in my job happened, until I document it.” This pressure was palpable to workers. As one worker at Suburban plainly expressed, there was a generalized feeling that daily activities had to end up documented and billed: “You have to understand, Kerry, that now we’re billing whores” (field notes). Similarly, a worker at Urban referred to the APA’s *Diagnostic and Statistical Manual of Mental Disorders (DSM)* as “our little book of witchcraft so we can bill” (field notes).

Thus, official diagnoses were tied, with looping, to meeting resource demands for the organization and its clients. However, much of day-to-day life in the organizations was affected more by *informal* organizational labels, and the looping involved with these labels served different purposes. The rest of this chapter will focus on these labels. There were two informal labels of client mental illness that workers used: *severely mentally ill* and *not severely mentally ill*. In meetings, case conferences, and in day-to-day conversations about clients, workers discuss clients’ diagnosis and capability *independent* of any official psychiatric diagnosis assigned, though the official and informal diagnoses often overlapped (Dobransky, 2009). The *severely mentally ill* informal label, which was the most common one applied to clients, was an informal version of the official diagnosis of severe mental illness that nearly all the clients at both organizations were given. These informal labels were similar to official ones in that they took into account both symptoms expressed (which might or might not in informal cases be discussed in terms of a *DSM* diagnosis) and the amount of functional impairment caused by the symptoms. If workers’ daily interactions with and discussions about clients gave the impression that client indeed suffered from severe symptoms and had trouble carrying out everyday life as a result, then the informal label would line up with the official diagnosis, and the client would be treated by workers as *severely mentally ill*, and their behavior would be looped back into their diagnosis.

The case of Riaan, a client at Urban, was a clear example of this type of informal labeling. With perpetual disruptions such as yelling with no one in her immediate presence, fighting with other clients, threatening violence, refusing services, and many others, Riaan constantly attracted the attention of workers. Similar to how they would do in official documentation, workers also informally framed her problems as symptoms of mental illness, saying that it resulted from her “responding to internal stimuli” (field notes). At Suburban, though the level and type of disruption presented by Riaan was rarely seen, client disruption in terms of more mundane things such as group attendance,

not talking while workers or other clients were talking, and keeping scheduled appointments was more common. One client, Janice, fairly regularly appeared to have trouble concentrating, laughing when no one else was laughing and whispering and mumbling when no one was around. However, these relatively benign problems eventually turned much more serious, and she engaged in “sexually inappropriate” behaviors in public. She was hospitalized several times within a few-month period (though primarily by her family, not by the organization). Workers described her as “out of it,” and discussed that her drug “cocktail” might need to be changed.

Though practically all clients provided mental health services by the organizations were *officially* diagnosed severely mentally ill, not all were informally labeled as such. Sometimes, workers informally labeled clients as *not severely mentally ill*. This might occur because of a perceived improvement in clients’ symptoms, because workers did not have sufficient information at initial official diagnosis, or because workers believed the client needed help and gave him or her a diagnosis so the organization could channel help to him or her (cf. Brown, 1987). The point here is, even though the official label of severe mental illness might remain in place, workers’ informal label of clients could be that the clients are *not severely mentally ill*.

At times clients informally labeled *not severely mentally ill* were nevertheless viewed by workers as having an actual mental illness, albeit, not a “severe” one that tremendously impacted their ability to function in the world. These clients did experience looping from workers – many of their disruptions of organizational operation were framed by workers as symptoms of mental disorder. This type of informal labeling frequently involved clients viewed as having a personality disorder. Because the symptoms of personality disorders tend to be more characterological and behavioral than the clinical disorders in Axis I of the *DSM* (American Psychiatric Association, 2000), clients who frequently were involved in disruptions, but who were not viewed as exhibiting symptoms of the Axis I disorders common at the organizations (i.e., psychotic disorders and mood disorders) would sometimes be discussed as suffering from a personality disorder (which is on Axis II of the *DSM*). Borderline personality disorder was the most frequently discussed disorder in these circumstances.

At Urban, a client named Rodney was informally labeled with a personality disorder. He was seen as very manipulative and conniving, often intentionally causing conflict and disruption among both clients and workers. Though Rodney’s official psychiatric diagnoses were paranoid schizophrenia and schizoaffective disorder (on different evaluations), workers did not discuss his behaviors in terms of being symptoms of these disorders, other than to argue that he was misdiagnosed. However, his

actions were frequently discussed as symptoms of personality disorder. For example, Rodney consistently had conflicts (and eventually a physical altercation) with another client. During a meeting, one worker said that the other client had decided to avoid Rodney to try to prevent further problems. However, the worker stated, “Rodney did not decide that, which brings up the Axis II issues again” (field notes).

Similarly, at Suburban, there was a female client, Frances, whose official diagnosis was bipolar disorder. However, most discussions regarding her by workers focused on her manipulative and tumultuous relations with other clients (especially men) and workers. While on at least one occasion it was discussed that her behavior might result from her being “manic” (a state associated with bipolar disorder) (field notes), more frequently her behavior was described in terms of personality disorder. For example, one worker stated that she would diagnose her with a “combination personality disorder,” histrionic and borderline (field notes).

While some clients labeled *not severely mentally ill* were nonetheless seen as suffering from mental illness, and thus experienced looping processes, others appeared not to be judged to have any symptoms of mental illness. Workers’ discussions of Jabar, a client living in a residence run by Suburban who sometimes also attended the day program, was an example of this type of client. Though Jabar was officially diagnosed with schizoaffective disorder and was on several types of psychotropic medications, psychiatric evaluations described him as reporting that he experienced no symptoms of mental illness (though they described him as delusional regarding his past). During my fieldwork at Suburban, I never observed workers describe Jabar’s problematic behavior as symptoms of mental illness. Instead, it was framed as behavior he was willingly participating in and which he could control – there was no looping. For example, a worker at the house where Jabar lived talked in an interview about “just [feeling] so sorry” for how the worker could not reason with an unmedicated severely mentally ill resident who refused to participate in most services and who caused disruptions in the house. However, when that same worker talked about Jabar and his refusals and disruptions, the worker’s tone was quite different. In a comparison of Jabar with most other clients in the residence, the difference in tone was noticeable:

[E]verybody else is maintaining their recovery and they’re basically not here. And mostly [the only time] you can [...] find the clients all at home at the same time is after 6 o’clock, and that’s the end of their day, whether they are working in school or coming from the [program]. [Jabar], that person that I spoke about that’s refusing the program, he just lays around, eats sleeps and smokes cigarettes. I’m trying to get him back in program (interview).

Thus, mental health services workers' labeling of clients as *not severely mentally ill* might or might not involve looping processes.

In sum, we see much more complexity in organizational labeling of clients, and in the looping tied to these labels, than Goffman described. Workers' informal labeling of client mental illness did not always agree with official diagnoses; clients could be officially diagnosed as *severely mentally ill* and still informally be labeled *not severely mentally ill*. Ironically, within this category, it was possible for looping processes to nonetheless occur, as workers could see clients as suffering from less severe mental illness than would warrant official diagnoses (and meet bureaucratic criteria). In the next section, I will explain how this complexity in labeling processes is mirrored by complexity in social control processes tied to these labels.

Social Control

While both classical and some more contemporary studies of mental health care describe relatively uniform interactional dynamics between workers and clients, I find that social control processes vary by workers' informal labels of clients. Further, I find that looping is not always tightly bound to social control – not all clients whose behavior is looped receive the same type of social control. Finally, while Goffman and other classic studies describe social control as involving moving clients to different wards *within* the hospital, I found that some types of social control in community mental health services works to *exclude* clients from the organizations' services.

Within the organizations I studied, I found two major patterns of social control: integrative and exclusionary. Integrative social control, which more closely resembled the type classical researchers of the mental hospital described (as well as that addressed by those who see medicine as an institution of social control), aimed to subvert client disruption without exiting the client from the organization (Braithwaite, 1989; Heimer & Staffen, 1995). This type of social control was tied closely to looping; problematic behavior from clients was seen as a symptom of severe mental illness, and social control efforts were aimed at maintaining the client in treatment through service provision to address symptoms. While at times that might have to occur through moving the client to a more intensive service provider temporarily (such as psychiatric hospitalization or a drug/alcohol rehabilitation facility), the goal was to eventually reintegrate the client into services through the organization.

Exclusionary control, on the other hand, was geared primarily toward eliminating disruption the workers saw the client as (at least partially) willfully engaging in. Because some clients were judged as able to control

their behavior, exclusionary social control was motivated by the thought that, if the client will not eliminate the behavior (which, again, they saw as possible), then workers needed to eliminate the client. Client exits through this type of control were at times made without arranging services from another provider. Though more or less intensive services might be arranged, exit could occur without them. Further, client exits could initially be short term, but they could also be long term, especially if there had been previous exits due to problem behaviors.

Because basically all clients in the organizations had official diagnoses of severe mental illness, these labels could not be used to determine the type of social control to use regarding clients. Instead it was workers' informal labels of clients that dictated the type of social control. Clients informally labeled as *severely mentally ill* were subject to integrative social control. Those informally labeled as *not severely mentally ill*, whose behavior might or might not be looped into a mental illness label (though never a *severe* one), were subject to exclusionary social control. Next I will briefly walk through some examples of the two types of social control in both Urban and Suburban.

For those informally labeled *severely mentally ill* in both Urban and Suburban, though workers were definitely motivated to contain disruptive and dangerous behaviors, they saw those behaviors as symptoms, which needed to be treated. This treatment was what the organization aimed for; thus integrative social control was used to reduce disruption and to bring the client back to the organization for more treatment. At Urban, for instance, Riaan was involuntarily hospitalized numerous times for her violent and threatening behavior. However, the organization continued to provide housing and other services to her. As one worker put it,

This is the person that we are supposed to most strongly embrace, you know. This is an individual that we need to aggressively continue to work with because, you know, this is somebody who used to fall through the cracks. [...] Just because they are a difficult person to work with doesn't mean that we shut the door [to] her from services (interview).

Even though the organization at times violated Riaan's wishes in hospitalizing her and having medication forced on her, clearly an instance of social control, this was done to "stabilize" her and have her return to receive services from the organization in the community.

Likewise, when Janice from Suburban was admitted to the hospital, her worker, Nicole, wanted to go and see her. However, Janice refused to sign a release so that Nicole could visit her in the hospital. Nicole was angry she

could not have contact with Janice, but she quelled some of the anger by looping the behavior into the informal label of *severe mental illness*, explaining, “That’s the paranoia” (field notes). Though Janice was a potential disruptive presence, and appeared to be attempting to sever the therapeutic relationship, Nicole and Suburban (as well as Janice’s family) worked to maintain it, using integrative social control. Janice eventually left the hospital and rejoined the program at Suburban.

For clients seen as possibly having a mental illness, but informally labeled as *not* having a *severe* mental illness, though looping might occur, it did not always lead to integrative social control. Instead we see that not all mental illnesses are seen as leading to the same level of impairment in workers’ eyes, regardless of official diagnoses. At Urban, Rodney’s purported personality disorder did not lead to him being informally labeled *severely mentally ill*. Though workers thought he might have a mental illness, they still viewed him as able to control his behaviors. Several times I witnessed workers both threaten to and actually carry through with kicking him out of groups and out of Urban’s day program for a time. Rodney claimed he was treated differently from other clients in the program.

Rodney is complaining, calling himself the “nigger of the program.” He says when he does the same thing as other people, he gets singled out. [...] He points to a group Pete was running and how all kinds of people were talking [...] but when he did it, he said, Pete “almost kicked me out” (field notes).

Workers freely admitted they held Rodney to a different standard from that to which they held other clients. That is because, even though workers saw Rodney’s behavior as possibly the result of a personality disorder, and thus looped his disruptive behavior, they nonetheless thought he had much more control over his behavior than others had, and thus applied exclusionary social control.

In much the same way, workers at Suburban judged Jabar as able to control his disruptive behaviors. Also similarly, Jabar pointed to the different standard to which his unmedicated disruptive housemate was held. While Suburban rarely involuntarily terminated services with clients due to organizational policy, they would frequently be less assertive in maintaining services for disruptive clients, or even encourage those clients to voluntarily leave services. Thus, Jabar sensed that the encouragement he had received from workers to move out into his own apartment might have been motivated less by their thinking that it was in his best interest and more by

how much easier it would make their job. Jabar talked about his interactions with a particular worker:

This is a big thing for him now. He'll wait a month, two, three month and ask me when I'm moving out. I say, "Well, have you asked [the unmedicated housemate] when she's moving out?" [The worker says,] "We're not discussing [her]. When I get to [her] and if we discuss it, I'll tell her who's askin'." I said, "Well man, you can be so childish to be so old." [...] Because it was childish. You bring something to me and I throw it back at you, you ain't got an answer for it, or you refuse to answer the question, so you gonna act like a little child? [...] I'm too old for this shit (interview).

In meetings, workers at Suburban constantly discussed ways to overcome Jabar's resistance to organizational rules and routines, and were to some degree at a loss. This, when considered with my observations of responses to other disruptive clients, makes Jabar's statement plausible, even though I did not observe workers directly state a strategy of solving their problems by pushing Jabar to move out.

In sum, we see two different social control strategies depending on how workers informally labeled clients. When a client was informally labeled *not severely mentally ill*, despite a conflicting official diagnosis, they were subject to exclusionary social control. When the official and informal labels did line up, workers used integrative social control. Finally, unlike Goffman's description, we do not see looping tightly bound with official diagnoses: those who are officially diagnosed are not necessarily subject to looping. Further, those who are informally labeled *not severely mentally ill* may be subject to looping.

DISCUSSION AND CONCLUSION

Previous work on labeling and social control in mental health services has underemphasized the diversity in the process. Instead of service providers treating all clients through a mentally ill "master status," we instead see that, though official organizational labels of severe mental illness are rather uniform, they serve a specific, limited purpose: meeting bureaucratic requirements. Further, we see that informal organizational labels vary. We also see that looping processes do not always predict either informal labels of mental illness or a specific type of social control. It is the informal organizational label of mental illness that determines the type of social control applied. Integrative social control is directed toward disruptive clients that workers informally label as *severely mentally ill*, while exclusionary social control, cutting clients off from an organization's services, is applied to disruptive clients who are informally labeled *not severely mentally ill*.

Not all mental illnesses are viewed equally by workers. Because informal labels of client mental illness – like official diagnoses – include both disorder identification and a judgment of functioning, simply being seen as having a disorder does not guarantee an informal label of severe mental illness. Workers are more likely to informally label clients they see as having personality disorders, as well as those who are experiencing fewer symptoms, as *not severely mentally ill*, and to apply exclusionary social control to them. Clients with clinical disorders (Axis I) and those with more symptoms are more likely to be informally labeled as *severely mentally ill*, and were more likely to receive integrative social control.

It is important to note that, while exclusionary social control might have more immediate negative consequences for clients in terms of loss of resources, integrative social control *is social control*, as well. Thus, when *severely mentally ill* clients' disruptive behaviors are subject to integrative control, though they are given more leeway in disruption, workers will still try to control the behavior at some point. Thus the use of forced medication, hospitalization, coercion, etc., should not be disregarded as unimportant in considerations of social control. At issue in this chapter are the ends toward which the different types of social control are directed, with integrative control applied to force the client to fit back into organizational rules and routines (on an ongoing basis), while exclusionary control removes clients from the organizational setting.

For a sociology of diagnosis in mental health care, this chapter has demonstrated the importance of examining the range of organizational labels that workers in mental health care apply to clients. Official diagnosis is only one of these labels, and serves specific, bureaucratic functions. If we were to ignore the informal labels used, or even to assume that such labels simply agreed with official diagnoses, we would miss a major determinant of staff treatment of clients. We would also have trouble understanding the large degree of variation in treatment and social control of clients who share an official severely mentally ill diagnosis. The point here is that this ignores fundamental realities about mental health care practice.

Some of the differences between classical studies like Goffman's and the present study no doubt have to do with the differences between the settings studied. As Heimer and Staffen (1995) argue, when organizations are "stuck with" clients, they are more likely to use integrative social control. Mental hospitals at the time classical researchers studied them were the location of last resort for many patients, and thus the hospitals were "stuck with" the patients they had. In the contemporary community setting, however, organizations have more ability both to prevent clients from joining and to

exit clients once they do join. Thus, whereas organizational diagnoses might only lead a patient being moved around to different wards within a hospital (all the while subject to integrative social control), in the contemporary community organizations I studied, at times they could lead to clients being excluded.

This study cannot be considered representative of the entirety of community mental health services system. While there is a great deal of variation between the two sites, they do come from the same metropolitan region. Future research could undertake larger-scale research to explore if these findings are borne out with on a national or international scale.

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FROM TALK TO ACTION: MAPPING THE DIAGNOSTIC PROCESS IN PSYCHIATRY

Rebecca Godderis

ABSTRACT

Purpose – There is a paucity of research that examines how diagnostic decisions are made by psychiatrists. Moreover, previous work in the area tends to be grounded in labeling theory, which highlights the conflict-based nature of diagnosis. The goal of this research is to examine the utility and benefits of diagnosis to psychiatrists' everyday work.

Methodology – Using institutional ethnography (IE), I undertook a small-scale interview-based study that documented the diagnostic processes of three psychiatrists in Calgary, Alberta, Canada. The IE-based goals of the study were to: (1) identify what texts were employed during the diagnostic process, (2) map sequences of action and text that coordinated psychiatric decision-making, and (3) theorize the utility of diagnosis for the everyday work of psychiatrists.

Findings – The analysis demonstrates how diagnosis can be understood as a valuable work process that produces a standardized diagnostic story in order to bring an individual's experiences of distress into relation with psychiatrists' daily practices, and institutional discourses more generally.

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Limitations – *Although IE-based research does not depend on large sample sizes for analytic accuracy, results from the current study need to be replicated because of the limited number of interview participants and to examine whether the diagnostic process is generalizable to other settings.*

Social implications – *This research challenges the idea that standardization through diagnosis is a negative process and highlights the value of diagnostic decision-making in the daily work of psychiatrists.*

Keywords: Diagnosis; psychiatry; institutional ethnography; decision-making; DSM

INTRODUCTION

Diagnostic classification systems provide the basic structure around which medical work is organized, thus influencing the performance of everyday actions by healthcare practitioners. Well over a decade ago [Brown \(1995\)](#) argued for the advancement of a “sociology of diagnosis,” a call which has recently been echoed and elaborated by [Jutel \(2009\)](#). Sociological research on diagnostic psychiatry has tended to be critical, focusing on the introduction of biomedically inspired diagnostic nomenclature, the implications of employing a biomedical framework to understand the mind, and the construction of specific diagnostic categories (see e.g., [Kirk & Kutchins, 1992](#)). In fact, so much critical scholarly work has been done that [Pilgrim \(2007\)](#) asks: “If psychiatric diagnosis has been criticized on empirical, logical, and sociological grounds, by so many for so long, how and why has it survived?” (p. 539).

What has yet to be examined in-depth is how psychiatric diagnostic decision-making occurs in practice. Common sense views of diagnosis tend to understand this act as a single moment in time where a doctor makes an pronouncement that relates an individual’s symptoms to a category and, (presumably) a treatment that will alleviate that distress. Accordingly, diagnosis is often characterized as a moment of relief, or even empowerment. In contrast, if a diagnosis is denied it can be devastating: “This judgment in turn impugns the person’s legitimacy to make a claim and to be suffering, denying them the sick role altogether” ([Dumit, 2006](#), p. 577).

Thus, it is clear that diagnostic judgment can be valuable for the patient in terms of validation and access to the benefits attached to the sick role. Yet, the portrayal of diagnosis as primarily being about relieving individual distress is a relatively simple analysis of a highly complex act. In addition to legitimizing an individual's suffering, the power of psychiatric diagnosis is that it: "locates the parameters of normality and abnormality, demarcates the professional and institutional boundaries of the mental health system, and authorizes psychiatry to label and deal with people on behalf of certain sectors of society" (Cooksey & Brown, 1998, p. 527). Although much has been written about the dynamics of diagnosis, most of this work is grounded in a version of labeling or social control theory that highlights the power differential between doctors and patients, and understands the diagnostic process, and medicalization more generally, as inherently problematic (Conrad, 1992). Even authors who have documented instances where individuals are fighting to have their condition medicalized tend to position the politics of diagnosis within this framework, recognizing the benefits diagnosis brings but emphasizing the negative aspects related to control and power (e.g., see Arksey & Sloper, 1999; Dumit, 2006).

In this chapter, I challenge this positioning of diagnosis as inherently negative by arguing that the creation of a standardized diagnostic story, which provides a general description of an individual's unique experience, can be beneficial in terms of the logic of large institutions such as healthcare. Thus, diagnosis is extremely valuable to the everyday work of psychiatrists. This process of standardization is also of value to patients because it moves them (and their stories) through large and complex institutions, thereby providing access to resources. Of course, diagnostic standardization is not only about the pragmatics of administering a large institutional system. Particularly in psychiatry, diagnostic standardization has occurred for a number of reasons, including the re-establishment of professional legitimacy in the face of criticisms from within and outside of the discipline itself (see Mayes & Horwitz, 2005; Wilson, 1993). Moreover, it is clear that rendering individual complexity into a standardized diagnostic story is full of complications. Certainly, scholars such as Zola (1972), Mirowsky and Ross (1989), and Rosenberg (2002) have established how the process of medicalization, and psychiatric diagnosis in particular, can be dangerous. Yet, Foucault (1978) also challenges us to examine how the governing of bodies by the medical community can be productive. To examine this possibility further, I used the analytic and methodological framework of institutional ethnography (IE) to explore how the psychiatric diagnostic process produces a discursive entity, which I refer to as a standardized

diagnostic story, that then enables an individual to (potentially) gain access to crucial healthcare resources.

To support this argument, the first half of this chapter will provide a brief overview of the history of diagnosis in psychiatry and discuss why IE is of particular value in the examination of diagnostic decision-making. The second half of the chapter will present the results of a small-scale empirical study that documented the diagnostic processes of three psychiatrists in Calgary, Alberta, Canada. The IE-based goals of the study were to: (1) identify what texts were employed in the diagnostic practices of the psychiatrists, (2) map the complex sequences of action and text that coordinated their psychiatric decision-making, and (3) theorize the utility of diagnostic decision-making for the everyday work of psychiatrists. This analysis demonstrates how psychiatric diagnosis can be understood as a valuable work process that produces a standardized diagnostic story in order to bring an individual's experiences of distress into relation with psychiatrists' daily practices, and institutional discourses more generally.

DIAGNOSTIC PSYCHIATRY

Within American psychiatric history, the reliance on standardized diagnosis is a relatively new phenomenon. The publication of the third edition of the *Diagnostic and Statistical Manual of Mental Disorders (DSM-III)* in 1980 by the American Psychiatric Association (APA) formalized a dramatic shift in the discipline from a dependence on psychodynamic approaches to a medically inspired diagnostic model. This paradigm shift has been called a "revolutionary transformation," which was made all the more remarkable because it occurred in less than 10 years (Mayes & Horwitz, 2005, p. 250). As a result of this change, psychiatrists began to classify mental illness according to patterns of explicit, overt symptoms. Under the previously dominant paradigm of psychodynamic psychiatry diagnosis played a marginal role. Psychodynamic psychiatry understood mental health problems as nonspecific manifestations of struggles that happened at an unconscious level. Thus, symptoms were thought to simply disguise the dysfunctions of underlying psychic systems (Cooksey & Brown, 1998). This causal framework is quite distinct from the biomedical doctrine of specific etiology, which states that diseases are caused by a single specific biological factor, which then manifests in observable and related sets of symptoms (Wilson, 1993). Diagnosis is the cornerstone of a biomedical framework

because the act of diagnosis enables a healthcare professional to determine what disease is present by observing specific patterns of visible symptoms (Horwitz, 2002).

During the 1970s, psychodynamic psychiatry was critiqued on a number of fronts by American government officials, insurance agencies, the anti-psychiatry movement, and psychiatrists themselves (see Mayes & Horwitz, 2005). To address these attacks, and maintain professional legitimacy, a group of psychiatrists known as the neo-Kraepelinians advocated for a biomedically inspired diagnostic approach, which would rely on symptom-based standardized definitions of mental illnesses. This group gained a great deal of influence during the mid-to-late 1970s and during the revision process of the DSM-II (APA, 1968) into the DSM-III (APA, 1980), American psychiatric nomenclature underwent a substantial transformation from loose descriptions of psychodynamic concepts to a highly structured system that provided detailed descriptions of disorders, sets of observable symptoms, and lists of operational criteria (Mayes & Horwitz, 2005; Wilson, 1993). Accordingly, the DSM-III presented the standardized classification system needed for symptom-based diagnosis in American psychiatry and is commonly viewed as the key symbolic moment when influence over the discipline shifted from dynamic psychiatry to a research-based, medical model (Kirk & Kutchins, 1992).

Social science researchers have been keen to understand this dramatic transformation and have studied why this shift occurred, as well as the impact that these changes have had on definitions of mental illness and the discipline more generally (e.g., see Horwitz, 2002; Kirk & Kutchins, 1992; Luhrmann, 2001; McPherson & Armstrong, 2006; Parkinson McCarthy, 1991; Parkinson McCarthy & Gerring, 1994; Pilgrim, 2007). Scholars have also extensively examined the politics of diagnostic labeling, including the removal of homosexuality from the DSM (Bayer, 1987), the inclusion of Pre-Menstrual Dysphoric Disorder in the manual (Figert, 1996), the creation of post-traumatic stress disorder (Young 1997), the development of the category “gender identity disorder of childhood” (Bryant, 2006), the role of the DSM in the increasing rates of major depression (Horwitz & Wakefield, 2007), and the framing of female hypoactive sexual desire disorder (Jutel, 2010). Thus, important scholarly work has documented the socially constructed nature of diagnostic categories, and the disciplinary politics of psychiatry more generally.

Commonly overlooked in this literature are questions about how, exactly, the DSM categories are activated in the everyday practice of psychiatrists,

and how making a diagnosis links psychiatrists, and their patients, into other institutional processes. For example, Bryant (2006) notes that although critics have devoted a significant amount of time and effort in challenging DSM diagnoses, these critiques may have a limited effect if it is not clear how psychiatrists actually use diagnoses in their day-to-day work. In addition, Pilgrim (2007) points out a need to develop a better understanding of how the DSM is produced and used because classification decisions are constantly being shaped by factors that are beyond the particular case at hand, or even external to the discipline of psychiatry more generally.

In his research, Whooley (2010) noted similar concerns claiming that the DSM is often positioned as a “monolithic, powerful object in and of itself,” which he argues “overstates the power of formal diagnoses and obscures resistance through informal work practices by psychiatrists” (p. 454). To begin to correct this imbalance, he interviewed psychiatrists about their day-to-day practices and found that these professionals often engaged in “psychiatric workarounds,” such as negotiating diagnoses with patients or changing DSM diagnostic codes on paperwork (Whooley, 2010). The concept of workarounds provides support for the idea that, as part of their everyday procedures, psychiatrists destabilize the power of formal diagnostic categories as presented in the DSM. Employing the techniques of IE, this chapter continues to address the call for a better understanding of the work of psychiatrists and how daily diagnostic decision-making may challenge the monolithic nature of the DSM.

INSTITUTIONAL ETHNOGRAPHY AND THE STUDY OF PSYCHIATRIC DIAGNOSIS

IE, as a general analytic framework and a specific method, is particularly well suited to develop a better understanding of psychiatric diagnosis because it conceptualizes decision-making as a work process that coordinates a series of activities (Smith, 2005). Viewing diagnosis as a socially organized work process highlights how a psychiatrist’s everyday work practices are related to larger institutional discourses, making visible the utility of diagnostic labels and external factors that have an impact on psychiatric decision-making. In other words, IE directs a researcher to

examine the interface between the everyday actualities of people and the work practices of the institutional agencies they encounter.

The concept of work is used in a “generous sense to extend to anything done by people that takes time and effort, that they mean to do, that is done under definite conditions, and with whatever means and tools” (Smith, 2005, pp. 151–152). Institutional processes coordinate diverse sites often by employing specific modes of knowledge (e.g., psychiatric knowledge) that tend to generalize, shifting perspective from an individual’s personal experiences to a “view from nowhere” (Smith, 2005, p.120). The empirical study discussed in the next section demonstrates how this shift from specific to general occurs during a series of events that take place in different spaces and at different times. Thus, “diagnosis” does not happen at a particular instant in time, such as when a psychiatrist makes a pronouncement, but rather is an institutional process that occurs over a period of time and in a variety of locations.

The term institution – for example in the phrase “the institution of psychiatry” or “the institution of healthcare” – does not refer to a stable organization or a single site, such as a doctor’s office or a government’s health department. Instead, “an institution” refers to the organizations, agencies, and people that are connected via translocal relations in order to do work related to a distinctive function, such as healthcare (DeVault & McCoy, 2006). Translocal relations are coordinated chains of actions that connect embodied experiences, which occur at a specific local site, to work that is performed at other sites. These relations create, and rely on, textually based realities to produce, re-produce and stabilize institutions because texts have the capacity to preserve meaning in the absence of local context (Smith, 2005). Thus, central to an institutional ethnographic analysis is the study of how texts (e.g., manuals, forms, and reports) coordinate people’s work (the local) within broader institutional practices (the translocal).

However, institutional work processes are not uni-directional, moving only from the particular to the general. These processes also facilitate the movement of results of institutional decision-making and procedures from generalized discourses back into people’s everyday lives, as is the case when a decision is made to reimburse an individual for their medications. If approval is given, then the individual receives the medication and begins the embodied experience of pharmaceutical treatment. This movement back and forth between different institutional sites, and from the specific to the general, is often referred to as “extended social relations” (Smith, 2005, p. 36), which connect people even if they never directly meet.

The term ethnography in the phrase “institutional ethnography” emphasizes a methodological focus on exploring and mapping everyday activities, such as individual work practices and their relation to translocal, coordinated processes. Institutional ethnographers may use a variety of methods to conduct their research, including interviews, focus groups, participant observation, archival research, and document analysis (DeVault & McCoy, 2006). Interviews have been used as the main source of data in the empirical study that is presented in this chapter. The purpose of institutional ethnographic interviews is to describe and trace a social process, and establish how this process hooks into translocal practices. This type of interviewing is not concerned with generalizing from the individuals who have been interviewed to a larger population. Instead, the relevance of the investigation comes “from the capacity of the research to disclose features of ruling that operate across many local settings” (DeVault & McCoy, 2006, p. 18).

AN EMPIRICAL ANALYSIS OF DIAGNOSTIC DECISION-MAKING

The current study involved in-depth interviews about the diagnostic work processes of three psychiatrists. As a starting point, I assumed that the DSM was a key text in the diagnostic process because the manual provides the classification system that defines the symptoms of each illness. Given this assumption, the specific objectives of the empirical study were to: (1) identify what other texts, in addition to the DSM, were employed in diagnostic practices that were performed within the localized context of psychiatrists who worked in Calgary, Alberta, Canada; (2) map the complex sequences of action and text that coordinated the work of diagnostic decision-making to produce a generalized description of this work process (Fig. 1); and (3) theorize the utility of diagnostic decision-making for the everyday work of psychiatrists. Visually mapping the diagnostic process makes visible how an individual’s unique experiences of distress are coordinated with texts, and with other people’s activities, to form text-talk-text sequences. These text-talk-text sequences demonstrate how psychiatric knowledge, as applied to an individual’s unique circumstances, then becomes socially organized through the process of diagnosis (Turner, 2006).

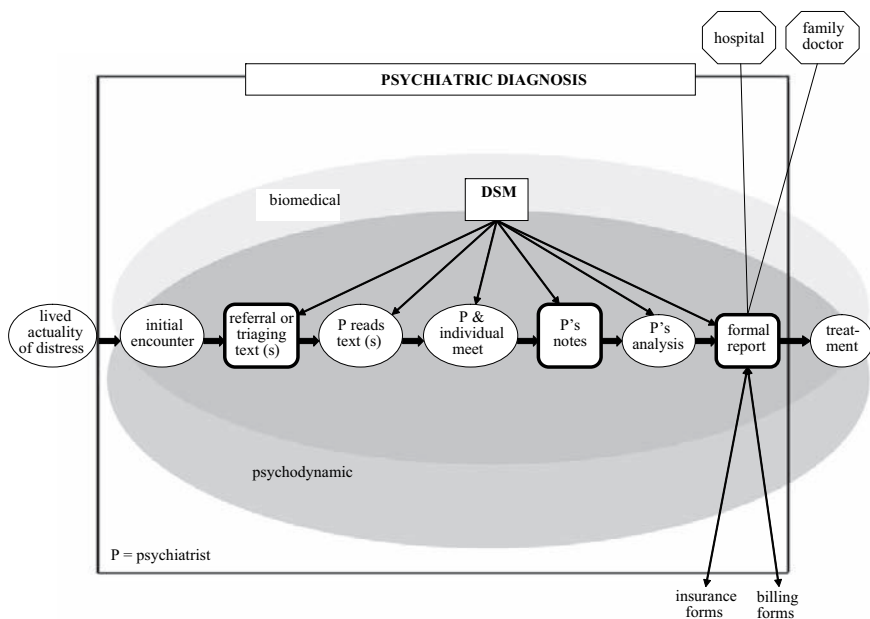


Fig. 1. Psychiatric Diagnostic Work Process.

Methods

Interviews were conducted in October 2007 with three psychiatrists (two females and one male) who practiced in Calgary, Alberta, Canada. The individuals I chose to interview represented a range of views on the biomedical-psychodynamic continuum, which enabled an exploration of the divergences and intersections between different psychiatric perspectives (DeVault & McCoy, 2006). Thus, I used the nonprobabilistic technique of purposive sampling to intentionally select participants because they illustrated concepts that I wanted to examine (Silverman, 2000). In contrast to positivist studies, analytic accuracy does not depend on a large sample size or the sample's relation to a population. Rather,

... fieldwork and interviewing are driven by a faithfulness to the actual work processes that connect individuals and activities in various parts of an institutional complex. Rigor comes not from technique – such as sampling or thematic analysis – but from the corrigibility of the developing map of social relations. (DeVault & McCoy, 2006, p. 33)

My objective in the interview was to access participants' "work knowledge," which included a description of their work, how their work was coordinated with the work of others, and what texts were involved in these activities (Smith, 2005). I asked each psychiatrist to provide a step-by-step explanation of how they would make a diagnostic decision, focusing on the work they had to do and the texts they activated. Each interview I conducted was between 1 and 2 h, during which time I took notes. In addition, all interviews were audiotaped and transcribed; however, one recording was inaudible and therefore I relied on the notes I made during the interview to complete the analysis. Although I am unable to give verbatim quotes from this interview, I do provide a general sense of ideas and examples that this participant shared. Ethics approval for the project was received from the University of Calgary and all participants signed informed consent forms. Names provided with quotes are pseudonyms (Michael, Karen, and Judy), and are linked to the same interview participant throughout the results section.

Using this interview data, and drawing on Turner's (2001, 2006) mapping techniques, I have created the graphic map presented in Fig. 1. This map provides a generalized description of the diagnostic work process that psychiatrists used when they engaged in their local work practices. The process displayed in the map occurs over time and space, and is a representation of a multiplicity of embodied actions – events that occur in a particular place, during a specific time period, and involve unique individuals. However, it is also an illustration of how those embodied actions are taken up into translocal processes that coordinate individual actions of the patient, the psychiatrist, and other institutional actors.

The following is a guide to the symbols I used in Fig. 1: circles indicate human activity, squares with rounded edges indicate texts produced by the diagnostic work process, squares with nonrounded edges indicate other texts that are activated as part of the process, and octagons indicate different locations that copies of a text may be sent. The large ovals that are light and medium shades of grey, which encompass most of the map, symbolize the interpretive frameworks that the interview participants discussed as having implications for the diagnostic work process, with light grey representing the biomedical frame and medium grey representing the psychodynamic frame. The area where these two ovals overlap, which is dark grey, indicates when these two frameworks are being applied at the same time.

Thick black arrows symbolize the progression of the diagnostic work process over time and space, thin black arrows indicate that a text is having

an influence on another text or action, and the lines with no arrow heads indicate a possible location to which a text may be sent. Finally, the thick black square surrounding most of the figure denotes the (somewhat artificial) boundaries of the psychiatric diagnostic process.

RESULTS

Producing a Standardized Diagnostic Story

Psychiatric diagnosis is a socially organized work process that is made up of relatively standard sequences of actions and texts that coordinate key institutional activities. Although individual psychiatrists may adhere to slightly different diagnostic practices, or may even professionally espouse quite divergent theoretical positions, there is a generalized work sequence that facilitates bringing an individual's unique experiences of distress into relation with institutional discourses more generally. To highlight the generality of this process, Michael commented that the referral phase of psychiatric diagnosis was similar to other kinds of medical specialties:

The processes that you are asking about for psychiatry are no different from anything else in medicine. We follow the same kinds of procedures. It's the same thing for someone who has an endocrine problem or a thyroid difficulty or if they have migraine headaches; for a neurologist the referral sources are exactly the same.

The generalized process of work activities are mapped in detail in [Fig. 1](#). The process begins with an individual experiencing distress, despair, or some other difficulty in their life (i.e., their lived actuality) that would put them in contact with a healthcare professional. Although this initial encounter was not fully explored in the current research, it is important to note that an individual must meet with another kind of healthcare professional in order to get a referral to see a psychiatrist. In most cases a referral or triaging text would be produced from this encounter, and then received and read by the psychiatrist before meeting directly with the individual. Judy noted that these brief referral or triaging texts tend to be read by psychiatrists as providing a general guide about what to look for in their assessment, but are not considered an authoritative psychiatric account. She provided the following example: if a referral letter stated that the individual was experiencing symptoms of depression, this may direct the psychiatrist toward asking questions about depression earlier in their evaluation;

however, the psychiatrist would not assume that this is a correct diagnostic impression of the individual.

Following the referral, the individual and the psychiatrist would meet with one another. During this meeting a vast amount of information about the individual was gathered, which was then used to make diagnostic, treatment, and management decisions. Although some of this conversation was explicitly organized by the classification system provided in the DSM, other aspects were not. In addition to collecting details that would help establish a DSM diagnosis, other information was gathered to develop an understanding of how the distress came about. Each psychiatrist had formulated a series of questions to lead them through this information gathering process. For example, Karen said: “We have a pretty standard set of headings which everyone develops in their own way over their training and then generally tries to stick with it because if you don’t kind of have your order, you’re going to leave something out.” Although a form or document with a similar series of questions may have been shown to them at some point in their training, all three psychiatrists said that they could not identify one specific text that outlined the process. Instead, early in their careers they had worked to memorize their own versions of these questions. As Michael said: “all those things are just engrained in our brain.”

A key objective of this meeting between the individual and psychiatrist was to establish a personal history, which involved gathering detailed information about the individual’s life. If the psychiatrist had an hour or more to meet with the individual, a large amount of time would be devoted to this part of the assessment. For example, Karen mentioned that she would usually spend about 25 min on this section, and Judy stated she would spend close to 40 min to collect this information. While gathering this personal history, the psychiatrist is oriented toward collecting particular kinds of information that psychiatry, as a discipline, has deemed valuable information that was expected to help the psychiatrist understand how the mental illness came about, how the illness could be treated, and what factors needed to be considered to manage the care of the individual. Questions that were used by all three interview participants included: Have you ever experienced physical or sexual abuse? Have you been able to maintain stable work as an adult? Do you currently have a home? What major life difficulties have you experienced recently (e.g., death of a friend, relative, or partner)? Judy described it as “wanting to hear their story.” Yet, it is important to note that the story which was solicited is a specific type of story – one which emphasizes certain aspects of an individual’s life that can

be translated or understood as indicative of mental health status. It needed to be the kind of story that can then be converted into a standardized diagnostic story if care is deemed to be necessary.

Thus the psychiatrists described diagnosis as a highly productive process during which they worked to transform in-depth knowledge about an individual's lived actualities into a generalized representation of those actualities. For example, after describing to me the vast amount of detailed information he collected about each patient, Michael said that his next step was to:

Make a formulation – that formulation is a comprehensive view of all the things we've just talked about. The physical, the psychological, the experiential, all of those things, all the systems, the organ systems, and put it all together into some coherent way in which you can say this is what we're going to come into some kind of a category (pause) and so then you are getting into what is (pause) what you would call diagnosis, but which is simply a categorization.

In order to make a formulation, Michael used psychiatric knowledge to generalize, shifting the diagnostic perspective from an individual's personal experiences to a "view from nowhere" (Smith, 2005, p. 120).

As indicated in Fig. 1, this shift from specific to general occurs over time and space. Diagnosis is a process that moves from the specific to the general beginning when an individual first makes contact with the healthcare system and ending with the completion of the formal report. To further illustrate my argument I offer two concrete examples of how the standardized diagnostic story that is produced during this process then serves to coordinate translocal relations, thereby increasing an individual's access to healthcare resources. The first example examines specific circuits of accountability, including psychiatric case notes, and insurance and billing requirements. The second example explores how the language of diagnosis works to efficiently coordinate the efforts of psychiatrists with other healthcare professionals. Psychiatrists' ability to engage in these common work practices enables individuals' unique experiences to become institutionally actionable.

Circuits of Accountability

The establishment of a diagnosis hooks psychiatrists' work into larger social relations that administer individuals across systems. Efficient administration in institutional settings requires that individuals with the authority to request resources engage in specific circuits of accountability where their

decisions are made accountable to others (McCoy, 1998, 1999). For example, interview participants indicated that an important element of reports produced from a mental status exam, which was performed during the meeting between the individual and the psychiatrist, was that information be presented as objective observations, rather than subjective interpretations. Judy noted that a psychiatrist would be expected to report that “the individual continuously looked around the room” rather than “the individual appeared to be distracted.” Karen further explains:

It’s supposed to be observational, not your interpretation of what is causing it, so that a reader could make their own independent assessment of what this was. They may not agree with your diagnosis, so a reader should be able to say okay they thought this was this, but based on what they actually saw on that day I actually think it’s this other thing. So they should be able to pull that out and not just your interpretation.

How the mental status exam is written up acted as part of an accountability circuit within the discipline, which assumes that the use of “objective” language to report observations, rather than subjective comments, created the opportunity for psychiatrists to review and evaluate one another’s work. Yet, the notion that this accountability circuit made the process completely objective dismisses the fact that, in writing such reports, psychiatrists are constantly making choices regarding what information to include or exclude. Moreover, interview participants stated that some psychiatrists may even chose not to complete a full mental status exam during their meeting with the individual. As Karen noted: “Its objective, only in a subjective way!”

The psychiatrists in the current study also discussed how the diagnostic process was essential to the completion of insurance and billing forms, which were crucial to coordinating the movement of an individual through the healthcare institution. Judy provided the example of an individual who needed to apply for disability status to receive paid leave from work. To do so, the psychiatrist would need to complete insurance forms that gave a specific DSM diagnosis. Similarly, if a psychiatrist was to be reimbursed for their own work, they needed to fill in billing forms that required them to identify their diagnostic decisions. Karen discussed this requirement:

We have a billing code as psychiatrists (pause) that is a certain amount of money for doing a first assessment, but it includes the production of a report. So legally we need to produce a report, even if it only goes to our own chart.

In their history of the DSM-III, [Mayes and Horwitz \(2005\)](#) note that insurance companies, and other third-party payers, actually had a significant influence on the transformation of the DSM because of the desire of payers

to increase psychiatric accountability. The argument made by third-party payers was that standardized language and uniform definitions of mental illness established a process of financial reimbursement that was more reliable and valid; however, the claim of increased reliability has been strongly critiqued (see [Cooksey & Brown, 1998](#)) and psychiatrists do find ways to workaroud such requirements (Whooley, 2010). Nevertheless, regardless of whether the DSM-III classification is more reliable than previous versions of the manual, what is clear from this analysis is that insurance and billing forms engaged psychiatrists in circuits of accountability that held them responsible for their decisions while (potentially) enabling their patients to gain access to resources such as paid leave from work.

Speaking a Similar Language

All three of the interview participants discussed how attributing a diagnosis to an individual was important for increased coordination of work that was being done between different healthcare professionals. For example, Judy talked about how “speaking a similar language” with other professionals gave her the opportunity to efficiently communicate important information, both verbally and through texts, to other professionals involved in an individual’s care. Similarly, Michael and I had the following exchange about the importance of having a common language:

Michael: We share the same nomenclature, we share the same categories. So that’s very, very important. If you don’t, say you would never know if you were dealing with the same illness or the same things, so you have to have some, it’s the same with anything in sciences.

Interviewer: So you are able to know that you are talking about the same thing when you say anxiety?

Michael: Yeah. That’s right. So that helps in your treatment that helps in the understanding and looking at the prognosis of the treatments and the kind of categorization of those... because you know you are working on the same kinds of things.

Thus, the classification system in the DSM was explicitly and reflexively seen by the psychiatrists in the current study as a tool that enabled professionals who were differentially located within the institution of healthcare to communicate and coordinate with one another. [McPherson and Armstrong \(2006\)](#) similarly discussed the importance of communication in their study about diagnostic labels for depression:

To a great extent, the integrity of psychiatry as a medical specialty depends on the consistency of diagnostic labeling. Without consistency there would be difficult

communication within the professional community, as meetings, correspondence, textbooks and journals would use conflicting language. Psychiatry therefore needs a certain level of diagnostic stability for its very survival. (p. 57)

Interestingly, in this quotation, there is a significant concern with the consistency of meaning attributed to diagnostic language, which is argued to support (or potentially weaken) the credibility of the discipline. In contrast, the psychiatrists in the study described here emphasized the importance of speaking a similar language in relation to the increased efficiency of their everyday conversations with other healthcare professionals. Thus, they found that the value of a common language primarily related to their daily work rather than broader concerns about the legitimacy of the discipline.

Potential Dangers of Producing a Standardized Story

Shifting an individual's complex and unique experience into a standard story is full of complications. In his classic paper on medicalization [Zola \(1972\)](#) warned: "medicine is becoming a major institution of social control, nudging aside, if not incorporating, the more traditional institutions of religion and law" (p. 487). Medical professionals hold a great deal of authority in Western culture, not the least of which is because they can grant or deny access to healthcare resources. It is, therefore, of the utmost importance to study how power operates within psychiatry. A number of scholars have done excellent work in this area, including [Kirk and Kutchins \(1992\)](#) who brought attention to the various political and economic interests that were at play during the construction of the biomedically inspired classification system in the DSM-III.

Although the central argument in this chapter is focused on the benefits of diagnosis, examples of the problematic aspects of diagnosis were also shared by psychiatrists. Karen was particularly concerned about certain institutional practices in relation to patient privacy. In speaking about this issue, she noted that the knowledge of where the final report would be filed could influence how she wrote that report:

Sometimes I have a (pause) really, really detailed history and I really don't think that all this stuff needs to go to the family doctor and be present in a different place. Also, at times, I will just do quite a brief letter for the family doctor and just give diagnosis and prognosis – like how well the person is going to do in my opinion and the current treatment and not go into huge details about the person's personal history, if they've, you know, had a major legal history or a lot of abuse or something that I think doesn't need to be in more places than it has to be.

Judy mentioned a related concern, but with specific reference to electronic hospital records because she felt that “almost anyone” in the healthcare field could access a computer-based system. Concerns about these specific institutional practices meant that psychiatrists significantly altered the textual versions of their standardized diagnostic stories. As a result, even more of an individual’s unique story may be lost to the generalized diagnostic work process.

Thus, there is a difficult, and perhaps blurry, line between an experience being generalized enough to be taken up by the institution, and being too generalized as to lose any sense of the uniqueness of that individual. Moreover, as so many critical feminist and race scholars have pointed out, the ability to access healthcare resources is often restricted by institutional sexism, racism, classism, heterosexism, and so forth, which are deeply embedded in Western institutional practices (for example of such analyses see *Boston Women’s Health Book Collective, 1973; Ehrenreich & English, 1978; Epstein, 2007*). To be clear, I do not advocate a noncritical acceptance of all institutional processes. Quite the contrary, I support analyses that challenge and politicize the practices of the healthcare system. However, even if specific institutional practices are illegitimate or morally unacceptable, it does not logically follow that standardized diagnostic stories are inherently problematic. Rather, standardization can continue to be valuable in the administration of healthcare resources while, at the same time, specific practices may need to be critiqued.

CONCLUSION

The generalizing and generalized process of diagnosis goes to work for psychiatrists in several important ways. By mapping the complex sequences of action and text that occurred during psychiatric diagnostic decision-making it became clear how an individual’s experiences of distress were brought into extended social relations with psychiatrists, other healthcare professionals, and institutional discourses more generally. Although each instance of psychiatric decision-making is a unique, embodied process that occurs in specific local contexts, the psychiatrists in the current study were constantly orienting to common work practices, including specific circuits of accountability and speaking a similar language. This generalized work process was illustrated in the analytic map presented in *Fig. 1*.

This visual map of “diagnosis” points to the value of producing a standardized diagnostic story, which can act as a discursive entity that

facilitates the designation of an individual's unique experiences as institutionally actionable. Thus, diagnosis is a social practice that has become an important component of the healthcare system because it enables individuals to receive institutional support. Perhaps this is one possible answer to Pilgrim's (2007) question about why psychiatric diagnosis has survived after weathering "nearly a century of criticism" (p. 536). Pointing to the value of diagnosis in relation to the logic of large institutions does not preclude the possibility that institutional practices may also be problematic. As critically engaged scholars, it is always important to ask questions about how power and privilege operate within the healthcare system, and whether certain institutional practices are morally acceptable. Yet, the analysis presented in this chapter also suggests that it is equally important to understand how producing a standardized diagnostic story can benefit psychiatrists in their daily work, and is valuable to patients in terms of potentially enabling them to access critical healthcare resources.

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PART III
CONTESTATION

“DSD IS A PERFECTLY FINE TERM”: REASSERTING MEDICAL AUTHORITY THROUGH A SHIFT IN INTERSEX TERMINOLOGY

Georgiann Davis

ABSTRACT

Purpose – Intersexuality is examined from a sociology of diagnosis frame to show how the diagnostic process is connected to other social constructions, offer new support that medical professionals define illness in ways that sometimes carries negative consequences, and illustrate how the medical profession holds on to authority in the face of patient activism.

Methodology/approach – Data collection occurred over a two-year period (October 2008 to August 2010). Sixty-two in-depth interviews were conducted with individuals connected to the intersex community including adults with intersexuality, parents, medical professionals, and intersex activists.

Findings – Medical professionals rely on essentialist understandings of gender to justify the medicalization of intersexuality, which they currently are doing through a nomenclature shift away from intersex terminology in favor of disorders of sex development (DSD) language. This shift allows medical professionals to reassert their authority and reclaim jurisdiction

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over intersexuality in light of intersex activism that was successfully framing intersexuality as a social rather than biological problem.

Practical implications – *This chapter encourages critical thought and action from activists and medical professionals about shifts in intersex medical management.*

Social implications – *Intersexuality might be experienced in less stigmatizing ways by those personally impacted.*

Originality/value – *The value of this research is that it connects the sociology of diagnosis literature with gender scholarship. Additional value comes from the data, which were collected after the 2006 nomenclature shift.*

Keywords: Medical authority; diagnostic terminology; intersexuality; disorders of sex development (DSD); intersex rights movement

It has been argued that scientific knowledge, diagnoses, and illnesses are socially constructed (Brown, 1995, 1990; Conrad, 1992; Conrad & Schneider, 1980; Cooksey & Brown, 1998; Mayes & Horwitz, 2005). And, as with all things socially constructed, the outcomes of such classifications play out in unequal ways that advantage a dominant group at the expense of marginalized others regardless of the condition in question. However, not all diagnoses are widely accepted by patients, and in the case of pediatrics, their families. Yet, given the medical profession's authority over bodies and the power to name and define disease, illness, symptoms, etc., diagnostic labels continue to be imposed on individuals that demonstrate a physical or social condition that violates what is socially acceptable (Conrad & Schneider, 1980; De Swaan, 1989; Dreger, 1998b; Fausto-Sterling, 1996; Freidson, 1972; Karkazis, 2008; Kessler, 1998; Lorber & Moore, 2002; Preves, 2003; Zola, 1972, 1986).

Intersexuality is such an example and a unique entry point into the study of the sociology of diagnosis. Although intersexuality has long been present in society, it was not until technological advancements in the 1950s and 1960s that the medical profession created intersex terminology and implemented medical treatment. Even though the diagnosis carried with it a surgical medical response, the intersex diagnosis was often kept from patients whose internal and/or external genitalia didn't match their sex chromosomes at birth (Fausto-Sterling, 1996; Hird, 2000; Karkazis, 2008; Kessler 1998, 1990; Preves, 2003). By the 1990s, the medicalized treatment of

intersexuality was heavily critiqued by intersex activists upset that they had been lied to about their medical condition, surgically modified in ways that left them with diminished sexual desire, minimal ability to reach sexual pleasure, and in some cases, an increased likelihood of incontinence (Fausto-Sterling, 1996; Hird, 2000; Karkazis, 2008; Kessler, 1998, 1990; Preves, 2003). Intersex activists responded by protesting outside of pediatric medical association meetings accusing doctors of pediatric “mutilation.” While their confrontational strategies were initially ignored by the medical profession, by the year 2000, the American Academy of Pediatrics (AAP) acknowledged that their historical treatment of intersexuality left their profession in a state of “social emergency” (Committee, 2000, p. 138). On paper at least, they critiqued the immediate surgical modification of intersex genitalia, and new treatment guidelines were even proposed (Blizzard, 2002; Chase, 1998a, 1998b, 1998c; Committee, 2000; Karkazis, 2008; see also Lee, Houk, & Ahmed, 2006; Preves, 2003, 2002, 2000). Most recently, in 2006, the medical profession has responded with a reinvention of diagnostic terminology where intersex language altogether has been done away with in favor of disorders of sex development (DSD) terminology (Lee et al., 2006).

The purpose of examining intersexuality from a sociology of diagnosis frame in this chapter is threefold. First, this chapter shows how the diagnostic process is connected to other social constructions, specifically the idea that sex and gender are neat interrelated binaries. This reveals the importance of studying the social construction of diagnosis, illness, and disease in the context of a society’s other social constructions. Second, it offers new support that medical professionals are able to define illness in ways that sometimes carries negative consequences. The third, and central, purpose of this chapter is to illustrate one way the medical profession holds on to its authority in the face of quite substantial patient activism. In this case, a nomenclature shift allowed the medical profession to frame intersexuality as a condition that could only be dealt with scientifically and thus surgically.

This chapter begins with a review of the processes by which medical professionals have come to name diseases, and the consequences such labeling has been shown to have on labeled patients. I then turn to a brief discussion of the history of intersex medical treatment that went from what has been labeled an “age of gonads” to the “age of conversion” (Dreger, 1998b; Fausto-Sterling, 2000a). I focus specifically on how “intersex” has been constructed, and responded to, differently throughout history. I then document how feminist critiques of such process, which rested on raising awareness of the social construction of sex and gender, helped fuel intersex activism and the birth of the intersex rights movement (Dreger, 1998b;

Fausto-Sterling, 1993; Kessler, 1998). With legitimacy gained from feminist scholarship, intersex activists were able to close in on medical authority. Drawing on 62 in-depth interviews with medical professionals that are experts on intersex conditions, the parents of intersex children, and those with intersex conditions themselves, I argue in the context of a challenge to medical authority, the nomenclature has once again shifted. This time the shift has been from intersexuality to disorders of sex development in order for medical professionals to reinforce medical jurisdiction. Until such renaming, the medicalization of intersexuality was successfully being contested by intersex activists who were framing intersexuality as a social rather than biological problem, and in the process, were also closing in on medical territory.

NAMING DISEASE

A medical condition is only as real as its definition. Until the medical profession acknowledges and classifies a particular symptom or condition of the body as abnormal, it does not officially exist (Blaxter, 1978; Conrad, 2007; Scott, 1990). The process by which this acknowledgment and classification occurs is a complicated one. The incorporation of diagnostic terminology into Western medicine is relatively new. According to Veith (1981), ancient Greek medicine existed without specific diagnoses. In lieu of nosology, descriptions of disease were used until 18th century medical professionals turned to a botanical model of classification that linguistically identified, labeled, classified, and named a wide range of medical conditions (Fischer-Homberge, 1970; Foucault, 1975; Sydenham, 1742). As Jutel (2009) demonstrates in her review of the sociology of diagnosis literature, not all medical professionals were in agreement on this move toward naming (Broussais, 1828), yet this “classificatory project” prevailed which resulted in “medicine shift[ing] its focus from individual symptoms to groups and patterns of symptoms that doctors could reliably recognise” (Jutel, 2009, pp. 280–281). Of course, the process by which medical professionals are able to name conditions is dependent upon a particular time and space and conditional upon technological advancements.

In the 1950s and 1960s, technological advancements in the medical profession led to the discovery that “normally” bodied males were distinguishable from females by their sex chromosomes, XY for males and XX for females. Here, “normally” bodied refers to the cultural assumption of a binary sex. Intersexuality is a direct challenge to this cultural assumption

because it is a condition where one's physical body doesn't neatly match his or her sex chromosomes at birth (Fausto-Sterling, 1993; Karkazis, 2008; Preves, 2003). Although it is true that intersexuality can result in outwardly obvious ambiguous genitalia, it is also true that many intersex conditions are not noticeable through external examination. For instance, people with androgen insensitivity syndrome (AIS) are "chromosomally and gonadally male (i.e., XY with testicles), but lack a key androgen receptor that facilitates the ability, fetally and onward, to respond to androgens (male hormones) produced in normal amounts by the testes" (Preves, 2003, pp. 27–28). Depending upon how much androgen the receptor blocks, some AIS individuals have ambiguous external genitalia (usually a larger clitoris that resembles a small penis) with either internal or external testes, while others have an outwardly "normal" looking vagina with a shortened vaginal canal and internal undescended testes. Therefore, before the discovery of sex chromosomes, many individuals with intersex conditions, such as those with complete AIS, were misdiagnosed as "normally" bodied females who, for some unexplainable reason, were infertile as evident by persistent amenorrhea. Today, however, these same individuals are viewed by the medical profession as "abnormal" XY females.

The consequence of naming medical conditions is that it can have severe implications for those being labeled. Consider, for example, Goffman's classical work on asylums first published in 1961. Those labeled mentally ill by the medical profession were forced to adopt an identity believed to be consistent with such diagnosis. When diagnosis and identity merge, there is little room for a reconsideration of a diagnosis. Merger makes it difficult for those diagnosed with a mental disorder to escape their label even when the symptoms that initially brought about the diagnosis disappear (Rosenhan, 1973). Those diagnosed with post-traumatic stress disorder (PTSD) and those medically labeled alcoholic face a similar scenario (Blaxter, 1978; Scott, 1990). In both instances, the application of the label imposes an identity that is believed to coincide with the diagnosis, whether or not the diagnosis is specified (Blaxter, 1978; Scott, 1990). Diagnoses sometimes even lead to retrospective reinterpretations of identity (Cooksey & Brown, 1998, p. 527).

INVENTING SEX

Brown (1990) maintains diagnoses involve two components: "diagnostic technique" and "diagnostic work." Diagnostic technique "involves

formalization of classification, including the specific tasks, techniques, interviews, and chart recording necessary to make the formalized classification,” whereas diagnostic work “consists of the process by which clinicians concretely proceed with their evaluation and therapeutic tasks” (Brown, 1990, p. 395). We can better understand the medical invention of sex, and ultimately the intersex diagnosis, when we dissect it into “technique” and “work.” As noted in the previous section, before the medical discovery of sex chromosomes, the recognition of intersexuality was not as widespread as it is today. This development led to a medical justification for the formal classification, and ultimately naming, of intersexuality (“technique”). Once intersexuality was named and widely accepted by medical professionals, diagnostic “work” was justified regardless of how problematic it was viewed by those outside the medical profession.

While intersexuality was being named by medical professionals (the “technique”), the medical profession was experiencing substantial surgical advancements, as evident by their performance of gender conformation surgeries (i.e., sex reassignment surgeries) on trans individuals. This advancement positioned the medical profession to similarly respond to the intersex diagnosis through surgical intervention, which we can think of as the “work.” This shift in diagnostic work was so significant that feminist scholars have labeled it a shift from an “age of gonads” to an “age of conversion.” During the “age of gonads,” lawyers and judges, in consultation with “doctors or priests,” were the “primary arbiters of intersex status,” given “their own understanding of sexual difference.” The “age of conversion” is characterized by medical professionals who “found it imperative to catch mixed-sex people at birth and convert them, by any means necessary to either male or female” (Dreger, 1998b; Fausto-Sterling, 2000a, p. 40).

The trajectory of intersex medicalization supports Conrad and Schneider’s (1980) five-stage model of medicalized deviance. Intersexuality was viewed as an unfavorable deviation from the sex binary (stage one). Then, with medical advancements, doctors had the tools to identify and describe intersexuality chromosomally (stage two). Soon after, medical professionals started claiming intersex expertise (stage three). What marks the fourth stage in Conrad and Schneider’s (1980) model is a battle over diagnoses (Brown, 1995). The medical profession faced a substantial amount of resistance in this stage from feminist scholars and eventually intersex activists determined to stop, albeit unsuccessfully, the fifth and final stage where the condition in question becomes a legally recognized “abnormality.”

FEMINIST CRITIQUES

As medical professionals claimed legitimacy over intersexuality, feminists argued medical professionals were using their newly invented tools to surgically “shoehorn” individuals who deviated from the sex binary system to fit into a male or female body (Dreger, 1998a, 1998b; see also Fausto-Sterling, 1993, p. 24, 2000a; Hird, 2000; Karkazis, 2008; Kessler 1990, 1998; Preves, 2000, 2003). In 1993, Fausto-Sterling argued if medical professionals must organize bodies into sex labels, they ought to move beyond male and female and include true hermaphrodites (the “herms”), male pseudohermaphrodites (the “merms”), and female pseudohermaphrodites (the “ferms”).¹ By arguing for the recognition of five sexes, Fausto-Sterling attempted to challenge medical professionals to recognize the sex binary system that they were perpetuating, subconsciously or not. In 1998, Kessler critiqued Fausto-Sterling’s “The Five Sexes” by maintaining that individuals with intersex conditions should be thought of as evidence of sex “variability” rather than sex “ambiguity.” According to Kessler (1998), it is neither possible nor logical to maintain the sex system when recognizing the existence of multidimensional sex variability. By categorizing individuals with intersex conditions by sex, one is perpetuating the validity of the categorization system (Kessler, 1998). In 2000, Fausto-Sterling accepted Kessler’s critique. Specifically she stated, “It would be better for intersexuals and their supporters to turn everyone’s focus away from genitals” (Fausto-Sterling, 2000b, p. 22).

Debates around naming, defining, and treating diagnoses are not unusual (Brown, 1995; Conrad, 2007; Cooksey & Brown, 1998). For example, consider attention deficit hyperactivity disorder (ADHD). Conrad (2007) argues that while the ADHD diagnosis expanded in the 1990s to include adults, it had its critics. The Church of Scientology, for instance, publicly critiqued the ADHD diagnosis (Conrad, 2007). Some therapists were also concerned that the ADHD diagnosis was “becoming too prevalent” (Conrad, 2007, p. 60). Disputes on the *Diagnostic and Statistical Manual of Mental Disorders* (DSM) are another example. While the DSM is embraced by psychiatrists, “criticism of the DSM comes from social workers, psychologists, and others for whom it does not foster professional dominance” (Cooksey & Brown, 1998, p. 549).

Professional dominance also plays out in other ways, notably medical authority and uncontested patient compliance (Conrad & Schneider, 1980; Zola, 1972, 1986). Dreger (1998a), for example, published a provocative essay

(“Ambiguous Sex or Ambivalent Medicine?”) that accused the profession of perpetuating the “monster approach” by performing sex assignment surgeries on the infants of uninformed parents (Dreger, 1998a, p. 33). While surgeons obtained legal parental authorization, Dreger (1998a) questioned the validity of parental consent. She argued that parents of children with intersex conditions, like many in our society, are uninformed about sex variability and consequently follow medical recommendations without hesitation.

Feminist critiques of the medical profession’s treatment of intersex conditions (Dreger, 1998a; Fausto-Sterling, 1993; Kessler, 1990, 1998) helped to organize and challenge the practices of intersex health care and the formation, development, and progression of the intersex rights movement. In true “reflexive” fashion (Giddens, 1990), feminist writers helped to spark an intersex rights movement by providing an analytic ground for intersex activists to challenge the medical profession and their essentialism. For example, in 1993, Cheryl Chase, known worldwide as the founder of the intersex rights movement, formed the Intersex Society of North America (ISNA) as a way to gain credibility in a response she constructed to Fausto-Sterling’s publication, “The Five Sexes.” The result was many intersexed individuals contacted Chase inquiring about membership with ISNA. Not long after, intersex activists were outside protesting at pediatric medical association meetings in order to raise awareness about the surgical, and in most cases unnecessary, modification of intersex genitalia (Chase, 1998a, 1998b, 1998c; Karkazis 2008; Preves, 2003).

By the year 2000, Chase was delivering a plenary address to the Lawson Wilkins Pediatric Endocrine Society, a group she was once protesting against. This successful activist encroachment into medical turf was highly unusual for two overlapping reasons. It marked the first time an activist’s perspective was solicited by organizers of a major medical conference (Karkazis, 2008). And, it was “the first time that the society’s annual symposium was devoted to intersexuality” (Karkazis, 2008, p. 257). One of the consequences of this challenge seems to be a nosological change, from intersex in the 1990s to DSD in 2006. I argue this shift was a reaction to activist challenges to medical jurisdiction over intersexuality, and doctors’ insistence on the DSD terminology was a reassertion of their medical authority.

METHODS

To explore the nomenclature shift from intersex to DSD, I rely on an extensive qualitative dataset that includes 300 hours of informal observations

in the public meeting spaces of intersex organizational meetings and 62 in-depth interviews with intersex activists, parents of intersex children, and medical professionals that are experts on such conditions. Data collection occurred from October of 2008 to August of 2010. As a feminist sociologist with an intersex condition, I began this project from a unique standpoint having lived my life impacted by intersexuality. At the onset of data collection, my training in feminist and gender scholarship also contributed to my conceptualization of gender as a stratification system far beyond individual characteristics. It is known, for instance, that feminists have long argued that gender is understood as not only residing in individuals but also at the interactional and institutional levels of society (Connell, 1987; Ferree, Hess, & Lorber, 1998; Lorber, 1994; Martin, 2004; Risman, 2004).

Participant Recruitment

Informants were initially recruited from four organizations: the Intersex Society of North America (ISNA),² Accord Alliance, the Androgen Insensitivity Syndrome Support Group-USA (AISSG-USA), and Organisation Intersex International (OII). Participants were targeted from these organizations because, based on my assessment of their websites, each organization appears to be involved in the intersex rights movement in different ways. For instance, ISNA and OII are activist organizations, while AISSG-USA is a support group and Accord Alliance is an organization that seeks to distribute educational resources to medical professionals. Snowball sampling was also employed by asking initial informants to name others who may share different views from their own (Biernacki & Waldorf, 1981). To protect confidentiality, all nonmedical professional informants were asked at the start of the interview to choose their own personal pseudonym that would be used in any presentations or writings produced from the project. In some instances, informants elected to use their given first name, and accordingly, such request was honored. Medical professionals were assigned a random letter from the alphabet beginning with "A."³ Since there are so few medical professionals in the United States that are experts on intersex conditions, only very limited demographic information is presented here. And, the demographic information that is presented is presented at my discretion to protect confidentiality. Informed consent was obtained at the start of every interview before the recording device was turned on. All interviews were transcribed and coded using ATLAS.ti, and after such, all audio files were deleted and destroyed.

Over 100 hours of interview data were collected with each interview ranging from 25 minutes to well over 3 hours. Interviews were conducted face-to-face in order to gain informants trust and establish a level of comfort only possible in person. All informants were able to choose the interview location which ranged from public spaces such as coffee houses and bagel shops to a person's office, home, or place of work. A total of 62 individuals including 36 adults with intersex conditions, 14 parents of children with such conditions, 9 medical professionals that proclaim to be experts on intersex conditions including surgeons, urologists, endocrinologists, and mental health professionals,⁴ 2 social movement organizational board members that weren't medical professionals nor had an intersex condition, and 1 medical professional that also identified as intersexed were interviewed.

FINDINGS

White Coat Gender Essentialists

Most medical professionals I spoke with held essentialist understandings of gender that were neatly tied to stereotypical western, white, and middle class expectations of femininity and masculinity. Given gender assignment is recommended by medical professionals for all intersex infants, I asked Dr. D., a well-respected endocrinologist, if there were instances when gender was incorrectly assigned. She passionately shared:

Yes. When an individual who's been raised as a female gender assignment, comes to the office having totally cut off all her hair, wearing army combat boots and fatigues ... it sounds very stereotypical, but it really happens ... wearing combat boots and fatigues, saying, "Oh God, I hate having periods, it doesn't make any sense for my life, I don't like this." Or they threaten to commit suicide or they're institutionalized with substance abuse, and part of what comes out of their therapy through that substance abuse is that they don't know who they are or they think they weren't assigned to the way they feel now. And those are not always permanent, by the way ... one of my fatigue-wearing persons came in a couple weeks later, wearing a miniskirt, make-up, and having dyed her hair.

Although Dr. D. seems to acknowledge that gender is, or at least can be, fluid by acknowledging an individual may present themselves stereotypically male one day and female the next, like other medical professionals that treat intersex conditions, she still holds on to essentialist understandings of gender. She went on to explain:

My experience with girls with [congenital adrenal hyperplasia] suggests to me that it's pretty hard-wired. A lot of the CAH girls are significant tomboys ... hey I was a tomboy,

it's not a slap, it's a description. They're more of a risk taker, like at age 5 or 6, they'll leap off the porch because they think they can fly kind of things. They wanna take their skateboard and turn it into a hang-glider and take off from a cliff ... Whether it's only with DSDs, or whether it's in folks where you couldn't find a DSD with a microscope, I think some of those behaviors are absolutely hard-wired.

As with many of the medical professionals I spoke with, what distinguishes feminine from masculine behaviors for Dr. D. are very narrowly defined types of risk-taking activities tied to potentially dangerous actions.

Explanations for gendered behaviors were grounded in hormonal exposure during gestation.

Without hesitation, endocrinologist Dr. A. shared:

I think there's no question, again, based upon the [congenital adrenal hyperplasia] experience, or the experience of kids who are exposed to androgens externally during pregnancy, that there's very good reason to believe, and there's probably experimental data about this, to suggest that androgen levels during fetal development produce male-typical behavior later on, there's just no question about that.

Consistent with a binary logic that suggests sex, gender, and sexuality are all neatly correlated, most doctors used each interchangeably in justifying their essentialist gender views. When I asked Dr. A. if he could clarify what he meant by "male-typical behavior" he elaborated with a discussion of sexuality:

Like in primates, where they've used high levels of androgens during fetal development in chromosomally female fetuses, those female monkeys are engaged in humping behaviors and things like that, which are much more typical of what male primates do as immature, and later sexually mature individuals ... how they engage in intercourse.

Here "humping behaviors" are associated with ideologies about males, specifically that they are naturally more sexually aggressive.

When I asked medical professionals to offer possible explanations for gender variation given their strong beliefs that gender was biologically determined, they commonly cited poor parenting. Dr. B.'s response to "gender deviants" was fairly typical of the medical professionals I spoke with. She shared:

I have worked with kids who've decided to kind of move forward in an opposite gender than the one that they were originally assigned to. But the cases that I've work with where that happened, were predominantly very poorly controlled kids with congenital adrenal hyperplasia, who were very masculinized by the time. I worked with one young boy, adolescent male, who was really a genetic female had been born in another country, very poorly controlled, very masculine.

Refusing to acknowledge gender variation across and within a given intersex condition, medical professionals are able to hold on to their essentialist understandings of gender. However, this places a tremendous amount of accountability on parents to police their child's gender in stereotypical ways.

Although rare, a few medical professionals did express some criticism of essentialist understandings of gender and also acknowledged that parents of intersex children were especially pressured to police gender. Dr. E. shared:

I think parents are really pressured ... from doctors. Yeah, because part of the outcome was that [intersex kids are] supposed to adopt that gender role. I was talking today about a client whose mother wouldn't let her wear tomboy clothes, wouldn't let her join the girls' softball team 'cause these were activities of men ...

Dr. E. expressed real concern for intersex children. And, as a parent herself, she also understood parents desire to raise "normal" children. However, she did her best to help parents understand one's gendered behaviors are not correlated with sexuality. Dr. E. explained:

When I talk with parents, for whom this is an issue ... it's a somewhat easier issue now, because 20 or 30 years ago, the beliefs about what gender roles/stereotypes were, were a lot stricter than they are now, most parents now don't have trouble with their girls or daughters being athletes ... but I really try to normalize that for them. There are lots of feminine, heterosexual adult women who were tomboys when they were little girls; this is not an ominous sign.

While Dr. E. still frames a queer lifestyle as less desirable than a heterosexual lifestyle, it is likely a political strategy rather than a value judgment. As a lesbian medical professional, Dr. E. understood the heterosexism involved in the treatment of intersex children. She shared:

I think homophobia is always under this. Absolutely, in the medical community ... and for a lot of parents there's a big anxiety ... they don't know who they're supposed to marry or have sex with ... That feels rough on some parts of me.

She was critical of such, but yet bit her tongue in order to push an agenda that allowed children to express their gender in ways they see fit. Since children aren't socially viewed as sexual beings, this approach made the most sense to her.

I did ask Dr. E. if she thought gender was biologically predetermined. Unlike other medical professionals I spoke with, her response was grounded in feminist scholarship:

Well here I'm gonna probably diverge from any biological explanations for this, cause I don't know if you've read any of Anne Fausto-Sterling's stuff ... she's very convincing to

me ... gender, sexual orientation, hormones, phenotype ... I think has to do with the way nature works, and nature loves variety ... maybe there's some way testosterone tends to make people act more boyish. But I think it's the way we then interpret that boyishness.

Although she didn't rely on feminist scholarship as did Dr. E. to critique sex, gender, and sexuality binaries, Dr. F. was still critical of binary logic. She shared:

So we still have this dichotomous society that thinks in black and white, male and female, and there's nothing ... you can't be anything but one or the other. It's some of these social constructs that seem to exist in the United States that maybe don't exist in other countries ...

While Dr. F. problematized binary views, she was also pessimistic when asked about the possibility for change citing moving beyond binaries would be "almost a dream of utopia, to think about our society even getting to that point" because "urologists would have less work, so there would probably be some ... you know ..."

The surgical modification of intersex genitalia is an incredibly lucrative practice for urologists because the surgeries are imperfect and often require revisions and modifications, or more directly, reoccurring visits to a costly operating room. Urologists, however, had very different justifications for modifying intersex genitalia. Dr. G. shared:

Some of the babies are born where the base of the penis is really where they're urinating from. If the baby is going to be raised as a girl, that's an okay place. But if they're gonna be raised as a boy, then it may be that they're really needing to create the urethra tube and have the urine come out of the penis' tip. Some of the surgeries that are done on older children, you really get terrible outcomes.

Dr. F. would disagree with Dr. G.'s assessment of outcomes. She shared with me:

Why do they have to be able to urinate standing up? What's wrong with sitting down? Women sit down to urinate, so why can't a boy sit down to urinate? There's nothing physically wrong with sitting down to urinate. The stigmatization of social differences like sitting down to urinate as opposed to standing up, and boys and girls seeing their physical parts in locker rooms ...

Medical professionals like Dr. E. and Dr. F. are rare in the medical world of intersexuality. Of the ten intersex experts I spoke with, there were only three doctors – Dr. E., Dr. F., and Dr. H. – that were openly critica of the binary sex, gender, and sexuality logic. It was, in fact, only after intensive purposive recruitment strategies that I was able to find medical professionals that deviated from the norm. Dr. H. is extra unique because he has been on

both sides of medical management. He treats individuals with intersexuality, and he has an intersex condition himself which resulted in numerous genital surgeries. Dr. E., Dr. F., and Dr. H. often face resistance from other medical professionals given the views that they hold question the status quo.

The majority of intersex experts are gender essentialists. They rely on stereotypical understandings of gender to make sense of intersexuality, and in the process tend to conflate sex, gender, and sexuality. While there was some deviation from this pattern as highlighted above, the deviation was likely the result of being influenced by feminist scholarship, as clearly the case with Dr. E. This isn't to say that the majority of intersex experts were never exposed to feminist scholarship, rather it's to say that they just weren't influenced by the theoretical arguments presented. In fact, one medical professional even jokingly shared with me that she thinks "feminist scholarship is great for a rage filled feminist agenda ... in medical practice, not so much."

When Gender Essentialists Create Diagnostic Terminology

Medical professionals rely on their gender essentialist views to justify the medicalization of intersexuality, and more specifically, the validity of the *disorder* of sex development diagnosis itself. Fundamental to a gender essentialist view is that gender is and should be neatly correlated with sex, and sexuality, and each is binary. If one deviates from the pattern, modification is needed in order for normalcy to be achieved. Medical professionals I spoke with believe intersexuality is often a visible abnormality of the body that warrants and justifies treatment. When I asked Dr. D. if a person with a DSD was recognizable in a crowd of people, her response surprised me:

Some of them, yes. Because some have some very specific phenotypic features ... it's as if you're trained to look for them. [Georgiann asks: And what are some of these big, obvious characteristics?] Okay, well Turner Syndrome. So there are phenotypic features of women with Turner Syndrome. And if you know what you're looking for ... Short stature, droopy eyes, very prominent ears, a webbed neck, there are characteristic features of the fingers, and Klinefelter's Syndrome, not always, but some of the forms of where folks are just gonadal, they have long, thin body proportions with big, long arms, and a high-pitched voice, and not much facial hair or facial musculature or shoulder musculature, you can sort of go, "That person looks like they might have a DSD."

Given this view, it's no wonder that many of the individuals with intersex conditions I interviewed expressed genuine concern that their diagnosis was outwardly obvious in public settings. The assumption that intersexuality is

visible is grounded in medical professionals' over belief in gender essentialism. For example, Dr. E., the progressive medical professional cited earlier, had a very different view than Dr. D. on this visibility issue. When I asked Dr. E. whether or not an individual with an intersex diagnosis was easily recognizable in a room full of people, she did not go to physical descriptions of the body that are alleged markers of sex. Rather, Dr. E. went to gender. She quickly replied to my visibility question, "No! [laughing] ... In my experience, intersex people are so raised to conform to a gender role that they do."

With strong gender essentialist views, medical professionals have the justification they need to rely on medical testing to reach a definitive gender assignment. As the following quote illustrates, medical professionals do so within a biomedical paradigm as evident by only a peripheral involvement of psychiatrists in the gender assignment process. Dr. C. shared:

We do all the biochemical information ... we do all the morphometrics, radiologic assessment, and then we sit down – the endocrinologist, myself, sometimes a general surgeon – really, surprisingly, within our setting, very rarely, a psychiatrist. And we'll discuss primarily – in all discussions that I've had input into – who the child thinks they're going to be later. Which seems to be a fairly simple thing, which is did the child have significant testosterone exposure, [inaudible] testosterone receptors in utero? And then once that's been established, discuss the issues such as fertility and functional success of surgery.

Framed through a biomedical paradigm (Foucault, 1980), the validity of the recommended gender assignment is left unchallenged which then rationalizes surgical intervention.

Fertility was almost always discussed as the single most important determinant of gender assignment. Dr. F. articulated this quite nicely. When I asked her to describe the processes involved with assigning a gender for those born with externally ambiguous genitalia, she explained:

Basically the outward appearance. To some extent, what structures the child has internally as well, can affect that ... [Georgiann asks, What do you mean by structures?] Well, like a uterus for example. If a child does have part of a uterus, that can be a guide ... Physicians tend to go toward the female sex of rearing, because that has the potential for carrying a child. This is kind of the *holy grail* of being able to bear a child and carry a pregnancy. So that does tend to drive sex rearing towards female, if there's a uterus present.

Critical of the medical profession's early approach to surgery, Dr. F. went on to share:

But what I would hope in this circumstance, is that they actually *don't* do surgery, is that they just leave this child as is at least until sometime later in the child's life when it's clear what this child's gender identity appears to be.

Although she remains critical of such approach, Dr. F. is unable to entirely escape hegemonic ideologies about gender. I asked her if a child's gender identity can ever be "clear" given her own view, expressed in the previous section, that gender is a "social construct." She explained:

I think there's ... yes, but I think there's plasticity in that, I think it's malleable. I think we're endowed with this certain level of masculinity or femininity at birth, due to whatever prenatal influences we're exposed to, but I think there can be post-natal influences that may modify that, whether they're hormonal influences, or whether they're external, environmental influences. I'm not entirely sure how environmental influences would change that, I think it's probably more biological than sociological, from my perspective. But I do think there are probably cases where it's malleable. And transgender individuals are kind of those examples, which are not part of this discussion.

As we can see with Dr. F., even the most progressive intersex experts are unable to entirely move beyond essentialist understandings of gender.

Medical professional's essentialist assumption that there is a rigid correlation between sex, gender, and sexuality resonates with the nomenclature shift from intersex to the pathologizing *disorder* of sex development. Dr. G. was one of many that held this view which explains her position on the diagnostic terminology:

I think it's so helpful to have such a broad category. So "disorders of sex development," that's a pretty broad category, and it doesn't imply judgment, it doesn't imply that one's more severe than another, because underneath that umbrella are many many different diagnoses. So I think parents, if they're being seen by the "disorders of sex development" clinic, they start appreciating that all of this has to do with how our sex develops, and how and that there is genetic and hormonal factors. We often use the analogy of ... there are many different types of heart defects. Well our bodies are complex how we're put together and there are many differences in body shapes and sizes, and there are differences in how genitals have grown and developed.

Medical professionals view gender as something that should function, and to function properly it must be in line with sex and sexuality. And, when gender doesn't neatly match sex, it's a sign they haven't correctly sexed the individual in question. The alternative feminist explanation centered on the social construction of sex, gender, and sexuality isn't even seriously entertained by most medical professionals. The problem with such approach is that medical professionals are in a position of authority to define and treat these social constructions how they see fit. However, in the case of intersexuality, their authority was challenged by a successful social movement in a relatively short amount of time. The result has been a

forceful push away from intersex terminology in favor of their new “DSD” language. Dr. C. explained:

First [are] the terms of the word “intersex.” Again, the word “sex” is highly emotionally charged, whether it’s your gender, whether it’s having sex, or anything else. And so moving away from a highly charged word like that which can mean a thousand different things to a thousand different people is what we should absolutely get away from right away ... and I think no one would disagree ... it’s amazing it took so long to get rid of the word “intersex.”

This nomenclature shift allows medical professionals to reassert their authority and reclaim jurisdiction on a condition that they once had exclusive control over.

AN ATTEMPT TO CHALLENGE MEDICAL AUTHORITY

From a social movement perspective, intersex activism was fairly successful in a relatively short amount of time by employing primarily confrontational mobilization strategies. For example, David, one of the earliest members of the movement, shared with me just how grassroots the movement was and the ways in which it targeted medical professionals:

I remember [Cheryl Chase, the founder of the movement] saying to me once in the car, will you help me create the Intersex Society of North America, will you help me you know, be this movement? And she was like, she would get people together to go to like pediatric conferences and protest outside them ... and she had this huge banner that said “Hermaphrodites with Attitude.”

When the intersex rights movement was first formed, medical professionals refused to engage intersex activists. Yet, activists remained committed to their goal of changing medical practices and treatments of intersexuality any way that they could. Cheryl Chase, the founder of the intersex rights movement who was herself lied to about her medical history shared: “Any movement that can’t get attention needs to do some attention-getting things, which we did.”

These attention-getting things involved everything from heated discussions to informal debates with medical professionals. Kimberly, an early activist, recounted one such confrontation:

So I did a talk a couple of years ago, and it was a group of nurses who worked with infants in ICU, the intensive care unit. Neonatal Nursing Conference ... I spoke to them twice. The second time, they had a guy come in. He was doing a study on how not

telling – it was a bunch of CAH women that were in the study – and he had all this proof about how not disclosing, doing the surgery, and this stuff was beneficial. We had this fight, like a literal ... [Georgiann asks, who was it a doctor?] ... It was a doctor, and I don't remember who he was. I'm kind of surprised it didn't come to blows, because I was ready to hit him. We just yelled at each other for like twenty minutes, it was terrible. I was completely unprofessional as was he.

Intersex activists were so incredibly angry because they felt violated and manipulated by medical professionals because they kept the diagnosis from their patients. Hannah recounts finding out about her condition in a college biology classroom:

I was doing a buccal smear in college ... when you swab the inside of the cheek ... And it came up 46 XY. And I'm like *what?* So I had to do some investigation and went to the teacher and asked about it, and she was kind of like "I'm not sure" and I don't know if she knew and was like "I'm not saying anything" or what, but I basically had to go research what I had. She was just like "well, write down your results whatever they are" kind of indifferent about it ... I knew I couldn't have children but I thought that I had some kind of hysterectomy when I was 13 because I was told that my ovaries were precancerous and they had to be removed. So I was always worried that the cancer was going to come back or something. Now I know I was worrying for nothing. But I went to the library in school and I found some books and that's where I found the term "testicular feminization" ... and I was like, oh my god, that's what I have.

Hannah's experience is not usual. Many medical professionals historically kept the intersex diagnosis from their patients, and sometimes parents, out of fear that the diagnosis would disrupt gender identity development.

In 1997, AAP refused to engage "zealous" intersex activists (Diamond, 1997; Fausto-Sterling, 2000a, 2000b). However, after several years of persistent intersex activism, AAP eventually invited intersex activists to deliver a presentation to their association where the activists questioned their morality, their ignorance, and their overall approach to intersexuality (Fausto-Sterling, 2000a, 2000b; Preves, 2003). Medical professionals even began to self-reflectively critique their historical treatment of intersexuality (Blizzard, 2002; Committee, 2000; Karkazis, 2008; see also Lee et al., 2006; Preves, 2000, 2002, 2003). In a *Gender & Society* article, Stephanie Turner (1999) even concluded that intersex activists managed to move beyond the sex binary and create a "third sex" by demanding, and arguably receiving, the respect and acknowledgment of medical professionals.

Shortly after activists were allowed into medical meetings, the medical profession instituted guidelines, with assistance from nonmedical folks, for diagnosing and treating intersexuality including, but not limited to, avoiding

the surgical modification of intersexual's either internal and/or external genitalia (Committee, 2000; Preves, 2000, 2002, 2003). The recommendations insisted that intersex infants "should be referred to as 'your baby' or 'your child' – not 'it,' 'he,' or 'she'" (Committee, 2000).⁵ They also noted parents should be informed that "abnormal appearance can be corrected and the child raised as a boy or a girl as appropriate." The guidelines stated that a number of factors should be considered when determining which sex category, or in their language "gender assignment," should be recommended for a given intersex child. Most notably, these factors included "fertility potential" and "capacity for normal sexual function."

The efforts of early intersex activists eventually brought about enough change that AAP issued their 2000 consensus statement that denounced keeping the intersex diagnosis from their patients and even began to reconsider their practices of immediate surgical intervention. In short, they acknowledged wrongdoing. Dr. D. recounts this quite nicely: "So the original folks who self-aggregated *hated* the medical community, or were very angry with them, not inappropriately, for the way that they had been treated." In the face of intersex activism, the medical profession's authority was successfully being challenged as were doctors' distinction as "expert." Dr. B. shared with me how their "expertise" was in jeopardy.

I feel like every parent we get now has got expertise. We've had people who get expertise and are convinced that their kid has a particular diagnosis, but that kid doesn't have that diagnosis it turns out, and we have to kind of do this let's go back to square one.

While many medical professionals across areas of expertise would likely face this challenge given technological advancements that place more and more medical information and knowledge on the internet, given intersex activism, such challenge to authority and expertise is heightened.

In 2006, only seven years after Turner (1999) documented the emergence of a "third sex," AAP revised their policy regarding the treatment of intersexual infants due to "progress in diagnosis, surgical techniques, understanding psychosocial issues, and recognizing and accepting the place of patient advocacy" (Lee et al., 2006). They offered a number of new recommendations in this policy revision including revisiting the language of "intersex," "pseudohermaphroditism," "hermaphroditism," and "sex reversal." The guidelines maintain "intersex disorders" should now be referred to as "disorders of sex development" or "DSDs" for short, yet throughout the document there is no real explanation for this terminology shift.

(RE)ASSERTING MEDICAL AUTHORITY

Intersex activism problematized the medical treatment of intersexuality, which challenged the authority of intersex experts, and ultimately their integrity. Dr. C. shared:

[A]nyone who ever heard the story, physicians, especially parents, and patients to be extremely suspicious of everything we do, and rightfully so. I mean, it was all coming out. Your integrity is the one thing that you work the longest to get and with just one slight fraction, results in total dismissal of integrity. And I'm trying to teach [my kids this] all day long, that authority is the one thing you have to guard like your jewels ... Now, it came under great suspicion, and I think that the only way to make it right is to make it now more clear.

Authority was made “more clear” by renaming intersexuality a “disorder of sex development” that wasn't as politicized as was intersexuality. I argue here this linguistic shift was advocated for in order to reclaim jurisdiction over intersexuality, a condition that intersex activists were successfully reframing as a social rather than biological problem.

The new DSD nomenclature prevented such reframing from going any further. By advocating for DSD language, doctors were able to draw comparisons to other diseases, including cancer. Dr. C. viewed DSD terminology as “an analogy. It's like talking about skin cancer and brain cancer.” Similarly, Dr. A. shared that “DSD is a somewhat more complete and accurate term ... DSD is a perfectly fine term, I now use it in my own work. I don't worry about it. Several of us wrote a paper about supporting that change [*laughs*].” While most doctors are in support of DSD terminology, many activists are not. Millarca, an intersex activist who has been involved in the movement for quite some time shared, “DSD is not ... is not something a lot of people want to identify with ... nobody wants to be a disorder ... who wants to be a fucking disorder.” Pigeon, a younger intersex activist echoed something similar but also critiqued the utility of the nomenclature shift. She shared with me that she prefers “hermaphrodite or intersex ... I feel like the language shift to DSD makes no sense to me ... I don't feel it was necessary.”

Medical authority over intersex conditions was also reasserted by advocating for and implementing medical management “teams” that would consist of various “experts” on intersex conditions. Such teams have been and continue to be viewed within the medical community as the best possible approach for treating intersexuality. Dr. A. shared:

I think it's pretty clear that the best care is care that includes people with expertise from endocrinology, from urology, from psychology & psychiatry, from ethics, etc. etc. There are only half a dozen places in the country that have them, if that.

In the face of challenged medical authority, medical professionals are able to reclaim and reassert their positions as experts by operating in teams. At the same time, they are able to minimize any potential liability for hormonally and/or surgically treating intersexuality. Dr. C.'s view summarizes such quite nicely:

We take solace in the fact that we're operating as a team, it's not generally blame, but the better way to look at that would be to say we're showing the families as clearly as possible just how much we're wrestling with the situation ourselves, and I think that's very important. ... We generally speak among all five pediatric urologists here as a group, telling the family we've had four second opinions without even needing anybody else here. But I think we take solace in that. I think it's a very important thing for the family to see, just how much we're wrestling with the choice ourselves.

The medical "team" then serves as a way for intersex experts to negotiate their authority given the tremendous amount of uncertainty around treating intersexuality. While the team frames themselves as knowledge providers rather than decision makers, parents I've spoken with see the team as the utmost authority on intersexuality, especially since it is made up of not one but several medical professionals.

Intersex medical management teams work together to decide on the best possible medical intervention, which actively rests on reaching a diagnosis and an attempt to discover a patient's true sex, albeit within a binary sex framework. Dr. I. detailed how this process works on her team. She shared:

Number one, the child is referred to as "baby" until we have a "boy" or "girl" status. Unfortunately, in the computer, they get assigned "boy" or "girl," because there's no just "baby." So the child is referred to as "baby." The family is aware that we are getting additional data. We have to wait for labs to come back, karyotypes to come back. We let the family know that there is not an emergency ... once you say there's no medical emergency here, then we say, let's get some more data. And then we get more data. Once we have the data, we meet as a team – a pediatric urologist, a psychologist, a geneticist, an endocrinologist, and a genetic counselor, for example, that's the makeup of the team, with the possibility that we have utilized the ethics team for ethics consultation. We meet as a team and think about what are the options, which option we feel is medically in their best interest, and then we present the options to the family. And then we help the family reach a decision as soon as possible.

Dr. I.'s description of how the team operates was fairly similar across all medical institutions that had teams in place. In line with their essentialist beliefs about gender, the team orders diagnostic tests that include assessments of hormonal levels, karyotype, and other biological "signs" of sex.

Although Dr. C. maintained the diagnostic process has little to do with gender identification, it remains embedded within any recommendation

through a belief that sex, gender, and sexuality are correlated. Dr. C. shared that the team “need[s] to figure out hormonally if the child makes testosterone. We need to figure out genetically what the chromosomes are and then discuss what little knowledge we have in 2010, how we think this child’s going to think. Not in terms of gender preference or who they’re attracted to of course, but for gender identification, who they think they are.” We can then once again see the congruence theory at play which maintains that one’s sex is neatly correlated with gender and sexuality.

Intersex experts, especially surgeons, need to operate in medical management teams in order to reclaim their challenged authority. And, they employ their gender essentialist views to justify their surgical intervention. Dr. C. shared with me how he discusses his suggestions with the parents of newly diagnosed children with intersex conditions:

I always talk about it as nature ... just about got it right but just this is the last few steps or last step, and we can complete that for you and then we take lots and lots of questions.

All of the medical professionals I spoke with maintained that parents approach the intersex diagnosis with lots of questions, and my interviews with parents support such. Medical professionals made it clear during the interview that parents welcomed their professional opinion with little resistance or hesitation. However, such wasn’t true for all families. Dr. C. recounted a recent consultation with a family that was very critical of his recommendations:

The father said, “[Doctor], can I ask you a question?” I said, “Absolutely, this is your forum. I’m at your disposal. You’re hiring me.” He said, “Why should we do anything?” And I acted physically surprised, I’m sure I did. And I said, “Well, I’m concerned that if you raise this child in a male gender role without a straight penis, he’s not going to see himself as most other males and he’s not going to certainly be able to function as most other males.” And the father said, “Well, in our family we like to celebrate our differences and not try to all be the same and feel the social pressure to do everything like everyone else does.” ... I said, I do have to say one thing, and I think it’s of key importance that you both see a psychiatrist.

While the 2000 and 2006 medical consensus statements encourage intersex experts to refrain from performing medically unnecessary surgeries to treat intersexuality, Dr. C., like other medical professionals I spoke with, continue to perform *cosmetic* surgical modifications. Given differences of power and expertise, in the end parents usually grant consent (Conrad & Schneider, 1980; Dreger, 1998a; Zola, 1972, 1986).

CONCLUSION

Intersexuality is a unique access point into the study of diagnostic processes because it very clearly demonstrates that medical conditions are defined through other social constructions. It is also a contemporary example of how framing a phenomenon as a scientific “abnormality” enhances medical credibility (Zola, 1972). The treatment of intersexuality has shifted several times in the last couple of decades initially with technological advancements that allowed intersex experts to medically define sex, albeit in binary terms, and later with intersex activism. In the 1950s and 1960s, intersex experts were exposed to new tools to surgically and hormonally treat intersexuality (Karkazis, 2008; Preves, 2003). As their surgical techniques developed, so did their confidence in withholding the intersex diagnosis from patients and, in some cases, their parents under the guise of protecting gender identity development (Karkazis, 2008; Preves, 2003). Such medical deception wouldn’t last for long. Feminist scholars like Fausto-Sterling (1993) and Kessler (1998) began to study, discuss, and highlight intersexuality in their writings in order to critique rhetoric about sex, gender, and sexuality binaries. Intersexuality, in short, became the go to example for feminist scholars of all disciplines to support social constructionist arguments about the body.

While some individuals with intersex conditions and scholars of intersex studies are critical of the ways in which their experiences were relied on to advance feminist theories (Dreger & Herndon, 2009; Koyama & Weasel, 2002), others have acknowledged that it has offered intersex activists a substantial amount of credibility in challenging the medical profession to reconsider their treatment of intersexuality (Chase, 1998b, 2002; Preves, 2003; Turner, 1999). Intersex activism was initially successful enough that the medical profession was forced to respond to it, as the medical profession did so only seven years after the formation of the intersex rights movement with their 2000 medical consensus statement on the management of intersex conditions. Intersex experts even acknowledged their profession was in a state of “social emergency” (Committee, 2000, p. 138), and consequently insisted medical professionals stop withholding information about the intersex diagnosis from patients and parents. They also insisted that the surgical modification of intersex genitalia should be avoided at all costs. These were more than satisfactory outcomes for many intersex activists, and relatively speaking, incredible progress in such a short amount of time.

However, such progress came at a cost for medical professionals. Their authority was challenged by intersex activists who were successfully framing

intersexuality as a social rather than biological condition. Medical professional's jurisdiction over the intersex body was left in jeopardy. In order to maintain their bio-power (Foucault, 1980), medical professionals responded by reinventing intersexuality through a shift in diagnostic terminology. Today, "intersexuality" is exclusively referred to in the medical profession as a "disorder of sex development" that necessitates medical attention. Many intersex activists that were once against the medicalization of intersexuality now support it. The new DSD terminology is also embraced by many individuals with intersex conditions, their parents, and even some intersex scholars (Dreger & Herndon, 2009; Feder, 2009; Feder & Karkazis, 2008; Karkazis & Feder, 2008).

The success of early intersex activism, centered on framing intersexuality as a social rather than biological condition, was short lived. Medical professionals needed to maintain their authority in the face of intersex activism, and they did so linguistically through a reinvention of the intersex diagnosis. The new DSD terminology constructs "sex" as a scientific phenomenon, and a binary one at that. Under such frame, intersex experts neatly link intersexuality to science, and thus are able to justify surgery. This places intersexuality neatly into medical turf and safely away from critics of its medicalization. At the same time, the connection to science increases medical credibility (Zola, 1972), which in light of intersex activism, is necessary. While DSD medical management teams are allegedly now operating in teams with expertise from across professions, those from psychiatry are typically less involved. Their exclusion makes sense because psychiatrists are less likely than surgeons to hold essentialist beliefs about sex, gender, and sexuality. Instead, psychiatrists are likely to see intersexuality as a social phenomenon, "or at the very least, a shared medical-cultural phenomenon" (PJ McGann, personal correspondence, January 31, 2011). Since social constructionist arguments are within the "terrain of the social, activists, social workers, psychiatrists, and even intersexed people themselves may justifiably make claims" (*ibid.*). With the new DSD terminology, intersexuality has been returned to medical turf where medical professionals, notably surgeons, are able to reclaim authority over the intersex body, a move that diminishes at least some of the earlier efforts of intersex activists.

NOTES

1. Although written "tongue firmly in cheek," Fausto-Sterling (1993) defined "herms" as having one ovary and one testis – a "true" hermaphrodite. Male

pseudohermaphrodites or “merms” have testes but do not have ovaries despite having some other “normal” component of female genitalia. Female pseudohermaphrodites or “ferms” have ovaries but do not have testes despite having some other “normal” component of male genitalia.

2. ISNA was the largest intersex activist organization in the world with a mailing list of 2,600 and over 600 donors before it closed its doors in the summer of 2008. A new organization, Accord Alliance, run by several former ISNA executive officers, including Cheryl Chase, took its place as the largest activist organization within the intersex rights movement.

3. During my earlier interviews, I asked medical professionals to provide a specific letter for me to use in any publications. Some medical professionals stated that I could use their actual initials; others chose a letter from the alphabet that wasn't at all connected to their legal name. In the end, I decided to randomly assign letters to protect confidentiality. I was worried that medical professionals would otherwise be easily identifiable.

4. Two of the medical professionals I spoke with were without an MD, PsyD, PhD, etc., yet I refer to such individuals as a “Dr.” throughout in order to protect my informants.

5. Unless otherwise noted, all quote hereon out received from [Committee on Genetics: Section on Endocrinology and Section on Urology \(2000\)](#).

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RESISTING PATHOLOGY: GID AND THE CONTESTED TERRAIN OF DIAGNOSIS IN THE TRANSGENDER RIGHTS MOVEMENT

Mary C. Burke

ABSTRACT

Purpose – To examine debates within the transgender rights movement over the GID diagnosis in order to demonstrate how diagnosis can be resisted as a source of stigma and social control at the same time that it is embraced as a means of legitimating experience and gaining access to resources, including medical services.

Methodology/approach – This chapter draws on qualitative data from: in-depth interviews with transgender rights activists and advocates, participant observation in transgender health care and activism settings, and content analysis of print and web-based materials on transgender health.

Findings – Transgender rights activists and advocates overwhelmingly reject the pathologization of gender variance. However, some actors advocate complete demedicalization, while others advocate diagnostic

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reform. Actors' advocacy for each position is influenced by the perceived costs versus benefits of diagnosis.

Social implications – The findings of this research shed light on the multiple and often contradictory effects of diagnosis. Diagnoses can both normalize and stigmatize. They can function to allow or deny access to medical services and they can support or act as barriers to legal rights and protections. Understanding these contradictory effects is essential to understanding contests over diagnosis, including the contemporary debate over GID.

Originality/value of paper – Through examination of an intra-constituent contest over diagnosis, this research demonstrates the need to distinguish medicalization from pathologization and illustrates the importance of examining the multiple and contradictory effects of diagnosis, both in and outside of medical settings.

Keywords: Medicalization; diagnosis; social movements; transgender; gender; LGBT

Our humanity is not insanity. Keep your disorders off my gender. Gender variance is not a disease. APA + DSM + GID = WTF.

–Poster slogans from a May 2009 protest against the APA

In May of 2009, protesters gathered for a demonstration at the corner of 4th Street and Howard Street, outside the Moscone Convention Center in San Francisco. While demonstrations are not unusual in downtown San Francisco, this demonstration was somewhat unique in that it was organized to protest a diagnosis. Specifically, the demonstration – one in a series that have taken place over the last two decades – was organized to protest the inclusion of Gender Identity Disorder (GID) as a diagnosis in the *Diagnostic and Statistical Manual of Mental Disorders (DSM)*, a text produced by the American Psychiatric Association (APA). Inside the Moscone Convention Center, the APA was holding its annual meeting and while attendees debated the diagnosis inside, activists gathered outside for a public protest. Speakers, many of whom were both transgender rights activists and medical professionals, offered critiques of the GID diagnosis, while demonstrators carried signs echoing these critiques through clever slogans. While the slogans varied, they all reflected activists' attempts to challenge the construction of gender variance as the basis of a diagnosable disorder, reject the authority of the APA to define what does and does not constitute normative

gender identity, and redefine the boundaries between gender identity and disorder.

Objections to the GID diagnosis are not new. In the United States, there have been organized protests against the APA and GID diagnosis since at least the early 1990s and critiques have been commonplace within transgender, LGBT, and feminist communities. Disagreements about the diagnosis have also occurred within the APA and the medical and mental health professions more generally, a fact that is reflected in the changes to the diagnosis that have taken place over the last three decades.¹ However, while debates over the GID diagnosis have taken place for some time, organized activism around the GID diagnosis has intensified in recent years due to revision process taking place in preparation for the May of 2013 publication of the *DSM-V*, which will feature the first major revisions to the text since the publication of the *DSM-IV* in 1994.² In this chapter, I draw on qualitative data to examine contemporary transgender rights activist and advocate positions on the GID diagnosis. Activists and advocates overwhelmingly reject the pathologization of gender-variant identities and expressions; however, as I demonstrate, this rejection does not always translate into calls for removal or declassification of the GID diagnosis. While many activists advocate complete demedicalization, others support diagnostic reform through advocacy for revision or alternative diagnosis. I explain these divergent positions and then draw on them to demonstrate the multiple, and sometimes contradictory, functions and effects of diagnosis. I then discuss how these findings demonstrate both the need to distinguish medicalization from pathologization and the need for a more nuanced understanding of the sociology of diagnosis.

LITERATURE REVIEW

Medicalization has been the subject of sociological study for nearly four decades (Ballard & Elston, 2005; Zola, 1972). Scholars in this area have often focused on how nonmedical problems become medicalized, as well as on the consequences, both negative and positive, of medicalization (Conrad, 1992, 2007). In this sense, scholars have sought to answer two central questions: what are the causes and effects of medicalization?

Early work, such as that forwarding the “medical imperialism” thesis, first introduced by Illich, (1976), focused on physicians as the central forces in medicalization (Conrad, 2007; Strong, 2006). In these accounts, medicalization was often treated, either explicitly or implicitly, as synonymous with

overmedicalization, or inappropriate medicalization (Conrad, 1992, 2007). Some work in this area built on labeling theory and the sociology of deviance, focusing on the medicalization of deviant behaviors such as drug use and same-sex attraction (Conrad & Schneider, 1992). Other scholars, building on feminist theory and the women's health movement, have considered the "medicalization of normality" (Klawiter, 2008, p. 25) or of "normal life events" (Conrad, 2007, p. 6; Lock, 2004; Morgan, 1998; see also Riessman, 1983; Riska, 2003). Here, the emphasis was on the medicalization of "normal" aspects of women's bodies and experiences, including pregnancy, childbirth, menstruation, and menopause. However, while different, in both bodies of literature medicalization appears as a process that occurs from the "top-down," expanding medicine's realm, authority, and ability to act as an agent of social control. Summing up the emphasis of these studies, Williams and Calnan (1996) write:

In the past two centuries a broad range of behaviours from homosexuality to alcoholism have been subsumed under the medical rubric and the current obsession with locating genetic precursors of illness, diseases, disabilities and behaviours, means that the knowledge base of scientific medicine has encroached still further into defining the limits of "normality" and the proper functioning, deportment and control of the human body. (p. 1609)

However, while these works posit medicalization as something that happens to lay populations, other work considers the role of people outside the professions in the process of medicalization (Conrad, 2005, 2007). Medicalization can be something actively sought by people outside of institutions of medicine and science (Brown & Zavestoski, 2004; Conrad & Leiter, 2008; Dumit, 2006; Scott, 1990; Zavestoski et al., 2004) In their work on embodied health movements, Brown et al. (2004) show that individuals can forge collective identities around shared illness experiences and advocate for recognition in the form of medicalization. In these cases, professionals may not be centrally involved, and may even be actively resistant to medicalization (Brown et al., 2004; Conrad, 2007; Conrad & Schneider, 1992). Scholars in this area contend that people are not merely passive victims of medical imperialism, but instead can actively participate in the process, at times embracing, while at other times resisting, medicalization. This work emphasizes that "medicalization is rarely an issue of "medical imperialism" asserted over "feckless patients," nor is it a simple issue of "wannabe" patients strong-arming physicians" (see also Conrad, 2007, p. 9; Klawiter, 2008, p. 28).

As Conrad (2007) notes, much of the scholarship on medicalization is critical, focusing on its negative consequences. "Critics have been concerned

that medicalization transforms aspects of everyday life into pathologies, narrowing the range of what is considered acceptable” (Conrad, 2007, p. 7). Other critics argue that medicalization is individualizing and depoliticizing, locating the source of the problem as individual rather than social and thus encouraging individual medical interventions rather than collective solutions (Conrad, 2007). Still others note their concern for the dangers of increased medical social control (Conrad, 2007; Conrad & Schneider, 1992; Zola, 1972). For example, medicalization can be used to deny a patient’s rights, such as in cases where political dissent is treated as mental illness (Jutel, 2009; Munro, 2002) or when children diagnosed with GID experience forced treatment (Burke, 1997). Other scholars note that the rise of what Armstrong (1995) refers to as “surveillance” medicine and the concomitant emphasis on disease potential is a salient means of social control, fostering heightened anxiety and unnecessary and potentially detrimental treatment (Black, 2000; Jutel, 2009). Likewise, new technologies such as genetic testing for disease potential may lead to stigmatization and discrimination (Jutel, 2009; Raz & Vizner 2008; Wertz, 1992).

However, while much scholarship on medicalization highlights its negative consequences, other research suggests that medicalization can also have positive effects (Broom & Woodward 1996; Conrad, 1975, 2007; Riessman, 1983). Perhaps most centrally, the medicalization of deviance has represented an important shift in the transformation from “religious to state-legal to medical-scientific” frameworks for defining and addressing deviance (Conrad & Schneider, 1992, p. 32). The transformation from moral-criminal to medical definitions of deviance did not necessarily signify a shift to moral neutrality; however, it did signal the potential for greater social tolerance and more humanitarian approaches to deviant behaviors and populations. As McGann and Conrad (2007) note, “The tendency to see badness – whether immoral, sinful, or criminal – as illness is part of a broader historical trend from overtly punitive to ostensibly more humanitarian responses to deviance.” For example, in 1897, Magnus Hirschfeld, a German physician and social reformer, cofounded the Scientific Humanitarian Committee, a group that aimed to undertake research to defend the rights of homosexuals and other sexual minorities. The motto of the Committee, “Justice through science,” reflected the belief that medicine and science could foster a more just and tolerant society.

Scholarship also suggests that medicalization can have numerous benefits for patients. “Medical explanations can provide coherence to patient’s symptoms, validation and legitimation of their troubles, and support for self-management of their problems” (see also Broom & Woodward, 1996;

Conrad, 2007, p. 11; Nettleton, 2006). Through medicalization, and diagnosis in particular, patients are also able to form collective identities, which foster the creation of support networks and advocacy groups (Barker, 2002; Brown & Zavestoski, 2004; Chiong, 2001; Jutel, 2009). Likewise, medicalization, and more specifically diagnosis, opens access to the sick role (Parsons, 1951), institutional recognition, access to services, and resource allocation (Conrad & Potter, 2000; Jutel, 2009).

Given these myriad potential negative and positive consequences, it is not surprising that medicalization and diagnosis represent sites of struggle. This fact can be seen in work on the contestation of illness (Brown & Zavestoski 2004; Campos, Saguy, Ernsberger, Oliver, & Gaesser, 2006; Gard & Wright, 2005; Saguy & Riley, 2005; Zavestoski et al., 2004). However, thus far studies have focused primarily on inter-constituent struggles, such as those between physicians and patients, or patients and pharmaceutical companies (Brown & Zavestoski, 2004; Dumit, 2006). Scholarly accounts, therefore, focus largely on groups struggling for more, or sometimes less, medicalization (Bayer, 1981; Conrad, 1992; Klawiter, 2004; Nettleton, 2006). The literature is, however, relatively silent on intra-constituency contests where debate occurs within a stakeholder group. As Conrad and Stults (2008) state, "Contestation can serve to limit medicalization, yet much contestation of illness ultimately seeks to increase medicalization. Among the interesting places for continued scholarly research are those sites where the processes of contestation and processes of medicalization rub up against one another" (p. 334). Although there are some examples of debates within a stakeholder group about things such as strategy, these debates do not turn on more versus less medicalization; however, this is the case with the GID diagnosis.

Work in transgender studies has examined the medicalization of gender variance (Cromwell, 1998, 1999; Hausman, 1995; Irvine, 2005; Meyerowitz, 2002; Rudacille, 2005; Stryker, 2008; Stryker & Whittle, 2006) and the GID diagnosis more specifically (Bryant, 2006, 2008; McGann, 2006; Sedgwick, 1991). Mirroring central trends in the medicalization of deviance scholarship, much of the literature on transgender issues is critical of medicalization. Numerous works argue that the medicalization of gender and sexual deviance through diagnoses such as inversion, homosexuality, transvestism, and transsexualism represented attempts to control the individuals who posed a fundamental threat to both gender and sexual norms and the sex/gender system itself (Bullough & Bullough, 1998; Cromwell, 1998; Denny, 1992, 2006; Ekins & King, 1998, 2006; Meyerowitz, 2002; Smith-Rosenberg, 1989).³ Other scholars argue that medicalization individualizes and depoliticizes gender-nonconformity (Billings & Urban, 1982; Denny, 2006;

Raymond, 1994a, 1994b; Roen, 2002). Work in this area also emphasizes medical practitioners as gatekeepers who deny access to needed medical services if transgender patients do not conform to a particular, narrowly defined set of standards (Bolin, 1988, 1992, 1997; Denny, 2006; Kessler & McKenna, 1978; Namaste, 2000; Stone, 1991). Similarly, in his work on the gender identity disorder in children (GIDC) diagnosis, Bryant (2006) notes that critics have argued that the diagnosis serves to enforce normative notions of femininity and masculinity, construct a social problem as individual pathology, and pathologize homosexuality. Work in transgender studies offers important accounts of the medicalization of gender variance and cogent critiques of both medicalization and the GID diagnosis. However, while these studies highlight inter-constituent struggles over medicalization, especially those between medical professionals and the trans community, they do not explain why contestation over the GID diagnosis takes place within the trans community.⁴

Thus, in this chapter, I address this gap in both the medical sociology and transgender studies literature by examining the intra-constituent contest over the GID diagnosis, a case wherein some argue for more (or at least different) medicalization, while others seek to inhibit medicalization. Moreover, I draw on the case of GID politics as an opportunity to fine-tune two phenomena that are often conflated: medicalization per se and pathologization. As I demonstrate, this is part of the fault line in trans communities. On the one hand, the GID diagnosis fosters legitimacy, provides access to services such as medically based body-altering technologies, and makes possible claims to disability status. On the other hand, the diagnosis pathologizes gender variance and places it under the purview of medical professionals. Thus, as I show, it is possible for stakeholders to defend and seek to preserve medicalization while simultaneously working to depathologize the condition by moving it out of what is seen as the stigmatizing psychiatric realm of the *DSM*.

CASE AND METHODS

Gender variance, at least in certain forms, has been characterized as a medico-psychological condition in Western cultures for over a century (Chauncey, 1982). For example, Krafft-Ebing's (1892) medical text, *Psychopathia Sexualis*, contains numerous case studies of "sexual inversion." Before transsexualism was first included as a specific diagnosis in the *DSM-III* (1980), nonnormative expressions of gender were variously

described with terms such as inversion (Krafft-Ebing, 1892), transvestism (Hirschfeld, 1991), genuine transvestism (Hamburger, Sturup, & Dahl-Iversen, 1953), eonism (Ellis, 1928), and transsexualism (Benjamin, 1966, 2006).⁵ After the publication of the first *DSM* in 1952, clinicians could also diagnose people exhibiting gender-variant identities and behaviors under the general category of sexual deviations, a broad diagnostic category that included both transvestism and homosexuality (APA, 1952).

GID as a discrete diagnosis, first appeared in the *DSM* in the extensively revised *DSM-III* published in 1980.⁶ In this version, GIDs were included as a subset of diagnoses under the broader diagnostic category of psychosexual disorders and clinicians could choose from three specific diagnoses: Transsexualism, Gender Identity Disorder of Childhood, or Atypical Gender Identity Disorder. In the *DSM-III-R* (APA, 1987), GIDs were recategorized under Disorders Usually First Evident in Infancy, Childhood, or Adolescence and the Atypical GID diagnosis was divided into two different diagnoses: Gender Identity Disorder of Adolescence or Adulthood, Nontranssexual Type (GIDAANT) and Gender Identity Disorder Not Otherwise Specified (GIDNOS). GIDs were once again reclassified in the *DSM-IV/IV-TR* (APA, 1994, 2000). In this edition, they were placed in a diagnostic category of sexual and gender identity disorders. The GIDNOS diagnosis was retained, as was the Gender Identity Disorder of Childhood diagnosis, although it was renamed GIDC. The Transsexualism and GIDAANT diagnoses, on the other hand, were replaced with a single diagnosis referred to as Gender Identity Disorder in Adolescence or Adults (GIDAA).

The *DSM-V* is not scheduled for publication until 2013; however, a draft of the revised diagnoses was released in 2010. According to this draft, the GID nomenclature, used since the publication of the *DSM-III*, will be changed to Gender Incongruence. Subcategories for Gender Incongruence in Children and Gender Incongruence in Adolescents and Adults will remain.⁷

From 2006 to 2010, I conducted research on transgender medicine and the transgender rights movement, including interviews, participant observation, and content analysis. In this chapter, I draw on data from this research to examine debates over the GID/GI diagnosis among transgender rights activists and advocates. In-depth interviews were conducted with 15 transgender rights activists and 15 medical professionals who specialize in working with transgender populations. Interviewees were identified using a combination of convenience and snowball sampling. Activists included individuals with experience in grassroots organizing and advocacy in areas

such as medicine and law, and providers represented a diverse range of fields including psychology, social work, endocrinology, surgery, and general medicine. All interviews ranged from 45 minutes to 2 hours and were conducted either in person or over the telephone. Here I focus on interviews with activists and medical professionals who were active in the transgender rights movement or saw themselves as activists or advocates for transgender rights.

I also draw on participant observation in settings related to trans health, advocacy, and support. My role in these settings was primarily that of a researcher. While in some settings I actively participated as an LGBT community member and trans ally, my preference was to observe in an unobtrusive manner whenever possible. Although fieldwork took place over the course of three years, I was only in the field intermittently during this time, mostly when relevant events took place. I focused on two types of settings. First, I attended a series of local, national, and international professional and community conferences that were either solely dedicated to transgender health or that had a heavy focus on issues related to trans health and health care. Second, I conducted participant observation at a variety of events organized by trans advocacy, social movement, and support groups. The majority of these events took the form of meetings, lectures, or special events such as film viewings and provider trainings, although I also attended both a rally and a protest.

Finally, I draw on data from content analysis of a wide range of print and web-based materials pertaining to transgenderism and medicine, including material produced by transgender and LGBTQ advocacy, support, and social movement groups. I also collected and analyzed data from online listservs, forums, blogs, and message boards related to trans health. Because the Internet is a central tool for networking and organizing within the transgender rights movement, and health social movements more broadly (Dumit, 2006; Goldstein, 2004; Jutel, 2009), these sources of data allowed me to examine a larger sample of perspectives on the GID diagnosis.

FINDINGS

Transgender rights activists and advocates in and outside the medical professions overwhelmingly reject the assertion that transgender identities are disordered. In doing so, activists and advocates reject biological essentialism and binary accounts of sex and gender, instead embracing social constructionist accounts of gender and “postmodern notions of

fluidity (for both bodies and genders)” (Roen, 2002, p. 501). Activists are therefore concerned that the medicalization of gender variance reinforces binary and essentialist accounts of gender and pathologizes gender variance. In this sense, criticisms of the GID diagnosis mirror scholarly critiques of medicalization, highlighting concerns over issues of stigma and social control (Denny, 1992, 2001; James, 2004; Wilchins, 1997; Winters 2008a). However, while the medicalization of gender variance is criticized, resistance to the GID diagnosis is complicated by issues of access, authority, and authenticity. Thus, some actors advocate the complete demedicalization of gender variance, whereas others support diagnostic reform through revision or the creation of an alternative diagnosis. In the following section, I first briefly discuss the rejection of pathological accounts of gender variance. I then detail the demedicalization perspective before exploring the varied positions among those who favor reform.

Gender Identity (Not) Disorder: Rejecting the Pathologization of Gender Variance

Transgender right activist and advocates assert that transsexualism, transgenderism, and other nonnormative forms of gender expression constitute identities rather than disorders. To support this argument, they draw on social constructionist and postmodern accounts of gender and sexuality forwarded in feminist, LGBT, and queer activism and scholarship. Essentialist and binary understandings of sex and gender are rejected in favor of more fluid accounts of sex and gender identity, embodiment, and expression. From this perspective, the GID diagnosis – and the medicalization of gender variance overall – both reflects and reinforces a broader social tendency to stigmatize nonnormative forms of gender identity and control their expression. For example, Arlene Lev (2004), a gender therapist and prominent critic of the GID diagnosis contends that “... the *DSM* has a long history of diagnosing oppressed people with mental disorders” (p. 181).

Many activists, thus, argue that GID misdiagnoses the problem, which does not reside in gender-variant identities but in rigid social standards dictating appropriate and inappropriate forms of gender identity and expression. Sarah,⁸ a trans woman, criticizes the GID diagnosis by stating, “Society is the one with dysphoria, not us.” In a protest against the APA and GID diagnosis, Madeline Deutsch, a physician and trans activist echoes this sentiment:

I look at the world around me and I see a world full of personality disorders, behavioral disorders, and psychotic disorders, which are undiagnosed, untreated, or unattended to.

But no one forces these people into a psychotherapeutic environment. It is time to stop forcing the same on transgender people. It is time to change society, and change the system, rather than placing the social, financial, and psychological burden on transgender people.

Riki Wilchins (1997), a prominent trans activist, argues in her book, *Read My Lips: Sexual Subversion and the End of Gender*, that the real disorder is not GID but “GenderPathoPhilia,” which she defines as: “(1) an obsessive fear or need to pathologize any kind of gender behavior that makes YOU feel uncomfortable; (2) a dread disease that strikes 9 out of 10 American psychiatrists” (p. 225). In Wilchins’ work, one can see how scholarly critiques of the dangers of medicalization (e.g., Conrad & Schneider, 1992) have been taken up by activists in the debate over GID.

From this perspective, the GID diagnosis contradicts the APA’s explicit exclusion of behavior considered deviant due to cultural norms and societal standards in the definition of mental disorder provided in the *DSM-IV*. “Neither deviant behavior (e.g., political, religious, or sexual) nor conflicts that are primarily between the individual and society are mental disorders unless the deviance or conflict is a symptom of a dysfunction in the individual ...” (APA, 1994, pp. xxi–xxii). Activists further argue that distress, one of the GID diagnostic criteria, is not the result of the gender identity itself, but the effect of living with social stigma and experiencing prejudice and discrimination. For example, one of the founders of GID Reform Advocates, a prominent organization in the trans health movement, criticizes the diagnostic criteria for “fail[ing] to distinguish intrinsic distress of gender dysphoria from that caused by external societal intolerance ...” (Winters, 2008a, para. 10). Winters (2008a) goes on to argue that this can lead to situations wherein “prejudice and discrimination can be misconstrued as psychological impairment for gender-variant individuals who are not distressed by our physical sex characteristics or ascribed gender roles” (para. 10). Therese, an activist I interviewed spoke to these concerns, saying:

What worries me is that GID doesn’t really separate stress a person feels about their gender from stress based on social problems people experience because they’re gender variant. It’s all kind of lumped together, so gender variant people end up being responsible for the way other people treat them.

Activists also suggest that the GID diagnosis not only reflects the stigmatization of gender-variant identities but also itself contributes to that stigmatization. One local chapter of NOW (National Organization of Women) argues for complete demedicalization in part because “... the

DSM-IV criteria for the Diagnosis of ‘Gender Identity Disorder’ creates and regulates heterosexist, sexist and bipolar gender stereotypes as “norms” for mental and social behavior in youth and adults, thereby rendering bisexual, gay, lesbian and transgender youth as inherently deviant” (as quoted at <http://womynweb.net/gendersb.htm>). According to an excerpt from literature produced by GID Reform Advocates:

The very name, Gender Identity Disorder, suggests that cross-gender identity is itself disordered or deficient. It implies that gender identities held by diagnosable people are not legitimate, in the sense that more ordinary gender identities are, but represent perversion, delusion or immature development. This message is reinforced in the diagnostic criteria and supporting text that emphasize difference from cultural norms over distress for those born in incongruent bodies or forced to live in wrong gender roles. (Winters, 2008b, para. 1)

This excerpt accurately depicts many transgender rights activists’ understandings of both the GID diagnosis in particular and the pathologization of gender variance more generally.

Solutions to Pathologization: Demedicalization and Diagnostic Reform

Widespread criticisms of the pathologization of gender variance and concerns about the negative individual and social effects of the diagnosis lead many activists and advocates to reject the GID diagnosis entirely. They favor complete demedicalization, including removal of the GID diagnosis from the *DSM*, *ICD*, and all medical texts. Speaking to this position at the APA protest in May 2009, Madeline Deutsch, a transgender activist and health-care provider, said:

... I am a queer, transgender woman. And I’m here to tell Dr. Zucker and the rest of the world that my identity is not pathological. My identity does not belong miscategorized in your book. We live in a society based on individual liberties and informed consent. Each individual should be allowed to make decisions about how to live their own life.

The majority of people I encountered in my various sites of study, like Deutsch, reject the construction of gender variance as a disorder. However, unlike Deutsch, not all activists translate this rejection into advocacy for complete demedicalization. Instead, some advocate demedicalization, while others focus their attention on reform.

Advocates for reform often support the eventual declassification of GID, but focus their efforts on improving the diagnosis rather than calling for immediate removal. The NGLTF (National Gay and Lesbian Task Force),

for instance, criticizes the continued pathologization of gender variance, but nonetheless adopts a reform-based focus in their position statement on the proposed change from GID to Gender Incongruence (GI) in the *DSM-V*:

While many psychiatrists and those of us in the LGBT communities find no “incongruence” in the expressions outlined in the proposed *DSM-V* – of being born in a female body and preferring trucks and football; or of being born in a male body and preferring pink jewelry and girls as friends – we understand that our culture and our nation has a long way to go in achieving gender justice and that this is one positive, imperfect step on a long journey. (Grant, 2010, para. 4)

As the NGLTF position statement suggests, reform advocates tend to see complete demedicalization as unrealistic. They do, however, believe that it is possible to improve the diagnosis through revision. Activists who adopt this position tend to advocate for a series of specific revisions to the diagnosis. Many of these are encompassed in the broad goals for revision identified by GID Reform Advocates:

It is time for the medical professions to affirm that difference is not disease, nonconformity is not pathology, and uniqueness is not illness

It is time for culturally competent psychiatric policies that recognize the legitimacy of cross-gender identity and yet distinguish gender dysphoria as a serious condition, treatable with medical procedures

It is time for diagnostic criteria that serve a clear therapeutic purpose, are appropriately inclusive, and define disorder on the basis of distress or impairment and not upon social nonconformity

It is time for medical policies that, above all, do no harm to those they are intended to help. (GIDReform.org, 2010, para. 6)

As these goals suggest, advocates for reform through revision to the GID diagnosis stress the importance of creating a diagnosis and diagnostic criteria that clearly distinguish between gender identity and gender dysphoria, which refers to unhappiness or unease with one’s assigned sex or gender.

Advocates for diagnostic revision are not the only group who support continued diagnosis; other reform advocates support the creation of an alternative diagnosis. Advocacy for revision focuses on improving the GID diagnosis in its current form and location, whereas advocacy for alternative diagnosis focuses on the replacement of the current mental health-based diagnosis with an alternate diagnosis. Those in favor of an alternative diagnosis most frequently argue for a purely medical rather than mental health categorization. These advocates support removal of GID from the *DSM* (and the mental and behavioral disorders section of the

ICD), alongside the creation of a new medical diagnosis. For instance, among activists who support the creation of new categories, several activists I interviewed hoped that gender variance in certain forms could be classified as an endocrinological condition. Moonhawk River Stone, a therapist and prominent transgender activist, has created a formal proposal for such a diagnosis to be added to the *ICD* and regularly gives presentations on this proposal at transgender health conferences.

If activists and allies overwhelmingly disagree with the construction of gender-variant identities and expressions as disordered, why do these same activists disagree about the *GID* diagnosis itself? In other words, if the majority of activists and advocates agree that trans identities do not constitute a disorder, why do some activists support reform rather than complete demedicalization? The answer to this question lies in the divergent perspectives on the relative benefits and costs of diagnosis.

Weighing the Costs and Benefits of Diagnosis

Advocacy for complete demedicalization is predicated on the belief that diagnosis comes with numerous costs but few tangible benefits. Central costs of the diagnosis identified by demedicalization advocates include the pathologization of gender-nonconformity, both over all and in terms of nonconformity among LGBTQ populations in particular; the reinforcement of sex and gender binaries; the social and psychological stigma attached to diagnosis; the ways in which diagnosis functions as a means of social control; the ways in which the diagnosis can make gender-nonconforming individuals vulnerable to abuse and mistreatment by providers; and the additional financial burden placed on transgender individuals when mental health-care professionals are gatekeepers of access to hormones and surgical procedures.

Similarly, demedicalization advocates argue that pathologization creates barriers to rights and recognition for transgender and gender-variant people. Activists who make this argument frequently draw parallels between the *GID* diagnosis and the medicalization and subsequent demedicalization of homosexuality. Like *GID*, homosexuality was a mental disorder in the *DSM*, but was demedicalized in 1973.⁹ As Drescher and Karasic (2005) note, gay activists argued that “the psychiatric designation of homosexuality as a mental disorder had exacerbated antihomosexual societal prejudices rather than ameliorated them, as originally intended.” For example, Ronald Gold, a lay activist, addressed the APA annual convention in 1973, characterizing

psychiatric pathologization as “the cornerstone of a system of oppression that makes gay people sick” (as quoted in [Stoller et al., 1973, p. 1211](#)).

The success of the struggle to demedicalize homosexuality, and its consequent normalizing effects on LGB identities, is a central reference point and source of inspiration for transgender activists and allies doing battle against the GID diagnosis. Indeed, comparisons between the two struggles were ubiquitous in my interviews, fieldwork, and analysis of print and web-based publications and discussions. At the 2009 APA protest, one sign read: “We’ve waited since 1973.” Another activist interviewed said “I don’t think you can really get rights as long as there’s this model that says we’re crazy, we’re pathological. So I think we have to get GID out for all the same reasons we had to get homosexuality out.” In an online message board discussion titled “G.I.D. O-U-T!,” one trans woman wrote:

I don’t like being considered mentally ill by the uninformed, and the fact that they have a big fat book to point at and say “See! The psych community says you’re a sick f***k!” just gives them ammunition and gets in the way of any real substantive discourse where they might consider the possibility that I’m not a man-in-a-dress who has mutilated his [sic] body.

The removal of GID from that book is just one step in the public acceptance of us as part of the diversity of the human experience. It’s not the *only* thing, of course, just as the homosexual population ... [sic] still working on acceptance! But it’s a huge leap forward to have the psychiatrists agreeing that we’re not mentally ill. ([sic] included by author in original post)

In an interview for the *Bay Area Reporter*, Arlene Lev, a therapist and vocal critic of the GID diagnosis, also draws a connection between the two struggles. Characterizing declassification as a necessary part of gaining civil rights, she says that without the removal of homosexuality, “as a lesbian, I would not have had domestic partner benefits. There would not be two women’s names on my child’s birth certificate” (as quoted in [Szymanski, 2008, para. 73](#)).

Advocates for demedicalization point not only to the broad ranging social consequences of having one’s identity constructed as disordered but also point more specifically to the ramifications of GID for gender-nonconforming individuals both in and outside of health-care settings. Many activists simply argue that the diagnosis forces individuals seeking medical treatments such as hormonal therapy and surgical procedures to enter into therapeutic settings, which places an unfair burden on them. For example, in one online discussion, a poster criticized the mental health professions for “wasting *our* time. And our money too. And *directly* contributing to stigma” (emphases in original).

Many other declassification advocates point to the potential psychological consequences of the diagnosis for individuals. For instance, Alisha, a trans activist argues that:

Being diagnosed with GID creates this whole other level of stress. Now you're not just stressed because you're having these gender issues. Or you're not just stressed because you're dealing with how other people are treating you or might treat you because of your gender. Now you're also stressed because you're wondering what this diagnosis says about you mentally, you know, what this says about your feelings – *about what you are* – being a disorder.

In some cases, activists argue that providers may assume that an individual's mental health issues all stem from his or her gender identity, and therefore fail to treat their actual problems. Dylan Scholinski, a San Francisco-based artist and author of *The Last Time I Wore a Dress* (1998), illustrates this issue during an interview for *In the Life* (2009). When Scholinski was 15 he was placed in a psychiatric facility to be treated for depression; however, he states that the GID diagnosis in his medical records overshadowed his depression and immediately became the focus of his treatment (In the Life Media, 2009). Supporters of declassification also argue that the existence of the diagnosis makes it possible for professionals to “treat” the condition with psychologically damaging methods. This argument is especially typical when declassification advocates discuss the diagnosis of GID in children and adolescents. In his interview for *In the Life*, Scholinski describes the doctors' approach to treating his GID as a “borage of just constantly you know like dripping water on my forehead over and over and over again – ‘You're wrong, you're bad, you're ugly. And you're crazy’” (In the Life Media, 2009).¹⁰ Many activists argue that the GID diagnosis is used as a justification for forcing gender-nonconforming youth into psychiatric treatment, an argument that is supported by scholarly work on GIDC (Bryant, 2006; Burke, 1997; Feder, 1997, 1999; McGann, 2006). For instance, in the same NOW resolution cited earlier, it states that “‘GID’ is used to pathologize and punish diversities of gender identification, gender expression, and sexual orientation, and is also used to justify forced psychiatric treatment of youth” (as quoted at <http://womynweb.net/gendersb.htm>). Some activists even equate treatment approaches used by psychiatrists who work with children diagnosed with GID with “aversion therapy” (Szymanski, 2008).

While advocates for demedicalization acknowledge that the GID diagnosis has been used to support the recognition and rights of transgender people, they argue that diagnosis has done more harm than good in this

regard. In other words, they argue that the diagnosis more often functions as a barrier to full acceptance of transgender as a legitimate identity. Furthermore, they argue that nondiscrimination laws that include protections for gender identity and expression represent a better and more inclusive means of ensuring equal rights for transgender people. This is the case because many trans and gender-nonconforming individuals are never diagnosed with GID. Additionally, while GID is an official mental health diagnosis, it is not always recognized as a protected disorder.¹¹ Likewise, while advocates for demedicalization acknowledge the importance of access to transition-related medical services for some trans people, they do not see the diagnosis as an efficient, necessary, or useful means of ensuring this access. For instance, they note that hormonal and surgical procedures are not covered under the majority of health insurance plans, despite the fact the GID is a recognized disorder and that hormonal therapy and surgical procedures are recognized treatments for the disorder. Thus, they tend to advocate for informed consent and harm reduction approaches, which enable continued access to medical treatment, but unlike the GID diagnosis, do not stigmatize gender-variant identities and expressions.

Advocacy for demedicalization is based on an assessment of the diagnosis as having negligible benefits but numerous costs. Advocates for reform, who support revision to GID or the creation of an alternative diagnosis, also see diagnosis as having negative consequences. However, unlike advocacy for complete demedicalization, reform advocacy is based on the position that diagnosis also has practical benefits. Specifically, reform advocates argue that diagnosis legitimizes gender variance by naming the condition and treating gender-variant identities and expressions as valid, albeit medicalized phenomena. Diagnosis can be seen as legitimizing both in terms of validating individual's experiences and, more broadly, in terms of defining gender variance as a "natural" or biological phenomena, what Joan Roughgarden (2004) deems "evolution's rainbow" and what Milton Diamond was in part referring to in his oft-quoted statement "Nature loves diversity, society hates it."

Reform advocates also argue that diagnosis can legitimate access to medically based body-altering technologies and afford for the recognition and rights of transgender people. Advocating reform based on the importance of the diagnosis for access to medical services, Jamison Green (2009), a transgender activist, states "If we didn't need hormones and surgery, we could wage these battles in a very different way; but we need to build alliances with doctors if we are going to demonstrate that responsible professionals treating us with dignity can make our lives easier ..."

(para. 24). JP, a transgender activist who I interviewed, similarly supports reform based on the role of the diagnosis in advocating for and securing both medical rights and legal protections for trans people: “Let’s face it, the diagnosis has been central in a lot of the successes we’ve had in our efforts to advocate for legal protections. Without it, it would’ve been and still would be much harder to make a case for legal protections or the right to change sex on personal documents or get access to things like hormones and surgery.” Echoing this sentiment, M. Dru Lasseur and Hayley Goreberg wrote in a letter to the Chair and Vice-Chair of the *DSM-V* Task Force on behalf of Lambda Legal Defense:

We believe that diversity of human expression, including one’s sexual orientation, gender identity, or gender expression, should not be considered a disorder ... At the same time, we know that the success of many of our court cases and much of our legal advocacy on behalf of transgender people has rested upon a medical diagnosis that clearly sets forth the medical necessity for transition-related treatment, including hormones and surgery.

Thus, although they recognize that GID is potentially pathologizing, reform advocates argue that complete demedicalization is potentially detrimental to transgender people, given the diagnosis’ current role in access to medical services and in helping to ensure legal rights and protections for gender-nonconforming people. For example, Karen, a nontransgender mental health professional who is active in the transgender rights movement, said, “The people I know who are working hard for insurance coverage, and I mean trans activists, are against it, against removing.” She then recalled an incident at a professional group meeting where a representative from a major trans rights organization had been invited to speak:

They were supposed to talk about what they would like to see changed or if it should be removed. They wouldn’t even talk about that. All they wanted to talk about is how they use it, how they use it to guarantee people’s rights, how they use it to get new legislation passed to protect trans people. They would not entertain it for a second. They said that it would be disastrous to have it removed.

While many reform advocates focus on revising the diagnosis in its current form, others advocate the creation of an alternative medical rather than mental health diagnosis. Support for alternative diagnosis is typically based on the argument that while a diagnosis is necessary to ensure access to transition-related treatment, a medical categorization would lessen the stigma experienced by trans-identified people. Advocates operating from this perspective do not necessarily view gender-nonconformity as a medical disorder; however, they argue that a medical diagnosis would better ensure

access to medical services. In an interview, Moonhawk River Stone, a trans activist and psychotherapist, states:

“Developing a new paradigm that allows people access to health care and to be able to move on productively with their lives is what’s really important. I think it’s more fitting for transgender people to access health care through development of an overarching *ICD-9* medical diagnosis” – a more general clinical description – “that would allow people access to care.” (as quoted in Baxter, 2007, para. 9–10)

In other words, advocacy for alternative diagnosis is premised on an interest in legitimizing transition-related treatments rather than necessarily on an underlying belief in an organic etiology of gender variance.¹² These advocates support recategorization because they see the diagnosis as important primarily for those trans individuals seeking access to transition-related medical services. Therefore, they believe that recategorization as a medical condition will emphasize medical treatment and further legitimize access to medical services, while simultaneously limiting the scope of diagnosis to only those individuals seeking out these services. In this sense, like other advocates for revision, supporters of alternative diagnosis agree that the benefits of diagnosis outweigh the costs. However, their advocacy for a medical rather than mental health-based diagnosis suggests that they see the consequences of diagnosis as stemming from psychopathologization rather than medicalization more generally, whereas revision advocates are less likely to draw a distinction between the two.

DISCUSSION AND CONCLUSION

Examining activist debates around the GID diagnosis offers important insights into our understanding of both health movements and medical diagnosis. Activist efforts to remove or reform the GID diagnosis reveal a type of embodied health movement not typically addressed in the literature on health movements. While there are numerous studies on illness contestation, these studies are based on the construction of contested illnesses as illnesses “that are either unexplained by current medical knowledge or have purported environmental explanations that are often disputed” (Brown et al., 2004, p. 52). Examples of such health-based movements include the environmental breast cancer movement and movements around illnesses such as multiple chemical sensitivity, chronic fatigue syndrome, and fibromyalgia (Barker, 2002; Brown et al., 2004; Hadler, 1996; Jason et al, 1997; Klawiter, 2004, 2008; Ware, 1992). These and similar movements regarding contested illnesses focus

on gaining recognition from medical and scientific institutions, organizations, and providers in order to legitimate illness experience and gain access to needed resources, including treatment, insurance coverage, and funds for medical research. The contested aspects of GID, though, concern depathologization and debates about removal versus reform.

Efforts at depathologization and struggles over the definition of transgender as an illness or identity do demonstrate transgenderism as a contested illness. However, it is not a contested illness in the way that the literature describes. While earlier in the history of trans community formation, efforts were certainly directed at gaining recognition for transsexualism as an illness that was “unexplained by current medical knowledge” (Brown et al., 2004, p. 52), now the focus of the transgender rights movement is on challenging the construction of transgenderism and gender-nonconformity as pathological. In other words, the contest now more centrally involves objections to rather than advocacy for medico-psychological constructions of transgenderism.

However, transgenderism is also a contested illness in a second sense. On the one hand, transgender as the basis of an identity is increasingly supplanting transgender as the basis of an illness. On the other hand, though, the transgender population continues to struggle with institutions of medicine, psychology, and health insurance over the right to access transition-related treatments for those who desire them. This not only complicates the relationship between medicine and the movement but also creates intra-constituent contests over how to resist pathologization while also maintaining and improving access to medical services. Thus, the contest involves both struggles *between* medicine and movement over the definition of trans subjectivities and struggles *within* the trans population over how best to negotiate the tension between resistance to and reliance on medico-psychological authority.

Furthermore, while the literature on health social movements is diverse, scholarship on illness contestation has tended to examine activism directed at institutions of health and science focused primarily on affecting change within these institutions (Dumit, 2006; Zavestoski et al., 2004). However, the material and discursive practices of medico-psychological, scientific, and health-care institutions do not simply shape treatment within these settings but also shape perceptions and practices within a multiplicity of institutional arenas, and within society more generally. Trans activists do not simply resist or support diagnosis because of the way it shapes their experiences within health-care settings. They also target the diagnosis for how it shapes the (trans)gendered subject. The diagnosis is also related to civil rights

(e.g., the ADA) and to recognition in other institutional arenas. Activists target institutions of science and health because other institutions often defer to medico-psychological actors and institutions in making decisions that affect trans people. Furthermore, medico-psychological and scientific discourse on gender-nonconformity plays a central role in perpetuating essentialist accounts of sex, gender, and the relationship between the two. Thus, transgender health activism plays an important role in more broadscale efforts to challenge normative constructions of sex and gender, as are evident in the transgender rights movement, as well as in feminist and LGBT movements.

In the preceding chapter, I have attempted to demonstrate the complex and at times contradictory functions of diagnosis through an examination of activist perspectives on the GID diagnosis. Gender nonnormative identities and expressions are currently diagnosable conditions in both the *DSM-IV/TR* (APA, 2000) and the *ICD-10* (WHO, 2007), and access to trans-specific medical services is determined by the diagnosis and assessment process as defined by the *DSM-IV/TR* as well as the *Standards of Care for Gender Identity Disorders* (WPATH, 2001). Thus, the diagnosis not only (psycho)pathologizes transgender identity but also allows for access to desired medical services such as hormonal therapy and surgical procedures. Further complicating matters is the role of medico-psychological discourse and practice in shaping both how other institutions define (trans)gender for the purposes of rights and recognition and how gender variance is more broadly understood in society. Divergent positions among social movement actors reflect tensions over these various functions and effects of diagnosis. Some actors advocate complete demedicalization, while others support reform through diagnostic revision or the creation of an alternative medical diagnosis.

The emphasis in the literature on movements seeking recognition from the medical community means that movements opposed to or divided over diagnosis have typically received little attention. It also means that the scholarship on embodied health movements and contested illnesses tends to focus on how medicalization will improve conditions. Of course, this stands in sharp contrast to much of the other literature on medicalization, which focuses on the negative effects of medicalization, including the role of medicalization in stigmatization and social control. GID, though, is a case of contested illness that simultaneously includes activism to secure the positive benefits of diagnosis *and* critiques aimed at revising or eliminating the diagnosis to avoid its negative pathologizing effects.

These tensions demonstrate the necessity of distinguishing medicalization from pathologization, given that the former does not always lead to the latter

and that activists can simultaneously embrace medicalization while rejecting pathologization. These divergent accounts of medicalization and diagnosis are partially a product of the tendency to focus solely on diagnosis and medicalization either within or outside of medical and health-care contexts. In other words, while the literature on embodied health movements and contested illnesses tends to stress the role of diagnosis within medical and health-care settings, the literature on medicalization tends to emphasize the broader social ramifications of diagnosis. However, medicalization and diagnosis affect experiences within and outside medical settings; these effects can be beneficial in one context, contradictory or detrimental in another. Debates over the GID diagnosis within the transgender rights movement demonstrate the need for a more nuanced understanding of the sociology of diagnosis.

NOTES

1. For a detailed account of these debates, particularly as they have surrounded the GID in Children (GIDC) diagnosis, see Bryant (2006).

2. The *DSM-IV-TR*, a “text revision” of the *DSM-IV*, was published in 2000. However, while some diagnostic codes were changed to maintain consistency with the *ICD*, diagnostic categories and criteria remained largely the same.

3. While a great deal of scholars are critical of classic sexology and the medicalization of sexual and gender variance, numerous scholars rightly acknowledge the humanitarian intentions of central sexologists such as Richard von Krafft-Ebing, Karl Heinrich Ulrichs, Friedrich Otto Westphal, and Magnus Hirschfeld (see, e.g., Hauser, 1994; Minton, 2001; Oosterhuis, 1997; Rudacille, 2005).

4. Roen (2002) examines the differences (and similarities) between “the radical politics of gender transgression and liberal transsexual politics” or the “both/neither versus either/or debate,” characterizing the two positions based in part on their relationship to medicalization; however, she does not look specifically at positions on medicalization or the GID diagnosis.

5. Cromwell (1999) provides a thorough analysis of inversion as a transgender category. Also, see Irvine (2005), Meyerowitz (2002), and Rubin (2003) for detailed accounts of the history of transsexual as a category.

6. See Bryant (2006) for a detailed account of the development and emergence of the GIDC diagnosis. Also, for discussions of the extensive revisions in the *DSM-III*, see Mayes and Horwitz (2005).

7. Recommendations for changes to the GIDNOS diagnosis have not been made. Proposed revisions can be viewed at: <http://www.DSM5.org/ProposedRevisions/Pages/SexualandGenderIdentityDisorders.aspx>.

8. Pseudonyms have been used to protect the anonymity of interviewees and participants in field settings and online communities. Real names are used when quoting or referring to individuals in the public record, such as individuals who

publish and present on the GID diagnosis or who are quoted in news coverage. When only a first name is used, this represents a pseudonym. In cases where a first and last name is used, this represents an individual's real name.

9. Although homosexuality per se was removed, a new diagnosis, sexual orientation disturbance, was retained as a compromise with those opposed to diagnostic change. Sexual orientation disturbance became ego-dystonic homosexuality in the *DSM-III* (1980). Vestiges of both appear in *DSM-IV* as "sexual disorder not otherwise specified" (Drescher & Karasic, 2005), which includes "persistent and marked distress about one's sexual orientation" (APA, 1994).

10. See *In the Life* episode, "Revising Gender," (2009) available at <http://www.inthelifetv.org/html/episodes/72.html>.

11. "Transvestism," "transsexualism," and "gender identity disorders not resulting from physical impairments" were excluded in Section 511 of the 1990 federal ADA (Americans with Disabilities Act) ((42 U.S.C. 12211) (*Americans with Disabilities Act of 1990, 1991*); however, numerous states afford disability protections to trans people. For example, California's state ADA no longer excludes transsexualism.

12. There are, however, a number of proposed medical diagnoses forwarded by lay activists that are based on various theories of organic etiology (see, e.g., GIRES, 2006).

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NAVIGATING PROFESSIONAL KNOWLEDGES: LAY TECHNIQUES FOR THE MANAGEMENT OF CONFLICTUAL DIAGNOSIS IN AN AD/HD SUPPORT GROUP

Paul C. Fuller

ABSTRACT

Purpose – I analyze how laypersons and professionals navigate challenges to the legitimacy of Attention Deficit/Hyperactivity Disorder (AD/HD). The disorder is modeled as a cultural object manifested in the discursive practices of multiple actors forming a knowledge coalition of professionals, laypersons, governmental, and corporate actors. Coalition members faced challenges to the disorder derived from popular skepticism and from professional's contradictory knowledge claims and diagnostic practices.

Methods – I observed these processes in a two-year, ethnographic case study supplemented with a two-stage, open-ended interview with core members of an AD/HD informational and support group.

Findings – Parents and coalitional professionals managed these challenges differently depending on the status of the source (professional

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vs. nonprofessional) and the alignment (within the coalition vs. nonaligned) of the challenge. Nonprofessional skeptics were easily countered as ignorant moralists who lacked objective knowledge of the disorder – a tactic termed credentialism. The contradictory diagnoses and treatments of professionals were managed as instances of mal-diagnosis – a construct employed by both professionals aligned with the diagnosis and laypersons associated with the disorder. Finally, while parents actively sought a diagnosis as an objective valorization of their status, they remained skeptical of AD/HD; however, in achieving diagnosis they also worried that the methods used to establish a diagnosis were possibly unreliable.

Originality/value – This study contributes to the emergent sociology of diagnosis by describing the techniques used by laypersons and some professionals in maintaining a contentious diagnosis.

Keywords: Diagnosis; discourse; AD/HD; sociology of knowledge; laypersons

Diagnoses are the suturing points that link the lay experience of problematic situations – bodily and otherwise – to institutionally authorized and professionally sanctioned knowledge. Blaxter (1978) distinguished two analytical elements of diagnosis as *categories* shaped through historical dynamics and as *processes* that are reproduced at the local level. This study contributes to the emerging literature on diagnosis by examining how the formation of a contentious diagnostic category (Attention Deficit/Hyperactivity Disorder, AD/HD) creates problems for laypersons and some professionals aligned with the disorder – specifically examining how they maintain the objectivity of the diagnosis in the face of both professional and lay skeptics. The tactics laypersons and aligned professionals use to combat this skepticism establishes how the process of the diagnosis is linked to its categorization. Drawing from a two-year case study of a local AD/HD support and educational group, I analyze how activist parents and associated health professionals maintain the objectivity of AD/HD diagnoses and manage skeptical challenges to the legitimacy of this contentious disorder.

In this study, AD/HD is modeled as a cultural object manifested in the discursive practices of multiple actors – lay, professional, corporate, and governmental. Each actor shapes the parameters of AD/HD through their circulation of the disorder; Hence AD/HD discourses are an interstitial form of knowledge that is secured as an official diagnosis that retains extensive

flexibility in its meanings and in its capacity to account for diverse local problems. While AD/HD discourses are sustained through a coalition of actors, the diagnosis is the suturing point between lay meanings, institutional orders, and “objective” forms of knowledge vouchsafed by those medical professionals aligned with the AD/HD coalition. At the same time, skeptical challenges from the media, popular culture, popular lay based counter-movements, and nonaligned professionals question the objectivity of the disorder. As with other functional disorders (Horwitz, 2002), AD/HD is inferred through external symptoms and is not itself directly observable. However, the polysemic nature of the symptoms, the wide range of problems putatively explained by the disorder, and the communities aligned with and against the disorder allow AD/HD to be understood as a contentious disorder (Brown et al., 2004). Nonaligned professionals and laypersons claim AD/HD is overdiagnosed and over-medicated (Breggin, 2001; DeGrandpre, 1999; Diller, 1998), while lay disability activists and aligned professionals argue it is both mis- and underdiagnosed (Barkley, 1995).

Because of this skeptical pressure, AD/HD discourses are ideal contexts for the analysis of lay and professional techniques in navigating the emergent dilemmas associated with professional knowledge. Because this diagnosis is a contested, interstitial form of knowledge, there are counter-vailing pressures on laypersons to both accept the objectivity of the “disease” classification and negotiate the substantial skepticism generated by the disorder. Interestingly, professionals also engaged these techniques, albeit for different reasons. Whether parent or professional, the polysemic nature of AD/HD both requires and enables navigational strategies. The analysis of these techniques for managing this skepticism thus contributes directly to the literature focused on the process of diagnosis for contested illness (Banks & Prior, 2001; Dumit, 2006).

The site for the study was a parent’s activist group (referred to by the pseudonym *Active*) that sought to educate the public, advocate for the diagnosis in various institutional settings, and provide a supportive environment for parents and children identified with the disorder; this group also had extensive ties to local professionals. As a local site for the circulation of the disorder, the group provided an ideal setting for investigating how potentially disruptive challenges to the objectivity of the diagnosis were managed. I examine how people who broadly identify with the diagnosis – for themselves and their children – manage three interconnected difficulties: laypersons who express skepticism about AD/HD, professionals who do not support the parents’ identification with the diagnosis, and parental moments

of doubt concerning the diagnosis. That is, I explore how laypersons and allied professionals navigate skeptical challenges yet still maintain the objectivity of AD/HD as a diagnosis. More specifically, I ask: what tactics (de Certeau, 1984) do laypersons and allied professionals use in managing these tensions?

Both parents and professionals in the group managed these challenges differently depending on the status of the source (professional vs. nonprofessional) and the alignment (within the coalition vs. nonaligned) of the challenge. Nonprofessional skeptics such as kin, teachers, and administrators were relatively easily countered as ignorant moralists who lacked objective knowledge of the disorder – a tactic I term *credentialism*. The contradictory diagnoses and treatments of aligned and nonaligned professionals were more problematic however. These were managed as instances of *mal-diagnosis* – a construct that maintained the objectivity of aligned professional knowledge in diagnosing and treating the disorder on the one hand, and on the other accounted for discrepancies through the differential “art” of diagnosis that individual professionals exhibited (Feinstein, 1967). The use of *mal-diagnosis* also allowed parents to actively “shop” for the disorder from competing professionals while construing a successful diagnosis as an achievement that vindicated the objectivity of the disorder – a tactic I term *achieved diagnosis*. Finally, parents in particular also exhibited subterranean forms of skepticism surrounding the objectivity of the AD/HD diagnosis. This ambivalence stemmed both from their experience of low diagnostic reliability and widely varying treatment outcomes, as well as from their submerged critique of corporate and market-based influences within professional practices. This ambiguity was expressed by the desire for faddish and relatively more objective indicators of the disorder.

AD/HD AS CULTURAL OBJECT

The theoretical approach to AD/HD in this study combines Foucauldian discourse analysis (Foucault, 1972) and the concept of articulation from cultural studies (Hall, 1996; Laclau & Mouffe, 1985). In these texts, discourses are characterized as decentered, dispersed, and anonymous forms of both *talk* and *practice* that create consistent subject positions that speakers occupy. Similar to Durkheimian social facts (Durkheim, 1982), discourses are *objective* to the degree that they are external to individuals, constrain their relevant talk and practice, and offer resistance to their whims. AD/HD discourses are, like other medical discourses, characterized

by a relatively high level of acceptance because their diagnoses are authorized as categories of disease (Brown, 1995; Jutel, 2009). However, because discourses are flexible, this authorization has multiple expressions as subjectively experienced forms of illness (Aronowitz, 1998). Moreover, because individuals occupy different social locations, these discourses are used to explain problems as articulations that link otherwise differentiated issues. For example, the flexible domains of AD/HD discourses include multiple possible causes (food dyes, television, genetics, sugar, overcrowded classrooms, unfulfilling modes of work), different modes of diagnosing the disorder (online tests, classroom observations, specialist interviews), widely varying symptoms (overfocused, poorly behaved, underperforming, lacking in social skills), with competing types of therapy (pharmaceutical, behavioral). Because AD/HD is authorized as a diagnosis, this considerable flexibility as to what the disorder is, who can have it, and what the consequences of the disorder are, can be used to provide an explanation and an account of multiple problems of living that become articulated as causes, problems, and their solutions. Thus, the potential causes of AD/HD include too much television, sugar, genetics, and poor parenting; these lead to problems such as inattentive children, family stress, and drug addiction. Authorized solutions to these problems include pharmacological interventions and behavioral therapy.

Modeling AD/HD as both discourse and articulation allows for specific insights to emerge that are otherwise hidden. The popularity of the diagnosis is partially explained by the flexibility of the disorder and the wide range of problematic life situations that can be articulated with this discourse (Fuller, 2010). The anchor that provides the stability for these flexible associations is the form it takes as the authorized knowledge of diagnosis. In contrast to religious belief or political opinion, AD/HD diagnoses are thus a class of cultural objects that have seemingly precise boundaries that operate as a technical “truth” – a knowledge rather than a belief. More generally, however, this study understands and explores the ways in which diagnosis, as a process and not simply as a category (Jutel, 2009), is navigated by laypersons at the local level.

AD/HD AS INTERSTITIAL KNOWLEDGE

AD/HD is by far the most prevalent childhood psychiatric disorder in the United States. A 2002 representative national survey of households found that over 10% of all boys and 4% of all girls below the age of 17 have ever

received the diagnosis. The distribution of diagnosed cases has doubled roughly every five years since 1980 (Lucas, Schiller, & Benson, 2004). While social problems can experience *domain expansion* as the scope of their purported effect increases through successful claims-making (Best, 1990), this quantitative growth in AD/HD is best understood as (in parallel to domain expansion) a *diagnostic expansion* beyond childhood; this opens diagnosis of the disorder to previously excluded adult populations and increasingly younger preschool children (Conrad, 2006; Conrad & Potter, 2000). While the problems attributed to AD/HD are vast (including unsafe driving, broken marriages, interrupted careers, academic failures, drug use, and criminality) and affect wide domains of functioning, the disorder is officially characterized by three overlapping sets of visible symptoms: restlessness and disruptive behavior, difficulty in concentrating attention on certain tasks, and impulsivity and antisocial behavior.

The institutionally organized force of contemporary AD/HD emerged in the early 1950s and grew in the 1960s under a thick patchwork of related pathologies such as learning disabilities (LD), minimal brain dysfunction (MBD), hyperkinesis, and impulse disorder (Conrad, 1975; Rafalovich, 2004; Schrag & Divoky, 1975). The disorder drifted from institutionalized to noninstitutionalized populations of children over the course of the 1960s; this drift also entailed a shift in etiological emphasis from a psychodynamic focus on interaction to a neurological basis. Proponents trace the first medical discovery of the condition to Still (1902), a turn of the century physician who described the relatively new medical problem of “defects of inhibitory volition” (Lakoff, 2000) in a group of ill-behaved, but otherwise intelligent children. However, Still’s “disease” was constituted within a different discursive stream that articulated new diseases “of” the will (Lakoff, 2000) – a prescient example of the later emergence of the “moral imbecile” of the early 20th century (Rafalovich, 2001, 2004). In contrast, AD/HD and its predecessor diagnoses are characterized by a mild, though global dysfunction in the regulation of information – a new language that constitutes a morally neutral, nonhuman agent that is divorced from the “will” itself but integrated into the “personality” and its future potentials. This informational dysfunction, couched in the dominant neurological-genetic paradigm of mental health, is thought to affect virtually all domains of functioning – interpersonal, academic, professional, and familial.

While the disorder has achieved professional closure in its institutionalization within the *Diagnostic and Statistical Manual (DSM)*, both intra- and interdisciplinary as well as professional and lay conflicts still arise as to

the “ownership” (Gusfield, 1981; Rogler, 1997) of the disorder. As with other contested illnesses (Dumit, 2006), these struggles are tied to disagreements regarding the proper diagnostic instruments, treatment modalities, degree of sensitive discernment from related disorders, and degrees of dysfunction associated with the disorder (Conrad, 2006).

These intra-professional turf wars over the disorder are, however, less important than the achieved classification of AD/HD in the *DSM* – a political, professional, and bureaucratic assemblage that produces encyclopedic definitions of various disorders. As scholars such as Brown (1987), Horwitz (2002), and many others have demonstrated, the *DSM* entails a socially necessary language or “code” that practitioners must employ irrespective of their paradigmatic commitments to the neo-Kraepelinian philosophy underlying the *DSM*, occupational position within the hierarchy of psy-professionals, or internalized commitments to the categorizations in the *DSM*. In short, the *DSM* organizes diagnosis and structures professional practice and lay identities. Achieving official diagnostic recognition has powerful financial, communicative, therapeutic, and bureaucratic consequences. For this reason, the production of the *DSM* is best seen as a political project rather than a transparent reflection of science (Kirk & Kutchins, 1992). Genealogies of specific disease entities such as PMS (Figert, 1995, 1996), post-traumatic stress disorder (Scott, 1990; Young, 1995), schizophrenia (Boyle, 1990), and AD/HD (Conrad, 1992, 1999, 2006; Lakoff, 2000; Rafalovich, 2001) illustrate the role of contingent historical forces as opposed to progressively purer forms of knowledge in shaping many disorders. Thus, the *DSM* falls somewhat short of its stated purpose – to provide a universal system of diagnostic classification that, because it emerges from “pure” observation, would transparently and reliably reflect disease states in individuals. The *DSM* is a classic locus of authorized knowledge (Swidler & Ardit, 1994); it is the main storehouse of available psychological diagnostic classifications (Jutel, 2009) and hence powerfully structures the various lay processes involved in maintaining, reproducing, and subtly using diagnoses.¹

Lay participation in the expansion of AD/HD has been extensive, although the process has been dominated by professional knowledge and corporate interest. Indeed, lay participation is often expressed through powerful national-level organizations dominated by professional and corporate interests. This organizational model is exemplary of CHADD (Children and Adults with Attention Deficit Disorder). However, smaller organizations devoted to particular facets of the disorder (such as Adult AD/HD) or

semiautonomously organized groups in local areas also operate within professional-lay knowledge coalitions. These lay organizations provide educational reforms to the public, distribute and organize professional knowledge, and increasingly operate under a disabilities framework that both instantiates the disorder and offers a political sensibility to participants combating the perceived stigmatization of AD/HD. This disability framework emphasizes the creativity, spontaneity, and even brilliance of a *differential* type of attention in contrast to a *deficit* of “normal” attention. In addition, other significant actors such as pharmaceutical companies are enrolled in these coalitional organizations. As [Conrad and Leiter \(2004\)](#) note, the alliance between corporate and lay groups – seen, for example, in the direct funding and interpenetration of both national advocacy groups such as *CHADD* and segments of the professions – indicates a new strategy for “big” pharmacy. They no longer merely promote medication but illness itself, and they do so at an increasingly grassroots level that blurs the distinctions between lay, professional, and corporate interests ([Conrad & Leiter, 2004](#)).

Other prominent actors – only partly enrolled in the broad coalition – include quasi-professionals such as teachers, institutional actors in education and political policy, and media cycles that represent the contentiousness of the disorder, as well as the technological and financial interests of large corporate pharmaceutical companies. These actors, briefly sketched here, represent a decentered constellation of positions that shape the possible meanings of AD/HD in terms of what is speakable, visible, and practicable in relation to the disorder. This participation – in the form of national and local organizations devoted to public education as well as national-level mobilization efforts, a voluminous self-help literature, and extensive, controversial media coverage – helps constitute AD/HD as a cultural phenomenon in its own right. AD/HD is a widely available medical category that, while differentially employed by adults, parents, and professionals, has evolved into a coherent entity characterized by an inter-alignment of actors that participate, deploy, and shape it as an interstitial form of knowledge.

STUDY AND SETTING

This analysis is derived from a two-year ethnographic study of a local AD/HD support and informational group. *Active* was predominately composed of middle-class married women with children located in a relatively wealthy suburb in an economically depressed northeastern city. The group sponsored a professional speaker series about AD/HD, offered

advice for those seeking institutional support for the disorder, and provided a social support network for parents and adults identified with the disorder. The primary work of the group was the production and organization of two regularly occurring events – presentations by local professionals relating to AD/HD and support group meetings where laypersons could discuss, share, and receive support from one another. As with other types of medically focused social movements, the group was enrolled in a broader coalition of actors and maintained extensive ties to local AD/HD practitioners, to a nationally funded, locally based AD/HD research center, and to national-level organizations promoting the disorder. The group provided the opportunity for a compelling theoretical sample of the broader AD/HD landscape – it was primarily composed of lay individuals who conceived of their task as educating the broader community and empowering those with the disorder while maintaining strong ties to aligned professionals and recent developments in professional knowledge.

The case study employed a combination of ethnography with the local mothers'/parents' group and two waves of open, semistructured interviews with the groups' core members. Participation in the group was premised on the full disclosure of my status as researcher. I have used pseudonyms throughout the study.

NAVIGATION TECHNIQUES

Active was a creative space that carved out an intensive domain of its own that operated under and with multiple hierarchical dominations. First, professionals (certainly through little fault of their own persons) occupied a superordinate role as gatekeepers for the diagnosis and treatment of both their children's problems and their own. Incontrovertibly, at a broad level, this gatekeeping function (Dumit, 2006) was tied to the authorized "truth" of certain situations as instances of disorder as much as it was tied to the institutionalized claims made for services in school settings and reimbursements from insurance companies. Yet, because AD/HD is a broadly controversial diagnosis, *Active* was forced to develop collective techniques that both lay and aligned professional actors used in managing the dilemmas of over-, mis-, and underdiagnosis of the disorder. The use of three prominent techniques, (1) *credentialism*, (2) *mal-diagnosis*, and (3) *achieved diagnosis*, helped maintain the AD/HD knowledge coalition. While partially subordinate to broad knowledge claims raised by professionals, lay actors were able to shape the discourse by challenging nonaligned professionals and other

laypersons with authorized knowledge derived through *credentialism*; securing their positive diagnoses as objective by discounting negative diagnoses as instances of *mal-diagnosis*; and, deploying their pragmatic knowledge of aligned professionals to positively *achieve diagnosis*. Conversely, aligned professionals were able to shore up challenges to the legitimacy of the knowledge coalition through their use of these same techniques.

Credentialism

Credentialism was employed by both lay and professional persons to distinguish the ignorant and the knowledgeable and to establish a loose scale of relative credibility to speak about AD/HD. *Credentialism* is similar to Becker's classic *hierarchy of credibility* (1967) whereby higher status individuals, such as medical authorities, are both able to and in fact are expected to "define what is real" in a given situation. In this study, however, *credentialism* established a range of credible speakers based on two overlapping axes: (1) professional credentials that distinguished the most authorized (specialist psychologists and psychiatrists, specialist researchers, nationally renowned experts) from the least (moralizing family members, unsympathetic teachers, investigative journalists) based on their relevant training in general and (2) the location of the speaker within the knowledge coalition on AD/HD. This combination produced the possibility that a lay expert might have more extensive, up to date, and hence credible knowledge than an "old fashioned" pediatrician or other nonaligned member of the knowledge coalition. *Credentialism* gave credence to certain speakers' views on AD/HD based on a broad array of relevant credentials that, while dominated by professional titles, also included primary lay experience and involvement in the advocacy group as valuable sources of credibility. *Credentialism* was employed by both professionals and laypersons as a defense against the rampant media cycles and exposes of AD/HD, the critiques from "lower order" professionals such as teachers or "unqualified" mental health professionals, and moral claims from "ignorant" family members. Below, I offer four examples of the expression of this logic of *credentialism* as a situated tactic.

First, Edith's (a group leader) response to my interviewing entailed a critique of both media expose's and the ignorant way these were conducted. Fortunately, as a main gatekeeper, Edith coded my position as an

“academic” one, and thus as legitimate in contrast to her positioning of the media.

Edith: I’m not worried about the students. In fact I’ve done several interviews with students and I’ve been involved in several studies. Yeah, so that doesn’t bother me so much. The press [PCF: Yeah], I have different thoughts about. I wouldn’t be sitting here – you know-if you were the press [PCF: Yeah, right.] ... and I probably wouldn’t be doing it anyway. PCF: Why?

Edith: Because they can take things out of context, they seem to have their own slant on it.

PCF: So, you’ve had bad experiences in the past?

Edith: I haven’t had any. No, actually, I was interviewed for the newspaper – did I show you that article? [PCF: No, I don’t think so] – I have an article in my office ... of uhhh, that was another one of the things I did for Rogers [a local AD/HD researcher], uhm, I was interviewed when uhh, the news came out ...

On further pursuing this question Edith responds by quoting a professional:

Edith: Not even that it’s drugs, but they just put a slant on it, and its interesting, one of the more interesting comments I heard from another one of the, uh, scientists, Russel Barkley was giving a talk, and he said: The problem with the media is that you get people reporting on scientific matters, such as AD/HD, and they have no scientific background. So, they’re not coming in, really, uhh being objective or trying to – you know-do an expose. It’s really such a coincidence that that’s how you get a lot of misinformation out there – you get a lot of people reporting on something that they don’t have any background information on.

Second, this *credentialism* also extends to certain forms of attack that stem from nonaligned professionals. This is evident in response to a relatively conservative editorial that the group was discussing concerning a prominent and popular lecturer on the parenting circuit. The critic in question was characterizing AD/HD as an excuse for bad parenting – a position the parents were vehemently and passionately opposed to on a number of levels. This was seen as a central “attack” on their position and the main defense was issued by Edith against the author: (Paraphrasing) “He’s not qualified to say AD/HD doesn’t exist, he doesn’t even have a Ph.D. He’s only got a Masters in family counseling He’s not an expert.”

Third, parents also deployed this credentialist distinction among family members – dividing those who were “knowledgeable about the disorder” and those who were not. That is, supportive family members were “knowledgeable” about the disorder and could recite credentialed expert opinion and hence sustain their legitimacy to the degree they didn’t move beyond the bounds of the experts’ knowledge. This established a subordination of lay to “official” knowledge that actually masked lay selectivity

of both the knowledge claims and those experts understood to be “truly” credentialed.

Fourth and finally, professional members of the group were also engaged in this tactic. Kevin (a professional therapist and member of the group) cited the use of WebMD and the rising popularity of the diagnosis as driven by “customer” (in contrast to “patient”) demand. He argued that popularity, together with layperson’s lack of overall knowledge of the disorder, did indeed produce quackery in some domains of the AD/HD market. His view thus turned the epistemological ambiguity that drives AD/HD on its head – AD/HD is not circulated and made popular *because* it is an essentially flexible diagnosis, rather it is circulated because those who are ignorant and noncredentialed misinterpret the relative stability of the complex diagnosis.

From the perspective of laypersons, *credentialism* is a useful but nonetheless problematic approach to the management of contradictory knowledge claims. As a tactic (de Certeau, 1984), it works to shift attention away from potentially disruptive questions of independent and reliable sources of truth claims through acceptance of authorized spokespersons. The limits of this deferral lie in laypersons’ eventual encounter with equally credentialed persons with contradictory judgments – a situation that requires new navigation techniques.

Mal-Diagnosis

How do parents and professionals contend with expert knowledges that do not support their identification? AD/HD diagnosis is characterized by low degrees of diagnostic reliability, by a multiplication of assessment techniques (Wolraich et al., 2004), and by an aura of contentiousness. These qualities stand in contrast to the claims of both professionals and lay participants that AD/HD is a transparently identifiable disorder. As with other functional disorders, the lines that divide the normal from the pathological are fluid and expandable. Yet, the cultural logic of AD/HD discourses is premised on the division between a disease formulation of biogenetic causes and a wide range of illness experiences tied to functional problems in a variety of domains – a formulation highly amenable to claims-making processes. Because of this disease foundation, AD/HD is staunchly defended as a highly objective form of knowledge. At broader cultural levels of diagnostic classification, the *DSM* operates as a set of standard, objective diagnostic criteria that secure this objectivity. At the local level of lay participants and practicing professionals, however, the very operationalization of these criteria pressures

actors to tacitly overlook or explain away discordant AD/HD diagnoses. For example, Edith's pathway to achieving a first diagnosis took her through multiple professionals, many who offered either ineffectual or derogatory forms of advice. Edith was forced to deny certain authorized yet negative diagnoses in order to ultimately achieve a positive AD/HD diagnosis; only this final diagnosis was deemed objective while the others were instances of poor professional judgment. This procedure entails a practical and discursive effort on the part of Edith and other parents.

Likewise, and more formally, while aligned professionals are frequently criticized for the expansiveness of the diagnosis, professionals frequently claim this is partially explained by a lack of skill among nonaligned diagnosticians. For example, in a speaking engagement offered to undergraduates, a nationally prominent AD/HD researcher argued that the question of the "over diagnosis of ADD/ADHD" was an "irrelevant" question, that diagnosis was not a fundamental concern, and that "we shouldn't care about diagnosis."² The real concern was helping children and their parents with their problems. The justification was that "parents come to get help with behavioral problems" and are themselves unconcerned with "official" diagnoses. The obvious difficulty with this stance is that the very nature of the problem (e.g., AD/HD vs. lead poisoning or immoral mothers or MTV) is itself in question *for* the parent or child seeking help because the "solution" to the problem will dramatically differ based on the type of problem faced. Similarly, other professionals also frequently answer the question of the over diagnosis of AD/HD with the response that the condition is both over and underdiagnosed.

The common vehicle that *Active's* parents and professionals used in distinguishing an objective diagnosis was *mal-diagnosis*. The concept of *mal-diagnosis* is centered on the notion of a true or real diagnosis that is missed in different ways. Both professionals and laypersons use the term to refer to those cases where diagnoses have been both overlooked *and* misapplied. Rhetorically, the term implies that there are "objective" cases of AD/HD and the mistakes occur in "seeing" these cases where they are not present or not seeing them where they are present. It is quite common then for both lay and professional persons to comment on the expansion of the diagnostic categories as an instance of this *mal-diagnosis* – a vehicle for managing the skepticism and doubt that surround the proper classification of cases. This technique operates by relating two elements: an objective truth of the disorder as evidenced by the symptoms it presents and a skill that the diagnostician employs to properly read these symptoms as an interpretive and skilled "art" – a common and frequent evaluative component of most

true professions that are autonomous, self-regulating, and discretionary in their judgment (Feinstein, 1967). The technique thus supports the contention that AD/HD is both under- and overdiagnosed based on a misreading of the objective symptoms – a position that implies that there is or has been a gold standard on which true cases might be judged. Hence, the deployment of *mal-diagnosis* entails both an epistemological defense of AD/HD's ultimate objectivity and a way of accounting for its erroneous categorization. Because of its utility, this tactic was shared by both professionals and knowledgeable laypersons alike. For example, *Active's* parent's support group frequently evaluated different individual professionals partly on this basis and partly on the equally variable skill of effective treatment. Likewise, aligned professional specialties critically evaluated other nonaligned professions on their acumen and rigor in diagnosing AD/HD – for example, psychologists interviewed in this study considered pediatricians in general to be relatively unskilled and cursory in their diagnoses. Yet, the deployment of *mal-diagnosis* for both professionals and laypersons does not develop into a form of noxious skepticism concerning AD/HD as a discrete entity. The rhetorical force of this position arises because two different instances are conflated: the evaluation of particular cases on the one hand and the evaluation of the entity itself.

As Aronowitz (1998) notes, medicine in particular has trended toward the rationalization of medical judgment over the “art” of clinical interpretation (Feinstein, 1967) – a trend that is exemplified by the use of standardized paper and pencil surveys and reliance on the *DSM* in the diagnosis of AD/HD. However, numerous difficulties arise in these official standardization procedures; the paper and pencil procedures yield extremely low rates of inter-rater reliability, diagnosticians frequently do not employ all available tests, the diagnostic standards themselves are in constant flux, and the proliferation of different diagnostic instruments are not themselves correlated with one another. All these factors lead to low rates of reliability for AD/HD diagnosis (Wolraich et al., 2004), certainly far too low to firmly establish the “objective” character of diagnosis that is imputed to it.

The possibility of an incorrect diagnosis from authorized professionals can, however, only emerge when the nature of the diagnostic process is clarified so that an authorized person can both have proper “credentials” and make a “mistake.” This is achieved, nonintentionally, through the emphasis on the “art” of good diagnosis related to the overall “complexity” of the disorder. In linking both the objectivity of the disorder and the complexity of a proper understanding, a space is created in which diagnosticians can be both well trained and hence authorized to make

judgments, but also more or less subjectively talented in fully grasping this objectivity of the disorder.

However, the interpretations of certain paper and pencil tests – ostensibly “objective” indicators of the disorder – are themselves problematic without sufficient attention to the clinical syndrome that underlines the disorder. Kevin describes the inflation of AD/HD cases through the indiscriminate use of such diagnostic tests. Because the disorder is operationalized in different ways, it is not at all clear what many of the scales appear to be tapping:

Kevin: Some people say, “Well give the kid a Conner’s scale.” If you popped one of those things on my kids, they’d both come out today as having an attention deficit disorder. [Neither son is diagnosed.] When using the Conner’s, you can get incidence of 50%. Take a population of kids, have parents fill out a Conner’s scale, you get an incidence of 50% based on just how parents are describing their kids. So, there’s variables other than measuring the neurobiology of the disorder there – there’s the parents frustration level, the kids anxiety and conduct problems, whatever. So, it has to be a comprehensive way. And, generally speaking, I think, not to toot our own horns, but psychologists do that kind of stuff better than other professionals.

PCF: Mm-hm.

Kevin: Testing.

Likewise, the use of the Conner’s is problematic because it merely demonstrates some symptomology; it isn’t designed to expose the causes behind it – a task that only clinical practice can satisfy.

Kevin: I mean use the Conner scales, but as a kit. But if you get, if you get a low score on the hyperkinesis index of the Connor scale – all it tells you is that this type of symptomology is present. It doesn’t tell you if it’s from anxiety, auditory processing disorders, or the fact that the kid is a brat. Then you’ve got to investigate it. And that’s the advantage of psychologists, we have a wide range of assessments available to us. And you use different assessments, looking for different things.

With *mal-diagnosis*, then, actors construct an axis that unites two poles: an objective method that can putatively be *independently* confirmed through paper and pencil test and other measurements, and a skill at ferreting out the complex layering of these scales in the “art” of diagnosis. Beneath the tools and methods used to achieve the results, respondents tend to reproduce an “objective-subjective” axis such that credentialed authorities can be simultaneously “credentialed” and “incorrect” in their estimates—resolving the dilemma posed by reliance on authority as the source of knowledge.

Achieving Diagnosis

Active members were equally interested in what might be termed the pragmatic achievement of diagnosis. As a form of knowledge that certifies a subjectively already understood condition, group members were frequently forced to find second, third, and fourth opinions from authorized professionals. Interestingly, those parents who were not self-identified, but who only sought a diagnosis for their children with the pragmatic intent of receiving necessary services would refer to their children's diagnosis as "getting certified." For these parents, the pragmatic appeal of receiving educational services was sufficient. Conversely, those members of the group who were self-identified with the disorder and who were successfully diagnosed spoke of this as both a relief and cause for some minor personal celebration – they were reassured of their own evaluations. The self-identified parents expressed a type of anxiety that highlighted the dilemmas of the disorder: If diagnosis could be achieved through the techniques of *mal-diagnosis* and *credentialism*, what other indicators could guarantee that the correct diagnosis was achieved?

Interviewees demonstrated a core ambiguity concerning the status of both professionals and professional knowledge. On the one hand, a traditional form of deference and respect for professional judgment was evident among the activists; at times this emerges as a form of extreme deference to professional judgment with scant prospect of an independent verification.

Edith: It's my opinion, its not uhhh – based on anything ... I mean anything scientific (paraphrased from field notes).

Yet, Edith also recounts that she ultimately arrived at the diagnosis by rejecting three professionals and their judgments on the basis of her own intuition. One early child psychologist, operating from a psychodynamic approach, suggested that Edith was suffering from counter-transference and needed more therapy than her son did. Edith recounts, "It was me, it was all on me ... I was in tears you know." This approach was rejected, as were various forms of "unhelpful" but well-intentioned advice by her pediatricians. Likewise, a behavioral specialist was rejected because Edith didn't get the sense that she liked children or had an authentic connection to them.

Edith: I just felt she had a canned presentation with the children – she called him buddy- and you just can't do that with a kid unless you have a rapport with them.

Indeed, this rejection is quite scornful in many instances. Edith relates how her three-year-old son was able to subvert what Edith thought was a

poor form of behavioral therapy involving the use of cheap (Edith: “I mean, cheap crap”) toys as inducements; her son (Manny) was able to steal items from the therapist’s desk – a moral victory because he returned them to the therapist “as if saying, see, I can get this stuff anytime I want.”

Edith: [after the “theft”] ... And she finally said to me in front of Manny, “See, you really need some help with this kid, he’s totally out of control.” And when she said that to me in front of Manny, I truly wanted to get up and grab her by the throat and say – “look here you stupid bitch” ... you know, I really wanted to just say, you know ...

This hostile sensibility is often repeated in interviews and exists as a subterranean thread woven throughout the fabric of AD/HD discourses. It is composed of the parent’s defensive response on behalf of the child (despite explicitly exasperating behaviors) and a submerged form of anger, indeed resentment, against expertise and the determination of pseudo-expertise. Yet, Edith is generally quite deferential toward physicians; it was she who invoked the lack of credentials on the part of an editorialist who articulated a more traditionally moral response to poorly behaving children. Others in the group likewise castigate family members and neighbors for “lacking knowledge” of AD/HD, according to the loose scale of credibility outlined above. So, parents appear to grant professionals speaking time, but if the types of interventions don’t achieve the right balance or tone as evaluated against their own desires and experience, parents have no difficulty in shunting some professionals aside. This is observable at the level of everyday conversations, in the pattern of referrals and “shopping” for professional help, and at the level of narratives that depict parents becoming “empowered” through lay advocacy knowledge of AD/HD. For example, Edith reports that after she began “reading up” on AD/HD and participating in CHADD, she began “interviewing” prospective professionals with a cogent set of demands.

While the pragmatic achievement of a diagnosis was reassuring, the very fact that this *was* an achievement introduced novel forms of skepticism that had to be further managed. For example, two of the members who were self-identified with AD/HD expressed ambivalence concerning their achievement. Danielle was diagnosed with AD/HD between our two interviews. In the first interview, she communicated a certain anxiety about the possible results of the diagnostic exam – expressing the possibility that perhaps she “is simply crazy” and not truly AD/HD.

Danielle: I think I mentioned to you last week that I was going to see Dr. F to be diagnosed. And, no surprise of course I was diagnosed. And uhm..

PCF: What did he use, do you remember?

Danielle: He-he used, he didn't do any test like on attention or anything like that. He just used – he had a list of questions he asked me, a two-sided typed up thing. I mean it was like an official [PCF: questionnaire], like it was an official questionnaire. And so we spent over an hour just going over these different things and based on my responses – [but] there was no measure. That sort of troubled me, but it didn't trouble me because I knew without him telling me ... so [PCF: right] ... there wasn't like a doubt in my mind that it might be something else or. [PCF: right, right]. I have attention deficit anyway, so who cares.

Despite this subjective knowledge of her illness, the diagnostic test is anxiety provoking because it risks the possibility of failing to secure and validate her experience. Despite the posttest assurance exhibited by Danielle, a successful diagnosis is necessary in order to “really” have AD/HD and not simply be “crazy.” Indeed, if she were really so assured then the test would be irrelevant and she would demonstrate no concern for the test's methodology. Danielle's case is representative of all members of the self-identified group and demonstrates a collective anxiety for legitimating their subjective knowledge through diagnosis.

For Danielle the diagnosis contains similar degrees of both utility and danger if it is not used in the proper way:

PCF: You mentioned just now, the teachers were inclined to attribute behavior problems to parenting issues. Had they been consistent with that?

Danielle: [...] And again, he wasn't doing like bad things or dangerous things, but, he would be, he would be ... wild!!!! And I would sit there and go, “Ohhh, he's so beautifullll.” “He's so smart, look at him, he's so wild and free,” you know. Little did we know, you know [light laugh] what we were doing [...]. And the other thing is that I don't like, is that, AD/HD has become ahh ... convenient . Not as a uhm, an anomaly, but as ... characteristics of a person's personality. And nurturing that – you give them Ritalin til they calm down – I got a problem with that. Ok. Yes, you do need to be calm, yes you do need to function in the world, but ... if you have all this energy, ok, let's channel it.

Meredith, another core parent self-identified with the disorder, also exhibited an unusual but nonetheless instructive form of skepticism surrounding the achievement of diagnosis. First, she discusses the ways that laypersons engage in a type of shopping expedition for medical solutions to a wide array of problems.

Meredith: I also looked into, you know, the allergies. You know, everyone – scuse me, there's a doctor down South that says there is no Attention Deficit. And uh, it's the allergies, food allergies and that. We went to an allergy specialist, and went through everything. I did step by step, the person I got off the internet was, fifteen symptoms that could seem like Attention Deficit. And I went through all of them, and I had everything

tested. I had her eyes tested, I had her hearing testing, I had the allergies tested. Because I would not accept the diagnosis either.

PCF: Oh, interesting. [Yeah]. So, when you first got the diagnosis, you didn't ... [no, no] – you wanted to be sure. [I wanted to be sure.] You were skeptical of the diagnosis.

But, once diagnosed, the achievement remained tied to an underlying desire for positivistic proof of the disorder – a transcendent empirical indicator that would make the disorder visible once and for all.

Meredith: Yea, yea, I'm still skeptical – I will always be skeptical. Why I don't know. Maybe I'll always be skeptical of this thing they call Attention Deficit because they haven't shown me a CAT scan of my daughter's brain. Show me that CAT scan of her brain, not only that it will prove to me, but I also want to see what part of her brain is working and isn't. Because that fascinates me. You know, when they talk about the connections that the brain makes.

CONCLUSION

With the slowly developing and long overdue attention focused on diagnosis itself (Brown, 1987; Jutel, 2009), researchers have shown that diagnoses are unique among classifications insofar as they contain a particular morality and seriousness (Conrad & Schneider, 1980; Jutel, 2009; Zola, 1972). Diagnosis matters deeply – both for therapeutic and symbolic purposes. In the former, diagnoses are tied to consequential treatments; for the latter, a proper diagnosis leads to a shift in identity. While a number of studies have focused on the historical process of certain classifications of disease over others, fewer have focused on the ways these classifications shape and are shaped by lay actors. This oversight is increasingly apparent in light of the growing number and type of coalitions mixing professional and lay actors.

AD/HD, unlike subjective “beliefs” or “faiths,” operates through the distinction of an authorized disease status – a diagnosis – linked to a flexible set of illness experiences. Because of this interstitial mode of AD/HD knowledge, wide-ranging skepticism of the disorder places pressure on actors to maintain the objectivity of the diagnosis. This pressure is not, however, abstractly epistemological, it requires practical tactics that are associated with the navigation of professionals and their, at times, contradictory knowledge claims. This research suggests three such common tactics: *credentialism*, *mal-diagnosis*, and *achieved diagnosis*. Tactics, as captured by Bourdieu's (1990; Bourdieu & Wacquant, 1992) concept of nonconscious action lies precisely at the edge of intentional action made pragmatically

available within a given “field” of relations. Laypersons are beholden to professional diagnostic opinion, whether this arises within or without the knowledge coalition. Tactics evolve as practices that allow laypersons to effectively navigate between and among professionals and professional knowledges. While these are successful tactics, they also express both an ambivalence toward and a resistance to expert determinations that are deemed unhelpful. Hence, through navigating professionals, lay actors exhibit extensive agency despite their subordinate status. At the same time, lay actors help secure the objectivity of the diagnosis while modifying them for their own purposes. Finally, the use of these tactics by aligned professionals speaks to the partially shared lay/professional task of managing the legitimacy of the disorder in the face of skeptical challenges.

NOTES

1. See Malacrida (2001, 2002, 2003) for excellent analysis of these processes in relation to AD/HD.

2. At another level, a disregard for diagnosis demonstrates a pattern long understood in the sociology of illness and social control – medical personnel treat interventions as always benign and seldom perceive the risks or dangers associated with it (Horwitz, 1990). Psy-professionals are most likely to risk overdiagnosis than underdiagnosis on this basis of this logic (Brown, 1987).

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PART IV
IDENTITY

THE VANISHING DIAGNOSIS OF ASPERGER'S DISORDER

Jennifer S. Singh

ABSTRACT

Purpose – This chapter discusses the proposed changes in the Diagnostic and Statistical Manual of Mental Disorders (DSM-V), which eliminates Asperger's disorder (AD) and replaces it as "autism spectrum disorder." Implications of these changes on the identity of adults with AD and the influence of everyday life experiences will be addressed.

Methodology/approach – This research is based on 19 interviews with adults diagnosed or self-diagnosed with AD. Central themes surrounding issues of identity and everyday life experiences were determined using grounded theory approaches.

Findings – This study demonstrates how the diagnosis and self-diagnosis of AD is fused with individual identity. It also shows how Asperger identity is positively embraced. The proposed changes to eliminate AD in DSM-V threaten these assertions of Asperger identity, which could potentially enhance stigma experienced by people with AD. Regardless of its removal, Asperger identity must be considered within the broader context of people's everyday lives and how experiences in social interaction and communication can be strong agents of identity construction.

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Social implications – *The proposed changes to eliminate AD in DSM-V is a social issue that will impact individuals with Asperger’s and their families, as well as health-care professionals, health insurers, researchers, state agencies, and educational providers.*

Originality/value of paper – *This chapter offers a unique insight into identity construction based on the diagnosis and self-diagnosis of AD.*

Keywords: Asperger’s disorder (syndrome); autism spectrum disorder; identity; everyday life; diagnosis; *Diagnostic and Statistical Manual of Mental Disorders (DSM)*

I was amazed by how many minor aspects of my life and personality fit different symptoms of Asperger’s syndrome. From the way I cook my food to the video games I like. Some of the minor things that I didn’t know are a part of it that I thought were just my own quirks. I’m probably not as original as I thought I was. I’m Asperger’s syndrome. (Jason, a 24-year-old Caucasian male diagnosed with Asperger’s disorder)

I look at [Asperger’s syndrome] more as a personality trait and not a disease to be identified, worked through or medicated. It’s more of a training to learn to live with the traits that you have. They vary a lot. Asperger’s is a difference between people. (Carson, a 55-year-old Caucasian male who self-diagnosed as having Asperger’s and has a child diagnosed with Asperger’s disorder)

The emergence of Asperger’s disorder (or syndrome) (AD) occurred in 1994 when “Asperger’s disorder” was included as a categorical diagnosis in the fourth edition of the *Diagnostic and Statistical Manual of Mental Disorders (DSM-IV)* (American Psychiatric Association [DSM-IV], 1994). Since this time, thousands of children, teenagers, and adults have received a diagnosis of AD and thousands more have self-diagnosed or identified themselves as having Asperger’s. As indicated by the opening vignettes, the meanings of Asperger’s disorder are associated with personal identity, a labeling of certain characteristics, or personality traits that require training to adapt in society. Clearly, the meaning of Asperger’s disorder is more than the sum of its symptoms or stereotypes and the implications of these meanings have the potential to affect a person’s identity and everyday life experiences. Since the addition of the Asperger diagnosis in *DSM-IV*, a community of “Aspies” has emerged, many who want their strengths to be acknowledged and wish not to be “cured” (Bagatell, 2007; Baker, 2006; Bumiller, 2008; Chamak, 2008; Silverman, 2008). The emergence of “Aspies” has been described as the neurodiversity movement, which is a new wave of activists who want to promote and celebrate their difference as a positive

identity, not a disability (Soloman, 2008, May 25). However, for many individuals diagnosed or self-identified with AD, the emergence of the Asperger diagnosis and now its potential removal, have come all too quickly. Under the proposed fifth edition of the *DSM* (*DSM-V*), which is due out in May 2013, the diagnosis of Asperger's disorder is currently being eliminated from a distinct category within the "pervasive developmental disorders" to a certain level of severity under the broad category of "autism spectrum disorder" (American Psychiatric Association [*DSM-V*], 2010).

The ability of a medical diagnosis to define current notions of individual and group identity is continuously emerging in our society (Adams, Pill, & Jones, 1997; Beard & Fox, 2008; Conrad & Potter, 2000; Jutel, 2009). Within the tradition of symbolic interactionism, a medical diagnosis has been described as a "status passage" that connects turning point experiences to person and group identities (Glaser & Strauss, 1971). Some medical diagnoses, especially in the case with mental illness, pose threats to identity and self based on the stigma attached to the label (Corrigan, 1998; Link, Struening, Rahav, Phelan, & Nuttbrock, 1997). As Goffman (1963) asserts, stigma or the failing or shortcoming based on tainted or discrediting attributes, enables a set of social attitudes and practices to discriminate against selves and others in daily encounters. Thus, the presentation of self in everyday life requires constant negotiation and adaptation to the social and physical environment once a stigmatizing label has been conferred (Goffman, 1963). Mental and psychiatric diagnoses not only have the potential to indict the whole person but also threaten to become their master status. Here, the diagnosis and identity can fuse which can potentially pathologize a person and depending on the diagnosis, pose an existential threat. As Scheff (1984) proposes, stereotypes of the mentally ill are continually reaffirmed in ordinary social interaction and exist alongside the medical diagnosis. He argues that when "role images" of the mentally ill become part of the social structure it is hard for individuals to relinquish their deviant status (Scheff, 1984). Thus, a medical diagnosis can invoke feelings of unacceptability or inferiority and shame based on the infringement of normative ways of being (Scambler & Hopkins, 1986). In the case of AD, stigma resides largely in the association it has with the label of autism. Here, the negative stereotypes associated with autism are improperly attached to a person diagnosed with AD.

The moral career between the self and its significant society (Goffman, 1961, 1963) also reflects the transformation of identity based on the diagnosis (or self-diagnosis) of AD, as well as the positive identity associated with Asperger's in broader society, especially through popular

culture and autistic autobiographies (Furedi, 2006; Hacking, 2009). As Furedi (2006) contends, a medical diagnosis can help explain individual behavior and constitute long term, sometimes positive, basis of identity. However, it must be noted that although the diagnosis of AD has legitimated social and communication barriers, as well as past and present struggles in everyday life, the transformation and construction of self can be a lifelong process that requires constant negotiation between diagnosis and identity.

There are a range of relations that exists between diagnosis and identity from resistance toward diagnostic labels (Bayer, 1987; Bryant, 2006; Scott, 2006) to calls for medicalization to develop meaningful self-identities, gain legitimacy, or to avoid stigma (J. N. Clarke & James, 2003; Dumit, 2006; Furedi, 2006; Zevestoski et al., 2004). For example, the inclusion of homosexuality in the first (1952) and second (1968) editions of the *DSM* ignited a politically active gay community in the United States to demand its removal, which eventually occurred in 1973 (Bayer, 1987). On the other extreme, Dumit (2006) demonstrates how chronic fatigue syndrome (CFS) and multiple chemical sensitivity are “incompletely biomedicalized” (p. 578), which creates a form of exclusion from health-care systems and the sick role. Diffused symptomatology and uncertainty connected with the illness of CFS are also significant for stigmatization (Asbring & Narvanen, 2002). Although the diagnosis of AD is situated within these debates of resistance and inclusion, this study illustrates the embracement of the Asperger identity (i.e., Aspies), which partly emerged based on its inclusion in *DSM-IV* (*DSM-IV*, 1994).

ASPERGER’S DISORDER AND DSM

Asperger’s disorder (AD) was first described in 1944 by the Austrian pediatrician Hans Asperger. In his original clinical accounts, he described a group of children who lacked nonverbal aspects of communication, demonstrated impairments in two-way social interaction, enjoyed repetitive activities, and were physically clumsy. He described this condition as an “autistic psychopathy” form of personality disorder (Wing, 1981). A year prior to Asperger’s publication, Leo Kanner, an Austrian psychiatrist and physician from Johns Hopkins University, described a similar condition that he called “early infantile autism,” which he portrayed as a somewhat psychotic or psychiatric state (Kanner, 1943). Unlike Kanner, who was internationally acknowledged for his work, Asperger’s contributions were

not known outside of German literature until Lorna Wing “rediscovered” Asperger’s clinical accounts in 1981 (Wing, 1981). In 1994, 50 years after Asperger’s original publication, the American psychiatric community granted AD legitimacy by including it in the fourth edition of *Diagnostic and Statistical Manual of Mental Disorders (DSM-IV, 1994)*.

Currently, AD is classified in the revised fourth edition of *DSM (DSM-IV-TR)* as one of the “pervasive developmental disorders” along with autistic disorder, pervasive developmental disorder, not otherwise specified (PDD-NOS), Rett’s syndrome, and child disintegrative disorder (American Psychiatric Association [DSM-IV-TR], 2000, pp. 69–84). AD is clinically described as a mild form of autism involving social and physical awkwardness, which is sometimes, but not always, combined with verbal precocity and intense but limited learning interests (DSM-IV-TR, 2000, pp. 80–84). According to *DSM-IV-TR*, the basic diagnostic distinction between autism and AD is absence of clinically significant delays in language, cognitive development, and adaptive functioning in the Asperger group (DSM-IV-TR, 2000). Prevalence rates are often reported under the broader term of “autism spectrum disorder” which typically includes those with autistic disorder, AD, and PDD-NOS. As such, autism spectrum disorders are increasingly prevalent. They now affect about 1% of American children according to the CDC (Center for Disease Control and Prevention [CDC], 2009). Prevalence estimates for AD in children range from 2.5 to 48 per 10,000 and the prevalence among adults is unknown (Fombonne, 2001, 2003, 2005).

ASPIES AND DSM DEBATE

The proposed changes in *DSM-V* intend to collapse autistic disorder, AD, PDD-NOS, and child disintegrative disorder into one broad category, autism spectrum disorder (DSM-V, 2010). Individuals along the spectrum will be differentiated by level of symptom severity. Since the announcement of these proposed changes in February 2010, there has been extensive debate in favor and against the elimination of the Asperger diagnosis among all the stakeholders involved, including people with Asperger’s, parents, clinicians, scientists, advocacy groups, and policy makers. Critics of the changes stem largely from the Aspie community. According to Michael John Carley, executive director for the Global and Regional Asperger’s Syndrome Partnership (GRASP), members of his organization are split down the middle (Hamilton, 2010, February 10). One of the biggest oppositions to

this change is the fear of the loss of identity. For Carley and others, who are diagnosed with AD, being labeled autistic and associated with people at the lower end of the autism spectrum is problematic. Unlike autism, AD has overcome much of the stigma attached to the diagnosis, which has been extremely helpful for individuals who are diagnosed or self-diagnose as having AD. Thus, folding AD into a severity scale under autism spectrum disorder has very little appeal for individuals who have a strong and positive identity associated with Asperger's.

Those who are in favor of the changes argue that the proposed diagnostic changes in *DSM-V* will help draw distinctions between discrete categories such as autistic disorder, AD, and PDD-NOS. This will allow clinicians to diagnose and treat specific symptoms of severity rather than a generic approach that addresses the categorical diagnosis (Wallis, 2009). Richard Roy Grinker, an anthropologist who studies autism around the world, points out that *DSM-V* changes will be more flexible compared to a narrow categorical diagnosis, especially as people grow older and experience different symptoms and levels of severity over time (2010, February 10). Proponents of elimination also argue that *DSM-V* changes acknowledge the multiple health problems associated with the autism spectrum such as anxiety, seizures, or sensory issues and that by being under one broad category, people might qualify and gain easier access to educational services and targeted treatment. From a researcher perspective, the changes have scientific utility and reflect the genetic and neurobiological similarities between individuals on the autism spectrum.

Although the final draft of *DSM-V* has not been published, the Asperger community and other stakeholders involved are undoubtedly anxiously waiting to see the final *DSM-V* version and its long-term effects. In the mean time, what can be learned from individuals who are living with Asperger's today? Are these legitimate arguments for and against the proposed changes? How do these concerns reflect the identity and everyday lives of people with AD especially for those who are not necessarily part of an activist community? Within the context of changes in the Asperger diagnosis – absence, emergence, and disappearance – this chapter explores the various social identities linked to Asperger's and the identity implications of the expanding and contracting range of classifications that fall under "autism spectrum disorder." It will also discuss the diagnostic tensions (and their implications) that exist between the specific diagnostic criteria for AD and the everyday life experiences and symptoms that are not bounded by the diagnostic criteria.

METHODS

Participants

The data collection for this study consisted of in-depth semi-structured interviews based on open-ended questions ($N = 19$). The sample consisted of referrals from professionals who work with Asperger individuals. The inclusion criteria were: a diagnosis or self-diagnosis of AD, 18 years or older, and the capacity to consent to a research study, which was determined by the referring specialist. The participants consisted of two different age groups and diagnosis status. The first set of participants were older adults, ages 40–55 years, who self-diagnosed as having Asperger's. This group all had a child (or children) with a formal diagnosis of AD and included four males and one female. The second set of participants were younger adults, ages 18–33 years. This group all had a formal diagnosis of AD and included 10 males and 3 females. This male to female ratio is consistent with the four to one prevalence estimates of males compared to females diagnosed with an autism spectrum disorder (Fombonne, 2003, 2005). All the participants were Caucasian and middle to upper middle class. During the interview, the participants were asked what they knew about Asperger's, their experiences with or without a formal diagnosis, and the major challenges they experienced in life. All the interviews were conducted face-to-face, tape-recorded, and transcribed. Each interview lasted 45 minutes to 1 hour.

Analysis

The analysis of the data consisted of grounded theory approaches of abductive guidelines for gathering, synthesizing, analyzing, and conceptualizing qualitative data (A. E. Clarke, 2005; Strauss, 1987). The analysis started with open coding, which is unrestricted coding of the field notes based on observations, interview transcripts, and all other textual data to help produce codes and then categories that capture the data more conceptually (Strauss, 1987). Due to the large volume of data generated, processes of “constant comparative method” (Glaser & Strauss, 1967), “focused coding” (Charmaz, 2006), and “selective coding” (Strauss, 1987) were used to help synthesize and explain larger segments of data. A key element of the analysis was writing theoretical memos on all conceptual categories to elaborate the processes, assumptions, interpretations, and

actions covered by the codes and categories (Lempert, 2007). This allowed for exploration of ideas, expansion of the processes they identify, and served as a tool for linking analytic interpretation with empirical reality. Key theoretical memos relevant to this study were the fusion between the AD diagnosis and identity, and the everyday challenges of social interaction and communication.

ASPERGER DIAGNOSIS AND IDENTITY FUSION

The diagnosis of AD and its associated characteristics and traits were taken up as a form of identity among several participants who had a formal diagnosis of AD. Furthermore, several of the participants, both diagnosed and self-diagnosed with AD, had a positive self-image based on their Asperger identity. For example, Jason, a 22-year-old male who was diagnosed with AD as a teenager, described how certain aspects of his life and personality fit different symptoms of AD and how his own “quirks” and other characteristics are not as original as he once thought. Similarly, Martin, an 18-year-old male who was diagnosed with AD at age 10, described his Asperger identity in terms of specific similarities he had with the Asperger stereotype. He stated,

There is usually a stereotype when there is somebody who has Asperger's. I think I kind of fit in that stereotype. I'm very fidgety. I'm very obsessive. I'm a little bit autistic. I kind of see it as that all fits under Asperger's in my opinion.

Another young adult, Richard, an 18-year-old male who was diagnosed with AD at a young age, found comfort knowing that there was other people like him and felt that the description of AD matched him very well. Richard went on to say that AD is part of his family, even if he was the only one who had an official diagnosis. He stated, “our family is the way it is and if Asperger's disorder wasn't in the dictionary then it wouldn't be in our family.”

The point made here is particularly poignant with regard to the medicalization of disease (Conrad, 1992, 2000), and how diseases are defined, categorized, and sometimes taken up as a form of identity within individuals and families. For this particular family, the medicalization of AD was viewed positively. For example, the father of this participant, Landon, who self-diagnosed as having Asperger's was particularly proud of his capabilities of deciphering complex systems and viewed his Asperger characteristics as what made him valued as a computer engineer. I highlight

these particular examples to demonstrate that not all of the Asperger characteristics described by these participants were framed in the context of a deficit model, which some advocates argue is how *DSM-IV-TR* currently frames Asperger's (Carley, 2008; J. Clarke & van Amerom, 2007). The meaning of Asperger's beyond the disorder in these cases demonstrates how the characteristics conceptualized as pathology in the context of the diagnosis can be completely adaptive in everyday life (O'Neil, 2008).

ASPERGER IDENTITY

Beyond the identity associated with the diagnosis of AD, is the emergence of the identity of Asperger's itself. The Asperger identity is becoming part of mainstream culture through shows such as "House" and "Monk" as well as popular books and movies. Here Asperger's is portrayed as a group of highly intelligent individuals and positive contributing members to society. In addition, Asperger's has been linked to famous intellectuals and innovative thinkers such as Albert Einstein, Emily Dickenson, Thomas Jefferson, Thomas Edison, and Bill Gates. These positive images have been embraced by thousands of people who are diagnosed, self-diagnosed, or associate themselves with AD. Hence, Asperger's has taken on a positive identity, one, which I argue, is moving beyond the diagnostic boundaries. For example, a few participants referred to their families as "Aspies," which represents people with high functioning autism or Asperger's syndrome who view autism as a "neurological difference," not an illness or disability (Bagatell, 2007). Seven of the participants in this study embraced the Asperger identity and viewed this "way of being" in a positive light. These adults were not embarrassed or ashamed to disclose their Asperger identity. For example, Landon, a 50-year-old male, who self-diagnosed as having Asperger's stated,

I have claimed in public to some affiliation with Asperger's or at least somewhere on the autistic spectrum. I don't think that certainly it's not something that one needs to be ashamed of. It does make for some deficits but mostly it's just thinking differently.

Landon goes on to acknowledge that his "weird way of thinking" was his most valuable aspect as a person, one that has given him a lot of freedom and respect in his profession as a computer programmer. Above all, he feels that people with Asperger's need to value themselves and the world around them exactly as it is, "with all its bad points and good points sort of mixed together."

Simon, a 52-year-old male who self-diagnosed as having Asperger's, also views his Asperger identity positively and uses it to help him explain why sometimes he acts improperly in social and professional settings. He has two children diagnosed with AD and refers to himself as an "Aspie." By embracing this identity and disclosing his difficulties in social interactions, Simon feels more comfortable being himself. For example, he described how he lacks a range of emotions, which can be interpreted as not caring or being insensitive. He stated,

Grieving the loss of a loved one tends to be a brief process for me. I have learned to understand that this can appear to others as insensitivity or lack of caring, but that's not the case. I used to try and "fake it" in an attempt to appear normal to others, but that was before I learned about Asperger's. Now I'm more comfortable with just telling people how I am ... at least most of the time.

Simon's disclosure of having Asperger's was his way of coping with his emotional deviance and how others would perceive his actions. Although his grieving process is shorter than others, it is important to note that he does care and uses his Asperger identity as a way to acknowledge his actions to emotional situations. Simon's positive identification with Asperger's also enabled him to be very open about his children's diagnosis and its possible congenital basis.

STIGMA BY ASSOCIATION

The elimination of the Asperger diagnosis to be replaced as a point within the broad category of "autism spectrum disorder" is particularly problematic for people who positively identify with Asperger's. This is largely due to the stigma associated with the autism label and the misconceptions of the relationship between Asperger's and autism. For people who recognize distinct differences between AD and autism, a diagnosis of "autism spectrum disorder" would be hard to accept. These differences exist especially in the negative stereotypes placed on autism and the lack of general understanding of the range of variability in symptoms in people diagnosed with autism compared to AD. Several of the younger participants who had a formal diagnosis of AD explained that this variability is often overlooked when they disclosed their diagnosis. For example, Grace, an 18-year-old female with a childhood diagnosis of AD experiences stigma when she tells people Asperger's is on the autism spectrum. She states,

A lot of people I think when they hear autistic spectrum they think mentally handicapped and sort of slow and they'll be like oh no, a retard. But what they don't understand is most Asperger's people are high functioning, so a lot of us appear normal and we're all quite smart when it comes to academic stuff. But it's the social situations that are harder for us. Everyone is like oh, she doesn't have problems. She's fine. But once they hear autistic spectrum they treat us differently.

As this quote indicates, the negative stereotypes associated with autism are improperly transmitted on individuals with AD. Several of the young adults in this study felt that people had preconceived notions of who they were when they heard the word "autism."

Another misconception about AD is that it is the same as autism. Young adults in this study lamented that people were unaware of the variability of symptoms that can manifest in AD and automatically linked it to autism. For example, Jason, a 24-year-old male diagnosed with AD explained,

When they think of autism they think of someone who can't talk, never learned to communicate verbally, can't make eye contact. They don't understand that there are different levels of autism. I have a level of autism that despite my disabilities I'm still able to function in society, at least to some degree.

These misconceptions prevented many of the young adults in this study from disclosing their Asperger diagnosis. For example, Grace would just tell people she had attention deficit disorder so people would not jump to the negative stereotypes associated with autism. As she stated, "I just don't expect them to understand that while I am on the autistic spectrum I'm not their idea of autism." Thus, given the stigma attached to the autistic label compared to the positive associations given to AD, the changes in *DSM-V* are likely to reduce the disclosure of a diagnosis. Furthermore, these examples reinforce the concern that people have of being improperly labeled and stereotyped once AD is replaced with autism spectrum disorder.

SELF-DIAGNOSIS OF ASPERGER'S

The construction of an Asperger's identity also took place when participants self-diagnosed as having Asperger's. This occurred in five participants who did not have a formal medical diagnosis. These participants described their life experiences as always "being odd," "different," or "not quite fitting in." These older adults were all parents of a child (or children) diagnosed with AD. Based on their experiences with their children getting a diagnosis, these adults reconstituted their identities after they self-diagnosed themselves as having Asperger's. Prior to the diagnosis of their children, none of these

participants previously considered Asperger's as part of their identity. It is not surprising that this age cohort (greater than 40 years old) did not have a diagnosis of AD since the official diagnosis was not available until 1994 (*DSM-IV*, 1994). For example, one father remembers reading through the diagnostic criteria, acknowledging, "well, this one is me, this one is me, this one is not me." This participant specifically recognized his lack of executive functioning skills (i.e., ability to prioritize, set goals, plan, and organize) and his auditory sensory issues. These issues were also apparent in his two sons, one of whom was diagnosed with AD. These findings are reminiscent of work conducted by Conrad and Potter (2000), who traced the emergence of "adult hyperactives" and adult attention deficit and hyperactivity disorder (ADHD). These authors described how one of the paths to self-diagnosis of adult ADHD resulted after parents encountered their child's diagnosis with ADHD. Through the process of their child's treatment for ADHD, these adults recognized similar difficulties they experienced while growing up (Conrad & Potter, 2000). Similarly, the adults in this study developed an Asperger identity after their child was diagnosed with AD, a process that highlighted qualities parents shared with their children.

The self-diagnosis of having Asperger's was also described as an evolving and lifelong process. For example, Andrew, a 50-year-old male, who self-diagnosed as having Asperger's, viewed his experience over the last 15 years as an evolving relationship with himself in terms of his Asperger identity. Throughout his life Andrew believed he was "odd" or "different" and described himself as "socially awkward." When Andrew's son was first showing signs of being a "late talker" like himself, he assumed his son inherited his family's legacy of late talkers. When Andrew's son was diagnosed with AD, he immediately viewed the differences in his son as not like himself but "abnormal." He stated,

I would say that the time [the diagnosis] happened, I really considered [my son] being no longer on the same journey that I was on and it became his problem. I didn't see any connection between my oddities and him.

From the time Andrew's son was diagnosed until just a few years ago (about 12 years), Andrew did not see any connection between his "oddities" and his son's diagnosis of AD. Only in the last couple of years has he acknowledged similarities to his son, and recognized that the communication challenges he has experienced throughout his life are most likely because of Asperger's.

As demonstrated by this narrative, Andrew's self-diagnosis and identification with Asperger's has been an evolving process and one with which he

continues to struggle. An official diagnosis of AD holds some appeal for Andrew, mainly to confirm that there was a place for him in society and to feel a sense of belonging. Although he realizes there is no “hard red line” distinguishing people with Asperger’s from people who are “normal,” he is interested in exploring how he fits in with the diagnosis for the novelty of being able to view himself with respect to the rest of the world. In this regard, the diagnosis of AD may confer a collective identity for people not diagnosed by removing them from the isolation of their differences and providing them with new potential networks of support (Jutel, 2009). This is reflective of literature that shows how diagnosis provides coherence to otherwise amorphous experiences, order to the disorderly, and organization to unorganized illness (Barker, 2002; Broom & Woodward, 1996; Dumit, 2006; Nettleton, 2006). For example, Broom and Woodward (1996) show how the diagnosis of CFS created constructive clinical outcomes for patients, which from the patient’s perspective was considered the most important event in the course of their illness. Essentially, the medical diagnosis brought some sense of legitimacy and rationale for their illness experiences (Broom & Woodward, 1996).

Although the diagnosis holds some appeal for Andrew, the other parents who self-diagnosed as having Asperger’s believed that getting an official diagnosis at this point had little value. For example, Carson, a 55-year-old male who self-diagnosed as having Asperger’s and has a child diagnosed with AD, described the diagnosis as useless. He states,

You still have to deal with it. Knowing doesn’t give you any advantage over not knowing as far as I’m concerned The action that is important is what you do with who you are and whether you give it a name or not is not important.

Similarly, another father, Landon, a 52-year-old male who self-diagnosed as having Asperger’s and has a child diagnosed with AD, feels that the diagnosis itself does not make any practical difference in terms of what actually happens. He states, “some people have it, some people don’t. Some people are in between. You deal with them based on who they are not how they got to be that way.” This father feels that it is more important to determine how people with certain differences can connect their specific capabilities and lives with the rest of the “neurotypical” world. Neurotypical is a term used by some people who have Asperger’s or autism to describe people who are not on the autism spectrum or who are perceived as “normal.”

SELF-DISCOVERY THROUGH MEDICAL DIAGNOSIS

Caught at the borderlines between younger adults who have a formal diagnosis of AD and older adults who self-diagnosed as having Asperger's based on their child's diagnosis, is Helen. She is a unique case in this study because she was diagnosed with AD when she was 32 years old and does not have children. She first learned about AD through various popular media venues and reading biographical accounts of people with Asperger's. Before her diagnosis, Helen remembers that she constantly felt ashamed of her actions and her inability to understand other people. This was so severe that she felt like an "alien." At the time of the interview, Helen was newly diagnosed with AD and was relinquishing much of the guilt and shame she had about the way she had socially interacted in the past and the difficulties it caused her. Here she describes her feeling of relief after being diagnosed,

No, I don't believe you. It can't be that. I don't want to be like that. But, then after I got over this, the initial shock I suppose, it was such a relief because it just explained all those problems I have had all my life and it made me feel less ashamed of it, less ashamed of how I am. I don't know, it's like someone switched the lights on. I understand what's happened now.

This quote demonstrates the sense of relief Helen had after getting the diagnosis because it helped her explain many of the problems she encountered throughout her life, including her inability to explain the challenges she faced with anorexia. Getting the diagnosis allowed her to feel less ashamed and to understand what was happening in the years prior to her diagnosis. She described her life as constant misunderstanding. Since the diagnosis she no longer views her behavior as pathological and something that should be fixed, but rather a character trait that is more acceptable. The legitimization of all the behaviors of her past through a defined diagnosis gave her a sense of relief that the actions of her past were not her fault. However, concurrent with Helen's relief was the upsetting notion that her social interaction will always be difficult. Again, these findings are similar to Conrad and Potter's research on the emergence of adult ADHD (2000). Like Helen, these authors demonstrate how adults who self-diagnosed as having ADHD recognized ADHD in popular media articles or books (Conrad & Potter, 2000). Furthermore, these authors reveal how the adult ADHD diagnosis provided a medical explanation for their "perception of under-performance," which allowed for the reevaluation of past behaviors and reduction of self-blame (Conrad & Potter, 2000, p. 573).

As this study demonstrates, the Asperger diagnosis and self-diagnosis allowed for specific identity constructions to emerge. The diagnosis was especially central for the self-diagnosed older adults. Although some diagnoses stigmatize the self, as we have seen, Asperger's is a positive identity. In light of these specific identity constructions around Asperger's, elimination of AD may be particularly problematic for those who rely on the diagnosis as a central hinge on which to hang their identity, such as Andrew and Helen. Both described lifelong struggles and a sense of relief at finding the Asperger community.

EVERYDAY LIFE CHALLENGES

Although there is evidence of establishing a distinct identity around the Asperger diagnosis and an indication that Asperger's has a positive identity, the adults interviewed in this study were often times more concerned with their social interaction and community than with their Asperger identity and/or diagnosis. Communication barriers lead to social isolation and feeling misunderstood. These issues will persist despite the changes in nomenclature and diagnostic criteria, and will continue to be everyday life challenges and threats to the self and identity regardless.

Social Isolation

Social isolation was described as the sense of not being a part of any community, finding it hard to fit in with other people, and not having any close friends. The inability to integrate in a social setting with peers was described by Andrew as a party he has missed his whole life. He stated, "I've described it as there's a party going on but I'm outside the building and I can see it through a glass wall. I can see what's going on. They're having fun and I want to have fun too. I don't know how to get into the room." Andrew is in his 50s and is a successful computer engineer. He grew up without a diagnosis of AD and did not recognize his "different way of thinking" compared to others until his son was diagnosed with AD. His statement reflects the feelings of being trapped and unable to participate in social interactions. He described that throughout his life he was unable to integrate with other people, be around other people, or have other people interested in him. As a result, Andrew felt like he did not belong to any community due to his social awkwardness. His inability to socially interact

with people has been very painful and at times he interprets it as a very depressing view of the world.

Social isolation for the participants occurred during most social situations throughout different life stages, whether it was during elementary school, high school, college, or in work and professional settings. For example, Helen, who recently received a diagnosis of AD in her 30s, remembers how she did not want to be with other people and could not relate to other children when she was young. As Helen got older, she realized that she could not figure out relationships and was unable to understand what people were talking about. She found college to be extremely difficult socially, resulting in a period of complete social isolation where she never attended class and basically self-taught her way through college. When she entered the work environment she found it hard to interact with people in the office everyday. Helen said,

I didn't know how to relate to them so I found that very hard. Whereas at college I could just, you know, be isolated on my own. I didn't have to talk to anyone if I didn't want to. But, at work I had to sit surrounded by people and I just hated it.

Helen's inability to socially relate and cope in a work environment caused her a lot of suffering including constant anxiety, shame, guilt, and obsessions about her appearance and weight. Similarly, many other participants discussed their inability to form peer relationships in school and their desire to "isolate ones' self" and "fixate on mechanical or concrete systems as opposed to people."

On Feeling Misunderstood

Related to social isolation and in the realm of communication is the concept of feeling misunderstood. This was a dominant theme running throughout the interviews where the participants repeatedly mentioned how they constantly felt misunderstood by other people. At the same time they did not fully understand "how people work" and "why they do the things they do." For many of the participants, the misunderstanding of their actions caused problems in school ranging from constantly being bullied by other children to getting in trouble by their teachers. For the majority of young adults, trouble in school and being misunderstood by teachers was often the trigger that led to getting a formal diagnosis of AD.

This lack of social reciprocity was especially challenging during nonverbal communication. Erich, an 18-year-old male who has a formal diagnosis of

AD described it by noting, “It’s very difficult for me to tell when I snap someone’s final nerve It’s the subtle quirks and slight facial shifts that I tend to miss, again, missing the obvious or what’s there.” This concept of “missing the obvious” or misunderstanding the nonverbal communication of others occurred during all types of social interaction for these participants, especially when emotions were involved, such as sadness, fear, anger, or frustration. For example, Andrew finds it extremely difficult to discern emotional and nonverbal communication to the extent that he identified himself as being completely deaf or blind to it. It was not until recently that he realized the volume of nonverbal communication he was missing and viewed this “blindness” or “inability to see the light” as a cause of much pain. Andrew has experienced pain and self-blame in most of his social relationships, which manifested when he was younger, and continues, albeit slightly less, as an adult. Such everyday struggles of social interaction and communication can cause feelings of anxiety, guilt, and a sense of shame. They may even constitute a threat to the self.

DISCUSSION

This chapter demonstrates how the diagnosis of AD is embraced and fused with individual identity. For some, the diagnosis–identity fusion was based on the specific diagnostic criteria that matched their own sense of self, while for others it was based on their self-diagnosis after having a child diagnosed with AD. Although positive associations were made with the identity of Asperger’s, stigma surfaced when it was associated with autism or as part of the “autism spectrum.” The diagnosis also served as a form of self-discovery for adults who self-diagnosed or received an adult diagnosis of AD.

This chapter also reveals the emergence of the positive identity associated with Asperger’s that moves beyond the boundaries of the medical diagnosis. Several of the participant’s embraced a positive Asperger identity by referring themselves as “Aspies” and identifying specific aspects of their lives that were deemed valuable and positive to society. The proposed changes to eliminate AD from *DSM-V* threatens these assertions of Asperger identity and the relief that has come for many adults who can relinquish past experiences with knowledge of an Asperger diagnosis or self-diagnosis. However, the elimination of AD must be considered within the broader context of people’s everyday lives and how experiences in social interaction and communication can be a strong agent of identity construction. For participants in this study, the central issue in their

everyday lives was not whether they had a diagnosis of AD, but rather the negotiations of day-to-day experiences of social interaction and communication.

The identity based on the self-diagnosis process for the older adults in this study also demonstrates the lifelong process of reflecting on past experiences and future possibilities based on shared experiences and challenges they had in common with their children. This cohort of adults represents a generation of individuals who grew up with labels of being “odd,” “weird,” or “quirky” during a time when the diagnosis of AD was not available. The ongoing reframing of past experiences and behaviors and coming to terms with what it means to be on the autism spectrum is reminiscent of autobiographies of adults who did not grow up with a diagnosis of AD (Lawson, 1998; Willey, 1999). For example, Liane Willey (1999) eloquently describes her past as follows,

Remembering can teach me who I am and guide me toward who I will be. Remembering can set me free ... I would never turn back in search of regrets or mistakes or misdirected thoughts. I simply use my past as a catalyst for conscious thought and for self-appreciation. (p. 17)

Similarly, the older adults in this study placed past experiences and challenges into perspective once they came to terms with their Asperger identity. Some were hopeful and optimistic like Willey, viewing their Asperger identity positively in the sense that it helped them explain problems they have had throughout their lives and gave them something that they could use to move forward in their lives. Others struggled with the past because it brought into perspective just how much they were “missing out” throughout their lives. This process of self-diagnosis and identification with AD also reflects the notion of a “revealed identity” (Armstrong, Michie, & Marteau, 1998) and the interconnectedness to past, present, and future generations based on character traits participants recognized in themselves and in their children. In this sense, diagnosis can be a source of identity retrospectively.

Complicating these different notions of identity based on the diagnosis, self-diagnosis, and the positive identity of Asperger’s are the broad range of symptoms associated with the current notion of autism spectrum disorder (i.e., autistic disorder, AD, and PDD-NOS). According to the participants in this study, the current diagnostic criteria distinguishing these groups is a “catch all” and “too loosely defined” to have any real meaning. One participant described the diagnostic labels as a “grab bag” of a number of different things that seem to have a subset of similarities. In such a case, he

argues that there is no “hard red line” that can be used to say for sure if someone was AD or some variation of it. Thus, the changes to eliminate the Asperger diagnosis has the potential to place individuals with huge variability and severity of symptoms into one group, which can interfere with understanding the unique differences and needs of individuals with Asperger's. One father, who self-diagnosed as having Asperger's, contended that until there is a clear understanding of these differences, people with Asperger's will not be able to seek appropriate care based on their specific needs. Thus, the proposed diagnostic changes in *DSM-V* from discrete categories of autistic disorder, AD, and PDD-NOS to one broad category of “autism spectrum disorder” can potentially exacerbate the broad range of symptoms and severity that currently exists between each of these groups.

These findings call to question the boundaries placed on medical diagnosis and what symptoms constitute a disorder when, in cases like this, people identify certain traits and characteristics to be associated with Asperger's beyond the diagnostic criteria. For example, the Asperger diagnosis was fused with identity based on specific characteristics associated with the diagnostic criteria, such as a lack of executive functioning skills, problems with social interaction, having obsessive qualities, and language delays. However, certain traits and characteristics associated with a positive Asperger identity moved beyond the boundaries of the diagnosis, such as aptitude for skills such as computer programming, exceptional memory, and the ability to solve complex problems. This is reflective of the work conducted by Bridgett Chamak and colleagues (2008) who highlight how personal experiences of adults on the autism spectrum and the core symptoms they recognize as autism, such as unusual perceptions and information processing, are not part of current diagnostic criteria (Chamak, Bonniau, Jauney, & Cohen, 2008). In the current study, the establishment of a positive Asperger identity was associated with characteristics and traits the participants recognized in themselves, regardless of whether these characteristics were part of the diagnostic criteria. Furthermore, it highlights that official diagnoses are not always the same as lived experiences, especially when the diagnostic category can be a positive basis for identity. Hence, folding AD into the autism spectrum threatens to taint Asperger's with the stigma associated with autism.

Although the interviews conducted for this study occurred before the announcement of *DSM-V* draft, the majority of participants clearly distinguished themselves from autism or autistic disorder and felt that this label misrepresented who they were – verbal, smart, and “high functioning” adults. Thus, the changes in *DSM-V* to dissolve AD under the label

of “autism spectrum disorder” may be somewhat problematic for the participants interviewed in this study. For these participants, the changes in *DSM-V* may have serious implications on their identity mainly due to the distinct stigma attached to autism compared to Asperger’s. Under the new diagnostic criteria, the negative stereotype associated with autism may cause missed opportunities for disclosure and self-identification, which can leave people feeling lost and confused as to how they fit in with society.

Regardless of the diagnostic label, the unique nature of this study reveals that with or without an official diagnosis, individuals must resolve everyday challenges of communication, social interaction, and misunderstanding that pose threats to self. Although the diagnostic boundaries are changing in the advent of *DSM-V*, the implications for everyday life experiences are rooted in how to navigate the social terrain and properly communicate on a daily basis. These everyday life challenges were not tied up with a single diagnostic label. Thus, these perspectives lend insight as to how researchers and people can create space, acceptance, and understanding toward people with Asperger’s with the aim of helping them live more independent lives and construct more positive identities.

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HIDDEN DIAGNOSIS: ATTENTION DEFICIT HYPERACTIVITY DISORDER FROM A CHILD'S PERSPECTIVE

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ABSTRACT

Purpose – The aim of this study was to examine the retrospective accounts of young adults who were diagnosed with ADHD in childhood to explore how children diagnosed with ADHD learn about and experience their diagnoses.

Methodology – Ten 18–22 year-olds who were diagnosed with ADHD in childhood participated in semi-structured, in-depth interviews. The interviews were transcribed verbatim, coded, and emergent themes were identified.

Findings – Data analysis revealed that children often experience both aspects of stigma and empowerment as they learn about and make sense of their diagnoses. The data suggest that parents, who often act as mediators between the medical community and their children, delivering and explaining diagnoses to their children, can influence this process greatly. Parents can help children utilize their diagnoses to develop coping strategies for their disorder, or exacerbate stigma by withholding

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information about diagnoses. Participants suggested that parents should talk openly about diagnoses with children and offer coping strategies to employ.

Research limitations – Findings are based on retrospective accounts, and the participants' views are not intended to be representative of the views of all children with ADHD. A goal of future research is to expand this study to other pools of participants, including children.

Practical implications – The findings can inform the delivery and management of children's ADHD diagnoses.

Originality/value – The current study adds to research on the sociology of diagnosis and medicalization of mental health by examining the experiences of children diagnosed with ADHD.

Keywords: Children; understanding; mental health; diagnosis; medicalization

INTRODUCTION

Once considered deviant behaviors, hyperactivity and attention problems in children are now generally considered symptoms of medical disorder. Physicians began linking these behaviors to biological causes in the first half of the twentieth century, with a focus on brain injuries and brain defects (Nylund, 2000). In the 1960s and 1970s, researchers began exploring the brain mechanisms, rather than brain damage, that are linked to hyperactivity and attention problems in children (Nylund, 2000). The American Psychiatric Association replaced the diagnosis of minimal brain damage with the label “hyperkinetic reaction of childhood” in the second edition of the *Diagnostic and Statistical Manual of Mental Health Disorder* (DSM) in 1968 (Timimi, 2002). They introduced the term Attention Deficit Disorder (ADD) in the third edition of the manual in 1980 (Timimi, 2002).

Since then, the number of children with this diagnosis, now termed Attention Deficit Hyperactivity Disorder (ADHD), has continued to expand. The percentage of children diagnosed with ADHD increased an average of 3 percent per year from 1997 to 2006 and an average of 5.5 percent annually from 2003 to 2007 (Centers for Disease Control and Prevention, 2010). In 2007, approximately 9.5 percent of U.S. children

between 4 and 17 years of age had ever been diagnosed with ADHD, including 13.2 percent of males and 5.6 percent of females (Centers for Disease Control and Prevention, 2010). Some critics conclude that the rise in ADHD diagnoses reflects a broadened definition of the disorder, rather than an increase in the prevalence or identification of the disorder. For example, in a review assessing the accuracy of the DSM's criteria for children's diagnoses, Kirk (2004) concludes that each revision of the DSM has made it easier to diagnose ADHD.

The increasing tendency to diagnose children with mental health disorders, such as ADHD, is part of the general phenomenon of medicalization, in which "nonmedical problems become defined and treated as medical problems" (Conrad, 1992, p. 209, 2007, p. 4). Diagnosis plays a key role in the process of medicalization, providing the "classification tools" that medicalize behaviors (Jutel, 2009, p. 278). According to Conrad (2007), there has been an increase in medicalization over time, as evidenced by the "growth of medicalized categories" (p. 6) such as ADHD. Medical sociologists have identified hyperactivity as an example of "medicalized deviance" – behaviors once viewed as deviance that have been re-conceptualized as medical issues (Conrad, 1992, p. 213). According to Conrad (2006), ADHD remains a "touchstone in our understanding of children's problems and medicalization" (p. xvi). Childhood deviance is considered to be more susceptible to medicalization than deviance among adults because children are not thought to be as responsible for their actions as mature adults and thus society resists blaming them for their deviant behavior (Conrad & Schneider, 1992).

Sociologists have noted the potential benefits of medicalization and diagnosis. Medicalization promises the possibility of finding a cure and may remove blame from those diagnosed with disorders by legitimating their behavior (Conrad & Schneider, 1992). As part of this process, diagnosis can explain what one is experiencing and why one differs from the norm (Jutel, 2009). It can also provide access to services and statuses such as insurance coverage. A diagnosis can give an individual "permission to be ill" (Jutel, 2009, p. 278). In a study exploring the experiences of parents with hyperactive children in Britain, Klasen (2000) found that diagnoses brought a sense of relief to parents, who generally thought that labels such as "stupid" and "naughty" were worse than the medical label of the diagnosis. Most parents in the study welcomed the diagnosis, noting that it gave them a sense of control, alleviated their guilt, and gave them a sense of legitimization that allowed them to be more active in seeking help for their child, even outside of the medical realm (e.g., contacting self-help groups) (Klasen, 2000).

Sociologists have also highlighted the potential downsides of medicalization and diagnosis. Medicalization may narrow what is deemed acceptable in society (Conrad, 2007). Medicalization and diagnosis may also lead to stigmatization, and may direct attention to the sick individual, deflecting attention from the broader social context (Conrad & Schneider, 1992). According to Timimi (2002), by scripting ADHD as an illness, the education system absolves itself of its responsibilities to meet the needs of children.

Critics of the increased diagnosis of disorders such as ADHD have blamed the medicalization of mental health for fueling the increasing use of psychotropic drug treatment for children and have pointed to the negative psychological effects of increasing diagnosis. Burston (2006), for example, warns that by viewing diagnoses as scientific objective realities rather than social constructions based on what society deems abnormal, diagnoses can become the core of children's identities. Ironically, these critiques might actually contribute to increased diagnosis; as Conrad and Potter (2000) note, controversy about ADHD increases the public's awareness and spread of information about the disorder, which in turn can fuel further diagnostic expansion.

Largely absent from this discussion are the perspectives of those most affected by this trend – the children who are diagnosed with mental health disorders. Link and Phelan (2001) note that most research on stigma has been from “the vantage point of theories that are uninformed by the lived experience of the people they study” (p. 365). Wahl (1999) asserts that those with mental illness themselves “can best inform us – from their own personal experiences and in their own words” (p. 468) how they experience stigma. Those with mental health disorders can also best explain how they *understand* and *make sense of* their diagnostic labels. Children diagnosed with ADHD, for example, can provide insight into how the medicalization of mental health shapes their experiences by sharing their accounts of the diagnostic process, including how they came to understand their diagnoses. Research that explores *their* perspectives would be in line with the approach of the sociology of childhood, which encourages a focus on the experiences and meaning-making processes *of children*, with an emphasis on capturing children's perspectives rather than the perspectives of adults in their lives (Corsaro, 2004; Prout & James, 1990). As Thorne (1993) notes, “Children's experiences should be taken just as seriously ... as those of adults” (p. 6).

Prior research has explored the perspectives of *parents* of children diagnosed with mental health disorders, including ADHD. For example, research has examined the experiences of parents in supporting children with mental health disorders, especially when in contact with mental health

professionals (Blum, 2007; Harden, 2005). Blum (2007) describes the mothers interviewed in her study as “vigilantes” in their advocacy efforts on behalf of their children with mental health disorders, navigating both the educational and medical systems, including the controversial world of medicating children. Yet, Harden (2005) found that parents often believed that their expertise as caregivers was undermined by mental health professionals, and often felt helpless and unable to fulfill the care-giving role. Several studies have also examined parents’ understandings of the causes of their children’s ADHD (Harborne, Wolpert, & Clare, 2004; Wilcox, Washburn, & Patel, 2007; Yeh, Hough, McCabe, Lau, & Garland, 2004) and how parental beliefs regarding the causes of children’s ADHD diagnoses affect decisions to seek care (dosReis, Mychailyszyn, Myers, & Riley, 2007; Singh, 2003). Mychailyszyn, dosReis, and Myers (2008) conducted interviews with parents of children who were recently diagnosed with ADHD to explore the stages that parents go through in conceptualizing their children’s conditions and expectations for treatment. Similarly, Rafalovich (2004) examined how parents of children with ADHD learn about the disorder through interactions with professionals and what steps they take to acquire information and knowledge about ADHD. Researchers have thus explored parental experiences with their children’s treatment as well as parental understandings of ADHD.

A small body of research has explored children’s experiences with mental health *treatment*. Several studies have examined the treatment experiences of children who are hospitalized for psychiatric disorders, generally suggesting that children should play a more active role in this treatment (Hepper, Weaver, & Rose, 2005; Roth & Roth, 1984). Similarly, research assessing children’s experiences in family therapy has highlighted children’s wishes to be more involved (Stith, Rosen, McCollum, & Coleman, 1996; Strickland-Clark, Campbell, & Dallos, 2000). Research on the experiences of children in treatment strongly suggests the importance of listening to children and involving them in treatment decisions (Buston, 2002; Davies & Wright, 2008; Laws, 1998).

There is very limited research evidence, however, on how children come to understand and make sense of their diagnoses and how this affects how they experience them. Cooper and Shea (1998, 1999) explored children’s experiences with diagnoses by interviewing 16 children attending a school for students with learning and behavioral problems between the ages of 11 and 16 in the United Kingdom. Findings indicate that many of the students felt stigmatized by both the ADHD diagnosis and the behaviors associated with this disorder. Many of the children in the study viewed the diagnosis as being

central to their sense of self. Some children welcomed the diagnosis, however, because it provided them with a rational explanation for their behavior and/or access to medication. Although this research greatly added to the literature by examining children's experiences with the diagnosis, further research is needed to explore how children develop these understandings.

The current study helps to fill this gap by examining the retrospective accounts of young adults who were diagnosed with ADHD in childhood to explore how children diagnosed with ADHD make sense of their diagnoses and how this process shapes how they experience their diagnoses throughout childhood. This knowledge could provide insight into how to better manage diagnoses for children.

METHOD

Data for this study come from semi-structured, in-depth interviews with ten 18–22 year-olds who were diagnosed with ADHD in childhood. This included participants who were diagnosed with ADD, which is subsumed under the ADHD diagnosis in the latest version of the *Diagnostic and Statistical Manual of Mental Disorders* (American Psychiatric Association [DSM-IV-TR], 2000). What was once called ADD now falls under the “predominately inattentive” type within ADHD. Both ADD and ADHD diagnoses are therefore referred to here as ADHD.

As young adults, participants had the ability to reflect back upon their entire childhoods not long after having lived through them. Participants were therefore able to describe how they made sense of their diagnoses throughout childhood. Young adults may also be better able to articulate and express themselves than children and youth. The limitation of these retrospective accounts, however, is that participants' recollections of how they felt in the past may not be entirely accurate.

Participants were recruited via fliers that were posted in several buildings throughout the campus of a large university, as well as via an email sent to a listserv of students by the university's office for students with disabilities. The fliers and email advertising the study indicated that participants between the age of 18 and 22 were being recruited for a study on the experiences of those diagnosed with ADHD before the age of 17. The flyer noted that participants would receive a gift card for participating in an interview lasting about an hour. Study participants were also given copies of the flyer at the end of their interviews and encouraged to pass the fliers on to others who may be interested in participating.

The 10 participants interviewed for the study included 6 women and 4 men between the ages of 18 and 22. One participant identified himself as “culturally ... white” but “technically Hispanic.” Another participant identified himself as African American. The other eight participants were Caucasian. Two noted that their parents were from the Middle East. Of the 6 participants who reported their parents’ incomes, 1 reported \$0, 1 reported \$80,000, 1 reported above \$100,000, and 3 reported \$200,000 or more. Two of the 10 participants were diagnosed before elementary school, 6 participants were diagnosed in elementary school, 1 participant was diagnosed in middle school, and 1 participant was diagnosed in high school.

Participants were asked questions about the following five topics: (1) their backgrounds, including information about where they grew up, the schools they attended, and their families; (2) their experiences learning about ADHD, including how they found out that they had ADHD and learned about the disorder; (3) their experiences with medication for ADHD (if applicable); (4) their experiences with ADHD in general and attitudes toward their diagnoses; and (5) their experiences talking about ADHD in childhood (e.g. with peers and siblings). While a prepared list of questions helped to guide the interviews, participants were asked follow-up questions based on their responses.

All interviews were transcribed verbatim, coded, and analyzed using the qualitative software program HyperResearch. Once all interviews had been conducted and transcribed, I reviewed all of the transcripts, making comparisons and identifying patterns and themes across the transcript data. Rather than using themes developed a priori, I coded the data using categories developed directly from the data; as new themes and subcategories emerged, I went back to previously coded data and applied these categories. Throughout this process, I wrote “initial memos” on the analytic categories that emerged and elaborated on themes by writing “integrative memos” that linked these categories together (Emerson, Fretz, & Shaw, 1995, p. 143). This inductive approach to qualitative analysis draws from the methods of the “grounded theory” approach, which emphasizes the emergence of categories through a systematic review of data (Glaser & Strauss, 1967).

All of the participants’ names have been replaced with pseudonyms to preserve anonymity. In many of the direct quotes presented here, I removed words and phrases such as “umm” and “you know,” dropped minor repetitions in speech (e.g., changed “I, I think” to “I think”), and standardized colloquial speech (e.g., changed “I dunno” to “I don’t know”). In no case did I supply words, rephrase, or change the meaning of a quote. This editing

constitutes a compromise between the “preservationist” approach, in which interview excerpts include literal transcriptions of original speech, and the “standardized” approach, in which edits are made to make interview excerpts easier to understand (Weiss, 1994, p. 192). While rephrasing statements and supplying words can be misleading, the minor editing I chose to do (i.e., removing words and standardizing language as described earlier) makes quotes more “accessible” to readers without changing the respondent’s meaning and presentation of self (Weiss, 1994, p. 194).

RESULTS

Experiences of Stigma and Empowerment

While participants largely emphasized the stigma associated with their diagnoses, they all described at least some benefit to learning about their diagnoses as well. They often described their diagnoses as being stigmatizing and empowering at the same time. For example, Daniela (diagnosed in first grade) explained that she remembers being “slightly comforted that other people have it, but at the same time being scared because there was a name to it.” Similarly, as Ashley (diagnosed in second grade) noted: “It was kind of a relief to find out what was wrong with me” but “kind of a stigma thing too.”

Only two participants described liking aspects of the disorder itself. Andy (diagnosed in eleventh grade) attributed his fast reaction time, which helped him in sports, to the disorder. Matt (diagnosed before elementary school) reported liking the “ability to multi-task” and be “more free with thought” than his peers, which he attributed to the disorder. According to Matt, “... it became a matter of pride that I was different.”

The other benefits that participants described all focused on the benefits brought about by *the diagnosis* rather than the disorder itself. In particular, they described the benefits that came when they first learned of their diagnoses, including a sense of empowerment. Ashley emphasized a sense of relief upon first finding out that she had ADHD: “It was kind of a relief to find out what was wrong with me.” Others emphasized a sense of empowerment when they later gathered information and learned more about the disorder. Both Matt and Daniela described experiencing a sense of validation when they discovered information about ADHD on the internet years after being diagnosed. Daniela recounted this experience:

I felt like I was pregnant for some reason ... it was just really strange knowing that there was something inside of me that I was trying to find information on ... And then

validating what was inside of me with that information, and then thinking, 'why didn't I know this all along because this information has always been on the internet?' How easy it would have been if my parents had printed it out and put it on the fridge.

Similarly, Matt explained: "I never really understood it until I went on the internet and got the info. Until then, I always figured there was just something wrong with me." Matt described the empowerment he experienced:

I'm very, *very* happy that they diagnosed me, because while it is possible to live with, [it is hard] unless you *know* what you have [...] [If I was never diagnosed] I would know that there was *something* wrong, but I wouldn't know how to deal with it. And I think that the diagnosis was one of the most empowering things I could ever have in my life.

Some participants explained that the diagnosis encouraged them to evaluate, and in some cases change, their actions. Krista (diagnosed before elementary school), for example, noted: "It's helpful to know it's there so you can kind of step back and ... evaluate where your actions and so on are coming from." Lilly (diagnosed in eighth grade) explained that the diagnosis helped motivate her academically. She recounted: "I feel like once I realized I had a problem, I started trying harder in school." If never diagnosed, she speculated: "I don't know if I would have come to the realization that I needed to change something."

When asked what their childhoods would have been like if they had never been diagnosed, *all* of the participants noted challenges that they would have likely faced. Several participants noted that they would have struggled academically if they had never been diagnosed. Matt, Daniela, and Lilly speculated that they would have had a tougher time focusing without their medication. Sarah (diagnosed around first/second grade) noted that her "grades would have really suffered" if she had not been diagnosed since her grades improved so drastically when she began taking medication. Sam (diagnosed in third grade) speculated that he would have struggled in school because he would not have received the extra academic support.

Sarah, Daniela, Ashley, and Courtney (diagnosed in second grade) also speculated that they would have gotten into "a lot" more "trouble" as children if they had never been diagnosed with ADHD. Sarah and Matt noted that they would have struggled more socially. Many participants indicated that these challenges would have had lasting effects on their lives. For example, Matt suggested that he would likely have had difficulties becoming as successful as he has if he was never diagnosed:

I would have had much, much, much more problems on the social level ... I would not be attending this university. I would probably be working at a dead-end job, at maybe a

fast food place. I don't think that I would have learned self-control ... [or the] social skills that I did, because I think I would have continued to just be a terrible little problem child. I probably would have been sent to an alternative school ... It would have been *much* worse.

A theme throughout these speculations is that one cannot manage the difficulties that come with ADHD, such as lack of self-control and difficulty concentrating, unless the disorder is identified. Participants reported that the diagnosis opened doors to treatment. Nine of the 10 participants took medication for ADHD at some point before coming to college. Although they all described some side effects of the medication, such as interruptions in their eating and sleeping habits, many found the medication helped them focus and led to a noticeable improvement in their grades. Several participants also described the benefits of having additional instruction in school, extra time on exams, and learning additional strategies that helped them cope with their ADHD symptoms, such as organizational techniques like note taking.

Yet, despite these descriptions of the validation diagnoses bring, along with an impetus to make changes and tackle the difficulties that come with ADHD, participants *also* described the stigma that comes with this label. Although the diagnosis may have brought them internal benefits (e.g., a sense of relief and motivation to try harder academically), this was not typically something that participants wanted to share with others.

The majority of the participants described not wanting to talk to their peers about their diagnosis in childhood. Matt, who did discuss his diagnosis openly with peers, recounted the following reaction from his classmates:

... a couple weeks into knowing me, they'd be like 'okay, something's odd with you. What's the matter?' 'Like, I have ADHD.' 'Oh no! Those are all capitals!' ... And so there would be a point of like 'uhhh, I'm not sure if I can catch it from him, you know – you know the other things that have capital letters – HIV. And so eventually they would get over the 'oh okay, it's only him that's got it. We can handle him.'

All of the participants had siblings, but 8 of the 10 never discussed their diagnoses with their siblings in childhood. Lilly only did so after years of hiding her diagnosis from them. As she explained, "I was kind of embarrassed."

Sarah and Daniela also emphasized feeling like their diagnoses were something to hide. According to Sarah, her diagnosis felt like a "big secret." She reported: "I always felt like I was hiding something." Meanwhile, Daniela explained that she "hid it really well" at school by consciously

sitting very still and staying very focused. Lilly noted that she “kept it a secret for a long time” from both her siblings and peers.

Most accounts of stigma were focused on participants’ fear of being seen as “different” or “separate” from their classmates. Both Ashley and Matt strongly emphasized the stigma that came with being “different.” Matt described how people responded negatively to any difference: “There was a big stigma with it ... because people are people and they see something that’s different and they immediately dislike it.” Similarly, Lilly noted that she was embarrassed by the diagnosis because she did not want peers to think she was “different.” Daniela and Sam both described not liking to take medication partly because it set them apart from their peers. Sam explained that even going to the nurse to take his pill during the school day made him feel “separate” from his peers. Similarly, when asked about the extra academic support he received in a separate classroom in school, Sam described: “I didn’t like having to be separate from my peers. Like I wanted to just be a normal student. I wanted to be like everyone else.”

Several participants also emphasized a fear of being seen as “stupid.” Lilly explained that she was partly embarrassed by her diagnosis because she did not want her peers to think she was less intelligent than them, even though she knew this was not the case. Mark (diagnosed in early elementary school) described: “I was like ‘am I stupid?’ I looked for that [online] ... ‘don’t see that at all, awesome ... I’m good.’” Sam also emphasized his fears of being labeled as “stupid” by his peers when he was diagnosed. He described how upset he was when he first learned of his diagnosis: “I was like angry about it. I didn’t want to think that I was behind other people. I didn’t want to be labeled by my peers [as] being stupid or slow or something like that.”

Despite the benefits and sense of empowerment participants experienced when they learned about their diagnoses, they generally saw their diagnoses as something to hide. Many feared the repercussions of telling their peers, worrying that they would think of them as different or “dumb.”

The Role of Parents in the Process

Although one might imagine that ADHD diagnoses are delivered and explained to children directly by the mental health professionals who diagnose them, many participants described their parents telling them that they had ADHD, thus acting as translators of their medical diagnoses. Only 3 of the 10 participants remembered a mental health professional delivering

the news to them. Meanwhile, 5 of the 10 participants described their parents delivering and/or explaining the diagnosis to them. While some parents sat down and deliberately delivered the news to their children, Sarah reported a very different experience; she described not being told about her diagnosis until her mother blurted it out while they were out running errands together a month after she was tested and diagnosed. Others noted that the mental health professionals might have tried to explain the diagnosis to them at the time they were diagnosed, but that they did not really learn about it until they later questioned their parents.

Meanwhile, the other two participants noted that they were *never* officially told about their diagnoses. Daniela explained that neither her doctors nor her parents ever explicitly told her about her diagnosis or explained the disorder to her. Daniela discovered on her own that the medication she was taking was for ADHD. Similarly, Krista noted that no one ever told her that she had ADHD. Rather, it was “kind of like a realization over time.” Sarah and Daniela both described being asked to leave the mental health professional’s office when the diagnosis itself was being delivered to their parents. Sarah emphasized that she did not even know why she was there.

The explanations that participants’ parents provided varied greatly. Matt’s parents, for example, explained to Matt that his ADHD diagnosis meant that he would have more energy than his peers and would need to learn self-control. Matt described his relief that they explained that it did not mean he was “bad.” Matt’s parents also focused on a genetic explanation, noting that it was passed down to him from his father who was also diagnosed with ADHD. Similarly, Ashley’s parents explained to her that she should not be ashamed of it; she recounted them explaining, “it was part of my genetics just like needing glasses.” Meanwhile, Sam’s mother emphasized that it is something that would affect his ability to focus and learn, though it in no way reflected his level of intelligence. Once Sarah’s mother finally explained the diagnosis to her nearly a month after she was diagnosed, she explained that it was a disorder that made it more difficult to concentrate and emphasized that this could be helped with medication.

Some participants described their parents helping them manage their ADHD by teaching them ways to cope with the disorder. Krista, for example, noted:

... it was mainly my mom who was really helpful ... I feel like she was really helpful just in like helping me go through my homework ... she was just really good at being like ‘okay, look over all of your homework,’ like ‘calm down.’ I don’t know if she talked to a doctor about it or if she was – just kind of was my mom. But I mean she would have been there no matter what.

Participants also described their parents helping them utilize their diagnoses to access needed services. For example, Sam noted his mother helped to put extra school support into place for him once he was diagnosed. By utilizing diagnoses to open doors to coping strategies and services for their children, parents often helped find ways for diagnoses to benefit them.

In other cases, however, parents blocked these benefits by withholding information about their children's diagnoses. Several participants described not being told why they were being tested; some reported that their parents did not tell them even after they were diagnosed. Some participants reported not even knowing why they were on medication. Sarah, who did not know why she was going to a doctor to be tested or why she was taking medication, noted: "they just kind of dragged me along." Similarly, Daniela described her parents not explaining why she was seeing a doctor to be tested or why she was taking medication:

They never fully explained why I needed to take [the medicine] ... it was never a discussion about 'this is what's going on and this is what we need to do as a family.' It was just 'okay we went to the doctor and now this is what you need to take.'

She questioned whether her parents' decision to withhold the diagnosis from her was a protective response:

Actually for some reason my dad didn't want me in the room when the doctor was going to tell my mom and him the news. I guess he just didn't want me to find out or he didn't want the doctor to see my face or something. And so I just remember waiting for them, sitting outside of that room and just waiting for them to come out so that we could go home. [In] the car ride home, there was just silence and I guess whatever my mom and dad needed to say to each other, they talked about it after I had gone to sleep ... I don't know if it was a protection thing ...

Sarah and Daniela both described feeling that their parents could have provided better explanations of ADHD to them. Sarah noted that her mother could have been more thorough: "I actually kind of felt she should have explained it better to me [...] She didn't ask me, 'do you have questions about it?' I feel like there needs to be more of a conversation there." Sarah described her frustration at her mother: "[she] *never* explained it to me so I guess I'm kind of upset that she didn't – because it did kind of contribute to how I acted in school towards other people. I always felt like I was hiding something."

Sarah and Daniela both suggested that by withholding information about their diagnoses from them, their parents *exacerbated* the stigma that they faced, including the sense that their diagnosis was something to hide. According to Daniela, it was "stigmatizing because it was never discussed."

Daniela described that by not explaining what ADHD is, her parents also made her feel as if she was hiding something:

[I remember] feeling like there was something wrong with me because my parents never talked to me about it. I just remember the silence in the car ride home after that doctor's appointment. And I feel like after that diagnosis, I felt like a different person just because there's something about me that I don't know so my parents are acting differently ... I feel like my whole life changed in that moment.

Krista, Sarah, and Daniela noted that they would have had better experiences with ADHD in childhood if they had been better informed. Krista noted: "it would have been cool if I had known [that I had ADHD] ... so I could tackle it a little bit better." She also noted that she probably would not have felt so guilty in her childhood if she had known about her diagnosis: "I feel like it wouldn't have made me feel as bad all the time ... If I had actually like understood that it wasn't all my fault [when I misbehaved]." She questioned whether her parents might not have told her because they thought she would not understand, or perhaps because they felt badly putting her on medication. She also speculated: "I don't know if they just didn't ever feel comfortable enough to sit down and tell me." She said that it was "frustrating" that she did not know about ADHD at a younger age. Similarly, Sarah emphasized that her experience would have been better if her mother had explained to her why she was being tested and why she was taking medication. Daniela noted that her experience would have been better if her parents had "been open about the whole thing."

Several participants noted that adults should be careful when explaining the disorder to children, noting that young children might not be developmentally mature enough to fully understand it. As Krista described, an in-depth explanation of the disorder could lead to a "little bit too much to be spinning in a little kid's head." Ashley suggested that parents should decide how much information their children are capable of understanding. Krista noted: "It probably has to be more of a process than just like telling them once."

Yet, even those who warned against giving young children in-depth descriptions of the disorder emphasized that adults (and parents in particular) should tell children about the diagnosis and discuss some key points with them. For example, participants suggested that adults should strongly emphasize that the diagnosis does not indicate that they are less intelligent than their peers. Several of the participants also noted that it is important to explain that it is safe to talk about one's diagnosis and that children should not feel guilty about it. Ashley noted it is important to

emphasize that it is common. Sarah explained that parents should be “up front” with their children, and that the diagnosis is “a good idea as long as the proper explanation can be followed.” As she explained: “I wouldn’t say that you would have to explain the whole disorder because it’s really kind of complex, but just say that you’re no different from anyone else.”

Some participants emphasized that the diagnosis is only helpful if children are given the tools to cope with it. Krista explained that it would have been helpful if her parents had told her “this is why you have trouble [and] this is how you can deal with it.” Mark explained:

[The diagnosis] makes you aware of what the situation is. But it doesn’t really help you any if you know what it is but there’s no solution. So it’s like when people got cancer ... and they died immediately from it ... it’s like ... ‘thanks for letting me be sad’ ... If you’re going to tell me, give me a solution. Give me a method to help me to be better ... give them the tools. If you’re telling the kid about it, give their parents the tools to give their kids to make them better.

Many of the participants emphasized that parents are responsible for having these discussions with their children. For example, Ashley noted: “it’s the parents’ job to talk to the kid about it,” adding that she was glad her parents talked to her about her ADHD diagnosis, rather than her teachers. She noted that children should be told about their diagnosis when their parents think they are of the “right age.”

Both Sarah and Daniela emphasized the importance of explaining to children that ADHD is a “disorder” rather than a “disease.” Sarah described thinking at first that it was a disease that was “poisoning” her and causing her to be different. Daniela noted that her doctor should have told her parents that it is “not like a disease.” Meanwhile, Courtney recounted arguments that she had with her parents about the medical nature of the disorder:

The fact that ... people can point [something] out medically about me that separates me from other people and that makes me abnormal, it was like being sick ... I kept on having to say [to my parents] ‘there’s nothing wrong with me. Why am I taking pills? It’s not like I have cancer’ ... [My parents] didn’t say this, but like ‘there’s still something wrong with your body ... so we’re fixing it. Like when you have a physical illness, you fix it’ ... I didn’t like the fact that ... I still had to take medicine, because I couldn’t see it ... I think that’s something that came up in arguments ... They were like ... ‘it’s still health-related,’ which I didn’t believe.

Participants emphasized that they wanted adults to listen to them. Courtney, for example, noted that her parents “could have listened” when she said she did not want to see a psychiatrist or take medication. Several participants also emphasized that mental health professionals should do a

better job of listening to children. Both Courtney and Krista complained about psychiatrists and therapists giving them toys and memory tests, which they found unhelpful. They both noted that simply talking to the child is much more beneficial. Andy suggested that psychiatrists should tell children about different strategies for managing their disorder, explain the side effects of taking medication, and allow the children to play a role in weighing their options.

DISCUSSION

This study aimed to examine the retrospective accounts of young adults who were diagnosed with ADHD in childhood to explore how children diagnosed with ADHD make sense of their diagnoses and how this process shapes how they experience their diagnoses throughout childhood. Data from this study suggest that children often experience *both* stigma *and* empowerment as they learn about their diagnoses, and that parents often play a role in this process.

While sociologists debate the promises and pitfalls of medicalization and whether diagnoses are empowering or stigmatizing for individuals, the findings from this study indicate that in children's eyes they are often both. Nearly all of the participants in the current study described experiencing both empowerment and stigma when reflecting on their experiences with their ADHD diagnoses in childhood. These findings are consistent with those of Cooper and Shea (1998, 1999), who found that children experienced stigma associated with their ADHD diagnoses, but also a sense of relief given that their diagnoses provided a rational explanation for their problematic behaviors and opened doors to medication as treatment. Similarly, participants in the current study described their diagnoses as empowering in that they opened doors to treatment such as medication and academic support. Some also described a sense of relief finding out what was "wrong" with them. Even those who described largely negative experiences with the diagnosis identified challenges that they would have faced if they had never been diagnosed. Meanwhile, nearly every participant emphasized the stigma that they faced due to their diagnoses. In particular, they emphasized disliking being "different" from their peers. Many also described a sense that their diagnoses were secrets that they had to hide. Few participants openly discussed their diagnoses with their peers or siblings, therefore cutting off these possible sources of social support. These findings add to debates about

whether the medicalization of mental health is harmful or hurtful by introducing children's perspectives, suggesting that it might indeed be both.

Findings from this study also suggest that in exploring the factors that contribute to experiences of stigma and empowerment, it is important to consider the role that parents play. While the increasing diagnosis of ADHD in childhood can be seen as part of the general phenomenon of medicalization, parents often act as mediators between the medical realm and their children. It is notable that such a high percentage of participants in this study were told about their diagnosis and/or learned about ADHD from their parents. Indeed, parents often act as translators of medical information and liaisons between doctors and children, thus mediating the impact of the medical context. This was perhaps most striking in the examples of children who were asked to leave the room when mental health professionals delivered their diagnoses to their parents, who were then expected to pass this information on to their children. Some parents share information openly with their children, while others withhold information about diagnoses altogether, illustrating that the explanations parents provide vary drastically. Some, for example, provide much more biologically based explanations than others, focusing more on genetic causes of the disorder. As mediators and translators of such information, parents likely have great influence on children's perceptions of their mental health diagnoses.

This study illuminates how parents can help translate diagnoses into benefits for their children, utilizing diagnoses as an impetus to finding services and strategies to cope with the disorder. However, it has similarly shown that parents can exacerbate the stigma children face by withholding information about their diagnoses. Some participants described feeling as if they had something to hide because their parents withheld information about their diagnoses, and many participants noted that it is parents' responsibility to explain diagnoses to children. While noting that an in-depth description of the disorder might not be developmentally appropriate for children of all ages, participants emphasized that adults should offer some explanation of diagnoses to children, as well as explain that the diagnosis in no way means that they are less intelligent than their peers. They also advised that parents offer suggestions for ways to cope with the disorder when delivering and explaining diagnoses to children.

The findings from this study should be viewed within the context of several limitations. The current study is an exploratory one, and the views of the 10 participants interviewed are not intended to be representative of the views of all children with ADHD. The experiences of the participants may

be particularly limited because fliers were posted and distributed on a college campus, and thus this study drew from a pool of participants now attending an elite university. The participants in this sample may have had particularly positive experiences with their diagnoses; the fact that they are current college students suggests that they were successful at managing them. Furthermore, the study is based on young adults' accounts of how professionals and parents delivered the news of their diagnoses to them; these events were not witnessed first-hand. Lastly, the young adults who participated in this study were asked to reflect retrospectively on their experiences in childhood. Young adults offer a unique perspective with their ability to reflect on their childhood experiences as a whole not long after having lived through them. However, time may have shaped or distorted their recollections and their attitudes may have changed since childhood.

A goal of future research is to expand this study to other pools of participants so that theoretical insights can be generated. Future research should explore, for example, how the social context in which diagnoses are delivered and managed affects how children understand their diagnoses. No patterns or themes in participants' experiences were detected based on demographic factors such as race, class, or gender. However, additional research with larger pools of participants might investigate how demographic factors, along with factors such as religion, family size, and school environments, affect how children's diagnoses are delivered and managed and how children make sense of their diagnoses.

Interviews with children themselves would also be a fruitful line of inquiry in future research. While participant observation and interviews with the adults in children's lives might help confirm whether their recollections are accurate, it is also important that future research aim to capture children's perspectives. Qualitative research including children would be in line with the approach of the sociology of childhood, which suggests that researchers should treat children as active agents in their lives, able to express opinions and relate their own experiences (Corsaro, 2004; Prout & James 1990).

The findings from the current study have implications for how ADHD diagnoses should be delivered and managed in childhood. They also suggest that parents should be supported in the important role that they play in explaining and managing their children's ADHD diagnoses. In particular, parents who are disadvantaged due to race, ethnicity, and class, should be supported in their efforts to help their children access services, especially in the medical and school environments where their voices might not typically be heard. As the data show, parents should communicate openly with children about their ADHD diagnoses, strongly emphasizing that it does

not mean that they are less intelligent than their peers, and provide them with strategies to help cope with the disorder.

The current study takes a step toward capturing a perspective that has been underplayed in the literature – the perspective of children diagnosed with ADHD. Additional research is needed to further examine these narratives. Future research should continue to explore how children come to understand and make sense of diagnostic labels.

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SICK BUT LEGITIMATE? GENDER IDENTITY DISORDER AND A NEW GENDER IDENTITY CATEGORY IN JAPAN

Satoko Itani

ABSTRACT

Purpose – This study examines the consequences of sudden influx of medicalized discourse of gender in Japan by introduction of gender identity disorder (GID) in the late 1990s where transgender identities and the LGBT activism have had a different history and meanings from Western societies.

Methodology – I use discourse analysis of autobiographies of people with GID in Japan and the limited studies concerning the history of GID and transgender in Japan.

Findings – The introduction of GID to Japanese society contributed to increased social awareness of transsexual individuals. However, it also resulted in transsexual fundamentalism, which has excluded individuals who do not meet certain rigid medical and social identity criteria. This development reinforces the conventional binary gender norms instead of problematizing them. Furthermore, a legislation strictly based on the diagnosis has produced two groups: transsexual individuals with GID

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diagnosis who will be legally and socially recognized as legitimate, and those who are not GID and thus undeserving of such recognitions.

Social implications – *Diagnosis cannot exist without criteria, therefore it is impossible for GID to function as an inclusive identity category. Therefore, we must seek a system to provide medical services that do not necessitate diagnosis. It is also crucial to nurture the social environment where people can freely choose gender identities and expressions that go beyond conventional binary gender system and to keep insisting on plurality and fluidity of gender so that people do not have to rush for a narrow window of recognition.*

Keywords: Diagnosis; gender identity disorder; identity; law; transgender

The very first case of the sex reassignment surgery (SRS) for a patient diagnosed with gender identity disorder (GID) in Japan was approved by the ethics committee of Saitama Medical University in 1996. In the following year, Japan Society of Psychiatry and Neurology (JSPN) published the first Guidelines of Care for Gender Identity Disorder, based on the *Standards of Care for Gender Identity Disorders* created by the World Professional Association for Transgender Health (WPATH). In 1998, Japan's first SRS as a treatment for GID was performed at the Saitama Medical University. Although it has a long history of gender ambiguous culture, gender dysphoria as a new category of psychiatric disorder made sensational news in Japanese society. Due to the extensive media attention, it has become one of the most well known psychiatric disorders in Japan today.

As a result, such pathologization of certain kinds of gender identities has provoked heated debate in Japanese society as we had witnessed in Western nations. Should gender-atypical behavior and gender-atypical identity be considered disordered development that should be avoided as the listing of GID in the *Diagnostic and Statistical Manual of Mental Disorders (DSM)* suggests? Or should strong distress experienced by transsexual people be considered the *effects* of extreme societal intolerance toward such individuals or the symptomatic of disordered gender identity development? Transgender activists' protest at the American Psychiatric Association (APA) meeting in 2009¹ in the United States, where this issue has existed for long period of time, is illustrative of controversial and complex nature of this ongoing debate. Since the first medicalization of cross-gender identification by Richard von Krafft-Ebing in 1886, the name of the diagnosis has changed

over the years as a result of the debate not only among medical authorities but also among activists.² As scholars have documented (see Bryant, 2006, 2008; Conrad, 2007), some have argued for the removal of the diagnosis all together while others argue for “reform” that enables SRS and reimbursement for the surgery. Recently, we are witnessing another hike of this debate as APA prepares for the publication of *DSM-V* in 2013.

In Japan, this conversation has just begun. Although it is still within limited communities, we also started to witness some movements toward the use of “transgender” and reconceptualization of gender beyond conventional binary thought (Tanaka, 2006; Yonezawa, 2003). Patrick Califia’s (1997) *Sex Changes: The Politics of Transgenderism* along with Sandy Stone’s (1998) influential essay, *The Empire Strikes Back: A Posttranssexual Manifesto*³ were translated and introduced to Japanese society in 2005. Although it may take sometime, I am certain that these precedent works will help us in reconceptualizing gender, sex, sexuality, and identity beyond normal–abnormal, healthy–pathology, ordered–disordered binaries in Japanese society.

Examining this recent development and debate around the notion of GID in Japan is an important work; however, the purpose of this study is to examine the consequential influence of this new medicalized discourse of gender to the identity and community development of transgender people in Japan where cross-gender identities and behaviors have had different cultural meanings and history from Western societies. Also the lack of visibility and recognition of the LGBT movement in Japan has produced quite a different discourse and phenomenon around GID from that of Western nations.

The history of GID is a very new one in Japan. It has been only about 15 years since the term GID appeared in Japanese transsexual communities. As Sachie Tsuruta (2009) pointed out, however, the generation change of the leaders of the transsexual and GID community is so fast that there are only a few people who can provide a thorough history of this relatively new community. Only a few scholarly studies concerning the transsexual and GID community have been done (Mitsuhashi, 2003b, 2003c; Nomiya, 2005; Tsuruta, 2009). Thus, here I rely on the few academic resources that exist and a few memoirs of activists.

To write a history of “transgender” in Japan, it is important to first define the terms. For the purpose of this study, I borrow the definitions of transvestite and transsexual from Leslie Feinberg. Feinberg (1996) defines a transvestite as a person who episodically changes into the clothes of the so-called “other sex.” A transsexual is a person who permanently changed

genitals in order to claim membership in a gender other than the one assigned at birth. Although transgender has been used in various ways since its creation by Virginia Prince in 1987, for the purpose of this study, I use transgender as an umbrella term suggested by Susan Stryker (1998) to refer to “a wide variety of bodily effects that disrupt or denaturalize heteronormatively constructed linkages between an individual’s anatomy at birth, a nonconsensually assigned gender category, psychical identifications with sexed body images and/or gendered subject positions, and the performance of specifically gendered social, sexual, or kinship functions” (p. 149). This definition includes transsexual, transvestite, drag queen, intersex, gender queer, and so on.

As is described later, those categories such as transgender, transsexual, and transvestite are all newer imports that only began to be used in the Japanese gender minority communities after the 1990s. However, although the term transgender is a recent one in Japan, the phenomenon of crossing gender binaries is not. There is an abundance of documents and historical records about people whose gender expressions and roles went beyond rigid binary gender of today, and they have historically played important religious, political, and cultural roles.

HISTORY OF TRANSGENDER AND GENDER IDENTITY DISORDER IN JAPAN

From the excavation of villages of the Yayoi Period (400 B.C. ~ 300 A.D.), bodies of shamans that were identified as male from the bone structure yet dressed in the same way as female shamans have been found. From the way they were dressed, these shamans were considered to be male transvestite (Mitsuhashi, 2003a, p. 97). Similar examples of male transvestite shamans can be found in a variety of drawings and stories from different eras. Today we can still find numerous examples of cultural festivals that include a ritual in which men disguise as female shamans. However, we should be careful when referring to such cross-dressing shamans as “transgender” since the crucial meaning of such cross-dressing practice may not have been about crossing of gender but transformation representing a more spirit-based identity that would enable communication with a spirit world. Cross-dressing therefore could be read as a representation of transforming to another *being*, not necessarily another *gender*.⁴

Cross-dressed shamans' sacred functions expanded to performing arts in medieval and modern times (Mitsuhashi, 2003a, p. 98). At the end of the 6th century, *Shirabyoshi*, which was performed by mostly women who dressed in male attire, gained popularity. *Noh*, Japanese traditional mask dance, from the Middle Age, developed performances that used mask changes to represent dramatic sex change by spirits. One of the most famous "transgender" performing arts in Japan is *Kabuki*, in which all male and female roles are played by male actors. *Kabuki* gained popularity in modern Japanese society. The female-role actors were encouraged to live as women off the stage in order to improve their performance. This change in their off-stage life is significant in the sense that they *lived* as an opposite gender instead of just *performing* on a stage like *Shirabyoshi* and other cross-dressed performers in cultural festivals.

"Transgender" individuals also existed outside of mainstream performing arts. Mitsuhashi (2003a) pointed out that those boys who could not succeed as a female role theater performer often worked as *kagama*, who dressed as women and performed and served at restaurants. *Kagama* also offered sexual services to the customers at the restaurant. Thus, *kagama* was established as a transgender profession that combined performing artist, server at restaurants, and sex worker. Mitsuhashi (2003a) argues that due to the sexual nature of their work, there is no doubt that there were prejudices and discrimination against *kagama*; nevertheless, it is worth noting that there was a system in Japanese society in which transgender individuals could live even if it was limited to theater performers and *kagama* (p. 102).

However, with the wave of rapid westernization and modernization in the Meiji Period (1868–1912 A.D.),⁵ cross-dressing and transgender culture came under criticism, if not hatred, and the practice of *Kabuki* actors living as a woman off the stage was banned. This change in the public attitude toward transgender practices should be understood as a result of governmental effort to demarcate what were modern and respectable practices from primitive ones. Unlike in the West, the rejection of these practices was not the result of religious teachings and medical "findings" but of the government's desire to create modernized society.

One of the most illustrative examples of this governmental regulation of gender expressions and sexualities is a series of ordinances issued at the beginning of the Meiji Period. Particularly, Ishiki Kaii ordinance of 1873 (the sixth year of the Meiji Period) had significant impact on Japanese people's lives since it prohibited and made various traditional practices and rituals punishable crime, including the selling of *shunga* (drawings of sexual activity, including those between the same sex), tattooing, mixed-gender

bathing, mix-gender sumo-wrestling, and the cutting of women's hair without authority's permission.⁶ Ishiki Kaitō ordinance was amended in 1876 and it added prohibition of cross-dressing for both women and men. *Mitsuhashi (2003a)* argues that gendered appearance and sexuality became the target of control along with other behaviors and cultural practices, which the Japanese government considered backward practices and had to be eliminated in order for Japan to become a member of modernized nations (p. 101). Building of modern nation required people to act as modern beings and it also required clear definition of modern womanhood and manhood, which left no space for ambiguity or practice of crossing such boundaries.

It is important to note that when the control of transgender practices first began in the Meiji Period, the discourse of the regulation did not involve medical discourse. It was in the Taisho Period (1912–1926) when such prohibition of transgender practices began employing medical terms and transgender people became labeled as “perverts” instead of a symbol of backwardness of the society. Analyzing the effect of these social changes on the discourse and the regulation concerning transgender culture in the 20th century Japan, *Mitsuhashi (2003a)* asserts:

In Japanese society, it is only after Taisho Period, when the psychiatric community adapted Krafft-Ebing's theory and defined transvestism as perversion, that transgender became the target of absolute social oppression and exclusion. Since then although the psychiatric community has changed the way they call transgender such as “abnormal sexual desire,” “perversion,” or “sexual deviation,” they have consistently invested transgender individuals with negative images until the early 1990s. (p. 103, my translation)

Borrowing from the Foucaultian notion of homosexuality,⁷ thus, various forms of transgender practices were packaged into a small box of a deviant personhood when Japan underwent rapid modernization, industrialization, and westernization, which also brought Western medical discourse concerning gender and sexuality. Nonetheless, cross-dressing religious and cultural rituals and performances have survived to this day and people who cross-gender binaries have never ceased to exist.

During the 1940s and 1950s, the community of people who would be considered transgender largely consisted of male transvestites who worked in show business or the sex industry. There are a few records of SRS during this time; however, most cases reported were that of male-to-female (MtF) transsexuals whose place in society was still limited to the “commercial” world, such as show pubs and gay clubs. I would argue that SRS performed during this period had a different meaning from that of today in Japanese society in the sense that SRS was strongly associated with their profession as

a transgender performer unlike today's strong association with GID. It should not be forgotten that this earlier association of transsexuality with commercial performers was the result of a strong prejudice in a society against transsexual people which prevented them from securing a job outside of show business and thus forced many of them into the business. However, in the public mind people who received SRS were nevertheless deemed abnormal and perverted. Kameya and Narita (2000) state that the term "sex change operation" (a term used before "SRS" began to be used in association with GID) had an "extremely negative connotation to Japanese because it was believed that such operations were done only in particular circles and were conducted exclusively for the sake of personal or sexual inclinations or for particular occupational reasons or benefits" (pp. 346–347).

In the late 1950s, the first community for amateur *josouka*,⁸ male transvestites, was formed and their community gradually expanded throughout the 1960s and 1970s. Tsuruta (2009) argues that this community offered a space for people who would later form MtF transgender communities (p. 216). Terms like "transvestite," "transsexual," or "transgender" were unknown and unavailable during this period. Instead, members were mostly known as *josouka* which included gay and heterosexual men.

The year 1965 marked the beginning of a dark era for SRS in Japan. In October 1965, a doctor who performed SRS on three male sex workers was arrested for violating the Eugenic Protection Law (currently, the Maternal Protection Law after revision in 1996) which prohibited such operations, deemed as removing healthy reproductive organs without a "reason." The doctor was convicted in November 1970 and this incident, named the "Blue Boy Case," created the equation in people's minds of SRS with male sex workers, prostitution, and illegal conduct. It has been argued that the trial judgment document actually stated that sex change operations were considered appropriate medical treatment if certain steps were taken; nevertheless, misinterpretation of the ruling by doctors and the public alike resulted in SRS being considered illegal regardless of the reason or procedures. This perception remained unchallenged until the resurfacing of the GID issue in the 1990s. As a result, transsexual individuals went underground or overseas to receive the surgery. Thus, SRS and the issue of gender dysphoria (discontent with the biological sex one is born with) became untouchable in the Japanese medical community (Mitsuhashi, 2003b, pp. 108–109).

Even during this dark era, the presence of transgender individuals gradually increased in Japanese society. By the 1980s, male commercial *josouka* had gained popularity in the media. Some of them had sex change

operations and/or hormone therapy and had achieved significant feminization of the body and mannerisms. In 1981, at his debut as a singer, a gay *josouka*, Betty, was given the name “new-half,” a catch phrase which refers to people who are “half man, half woman.”⁹ Mitsuhashi (2003b) recalls that the increase in the popularity of new-half during the years 1981 and 1982 was so significant that it could be called “new-half boom.” Although the boom did not last long, the very first new-half singer left a strong impression about this “new gender” on the public and improved the image of commercial *josouka* (p. 110). The term *josouka* and new-half are often used interchangeably; however, creation of the term “new-half” was significant since it connotes a new gender instead of cross-dressing practice. However, new-half did not gain popularity as a new identifiable gender identity category outside the show business world probably because it had strong connection to show business, gay bars, and night clubs, and it was thus considered for “professionals.”

The new-half community increased its presence throughout the 1980s and the community was gradually separated from that of gay men and *josouka* (Mitsuhashi, 2003b, pp. 110–111). It was within new-half and *josouka* communities that the concept of transsexuality was first introduced outside the medical community. Masae Torai, a female-to-male (FtM) transsexual who completed his SRS in the United States in 1988 and one of the earliest leaders of transsexual community, appeared on *Kuiin* [queen], a magazine for *josouka*, for the first time as a transsexual. The article recorded Torai and *josouka* Junko Mitsuhashi in dialogue about the differences between transvestite and transsexual experiences. Up to this point, people who would be considered transsexual today were included in *josouka* and commercial new-half community. This appearance of Torai and his conversation with Mitsuhashi on the magazine helped define transsexual as full-time *josouka* who wish to have SRS and distinguish from *josouka* or transvestite,¹⁰ who are part-time cross-dressers who do not wish to have SRS (Mitsuhashi, 2003b, p. 115). A word “transgender” in a narrow sense of the term (full-time cross-dresser who do not wish to have SRS) was introduced in 1994 on *Kuiin*.

Contrary to *josouka* community, it seems that there was no significant amateur *dansouka* (female transvestite) community that would later branch out to form FtM transgender community. Instead, the FtM transgender community first emerged out of lesbian community (Nomiya, 2005). According to Sugiura’s (2006) discourse analysis of major magazines concerning the emergence and development of the concept of “rezubian [lesbian],” until the 1980s, lesbian was divided into three different

subcategories: *tachi* refers to women who plays “male role” in a relationship; *neko* are those who assume “female role”; and *onabe* are those who dress like men and work at bars (p. 128). Since the 1980s, masculine identified lesbians had been thought to be reproducing or mimicking conventional misogynistic gender role in a relationship. They thus became a target of criticism by the lesbian feminist movement. As the definition of lesbian became increasingly rigid, *onabe* was gradually alienated from the lesbian community (Sugiura, 2006). From the testimony of masculine identified women in the 1960s and 1970s, it seems that there were people who today would be called FtM transsexual who did not want to be categorized as lesbian (Sugiura, 2006, p. 136). However, neither a major movement to redefine and shift the image and the discourse of *onabe* from “commercial female cross-dresser” nor alternative gender category available, *onabe* and the male identified female continued to be categorized as “a kind of lesbian” in the public sphere until the 1990s. It was only in 1994 that the word “transsexual” finally appeared in a newsletter of small circulation for the lesbian community (Nomiya, 2005; Sugiura, 2006) and provided a more specific identity to some individuals in the lesbian and *onabe* community.

The first newsletter for the transsexual community in Japan was published in 1994 by Torai. He worked for the legalization of SRS, hormone therapy, and correction of gender on family register. In his memoir, Torai (1996) recalls the first major academic conference that dealt with the issue of GID, held in Japan in 1995 in Yokohama, Japan, as a part of the 12th World Congress of Sexology. Although it was the first World Congress of Sexology held in East Asia, it received scarce media attention. Yet, soon after this conference, transsexuality suddenly came into the center of the media spot light when it was announced that a professor at Saitama Medical University applied SRS for the ethical review in 1996. Receiving the application, in the following year, JSPN formed a special committee on GID and created the first “Guidelines for the diagnosis and treatment of GID.”¹¹ It was the first time in Japanese history that medical community made a major movement toward performing SRS as a treatment for GID and held extensive discussion on its ethical issues and social and legal implications. Particularly, it was important to maintain consistency among the Article 28 of the Maternal Protection Law and the conditions provided in the ruling of “Blue Boy Case”¹² in order for SRS to be recognized as legitimate medical treatment and to avoid conviction of doctors who perform SRS. In 1998, based on the newly created guidelines, the first legal SRS as a medical assistance for GID¹³ was performed at Saitama Medical University. It again attracted significant attention from media and Japanese society.

This series of events in the mid-1990s marked the beginning of the GID-based transsexual community in Japan.¹⁴ The first GID-based self-support group was born in 1996 and such groups have been rapidly formed throughout the nation. It was the first time the word and the concept of GID became public knowledge and this “new mental disorder” was received as sensational news in Japanese society. There have been several television drama series that featured GID individuals who often played a central role, and various news programs focused on GID issues. Furthermore, numerous autobiographies and memoirs have been written by people with GID. There have been even novels and comic books concerned with transsexual individuals. Thus, this medicalized transsexual discourse became easily available and even popular. After the flux of media attention, GID seems to have become one of the most well-known mental disorders in Japan. Tsuruta (2009) asserts that there are almost no college and university students who have never heard of GID today (p. 220).

As GID became public knowledge, policy makers could no longer ignore the issue. In 2000, Chieko Noono, a member of the ruling Liberal Democratic Party formed “GID study group,” whose purpose was to examine the current situation for people with GID in Japan and overseas. They considered possible social support system as well as legal implications, including passing of a new legislation for correction of gender on family register. Three years later, in 2003, these efforts by activists, medical authorities, and congress members bore fruit as the “law concerning special cases in handling gender for people with gender identity disorder,” so-called GID Act. The act legally defines GID and enables people with GID to change their registered sex in their family registries. However, this bill came with various strict conditions that exclude most individuals who wish to change gender on their family register. Article two of this law defines a patient of GID as:

a person who persistently identifies with the opposite gender of the biological gender and has the desire to live and be treated as another gender, while the diagnosis should be affirmed by more than two doctors who have the necessary knowledge and experience to give an accurate diagnosis based on the generally recognized medical knowledge. (my translation)

Article three also requires further conditions for the Family Court to judge the cases of gender change on family register. According to the Article, the person must: (1) be above 20 years old, (2) not be currently married, (3) have no child, (4) have no gonad or permanently lack gonadic functions, and (5) have genitalia with approximate appearance to that of the

opposite gender. The third requirement has been revised and now the person must have no child younger than 20 years old.

Some praise this new legislation for a significant progress, while others argue that the conditions are too strict and it excludes people who for variety of reasons could not meet the criteria. Particularly, the term three, which excludes transsexual individuals with underage children, is unique to Japan. The term has been severely criticized not only by human rights and transsexual activists but also from legal and medical experts. Although it is important to analyze this law itself, in this study, I focus on the impact of the GID-based transsexual movement on the transgender community in Japan at large and on the way in which people take up GID as their gender identity instead of other possible gender identity categories such as transgender, transsexual, gender queer, or unique Japanese categories like *onabe*, *okama*, new-half, and so on.

TRANSSEXUAL FUNDAMENTALISM AND DIAGNOSIS–IDENTITY FUSION

GID-based transgender movement became mainstream compare to other transgender movements that do not employ GID as their identity base. It resulted in three interesting phenomena that became apparent in the late 1990s and the early 2000s. The first was the rise of “transsexual fundamentalism.” The second was the shift of the terminologies used in transgender communities from “transgender” to “GID.” The third was a diagnosis–identity fusion in which GID became identity categories – a statement, “I *am* GID,” appeared.

Transsexual fundamentalism is an exclusionary thought that emerged in the late 1990s. Although the thought has gradually lost its significance in transsexual discourse in the past few years, it is still alive today. It took a form of a dispute over who was the “true transsexual,” and it was mainly fought in the online transsexual/GID communities. The criticism targeted transvestites and transgender who do not wish to receive SRS, who were eventually excluded from transsexual self-support groups. [Mitsuhashi \(2003c\)](#) explains that the thought of transsexual fundamentalism had the following characteristics:

Firstly, gender is only male or female (gender binarism) and there are no other ones like middle or third gender. Therefore, they think negatively about the existence of new-half and part time transgender. Secondly, the only thing wrong about transsexual is their genitals, and everything else is perfectly woman for MtF transsexual and perfectly man for FtM transsexual. Since they are originally woman (man), they think it is not

necessary to think about the possibility of passing or coming out. They do not consider those transsexual people who come out or cannot pass as “true transsexual.” Thirdly, they think that the conventional femininity and masculinity are self-evident and they have strong obsession with “normal woman” and “normal man.” They thus judge the “true transsexual” according to the degree of adaptation to the existent gender order. (p. 126, my translation)

For this group of transsexual individuals, what is wrong is their body and social gender (gender on documents); therefore, medical and social “correction” must be done. And many of the individuals in this group strongly wish to be integrated into the society as a “perfect” member of the gender they identify with. This means that “part-time” transgender (people who do not always live as a member of the gender they identify with, e.g., a person who identifies as man but works as woman and lives as man outside work is considered “part-time” transgender) or transgender who, for a variety of reasons, do not or cannot seek medical treatments are not transsexual and do not belong to their community.

One of the most influential and representative members of this new transsexual community is Masae Torai. As I mentioned above, he traveled to the United States alone in order to start his gender reassignment processes and had no association with the older transgender communities. His understanding of his identity is well aligned with the criteria for the diagnosis of GID and is quite typical for people in the new transsexual community. He believes that transsexuality is a *disorder* of gender identity. For him, transsexuality/GID is like “cancer that must be removed” while transvestite can be compared to “inflammation” (thus treatable by mere ointment?) and transgender who does not seek SRS to “ulcer” (Torai, 1996, p. 16). These analogies clearly speak to his belief that it is the body of transsexual that must be fixed rather than the social system and attitude.

Being desperate for social recognition and understanding of transsexuality and the necessary transition processes, Torai has made considerable amount of effort differentiating transsexual from “other” transgender who may not always seek SRS or hormone therapy. According to his definition, transgender is not an umbrella term under which transsexuality is included but a term that refers to people whose gender identities are incongruent with the gender given at birth, yet do not seek SRS and/or hormone treatment. In his memoir, Torai (1996) demarcates transsexual from transgender by using two stories to illustrate his point.

1. If a person with “trans-problem” drifted ashore to a desert island, a transgender person would experience a sense of relief since transgender persons are concerned about others’ perception of their gender. On the

other hand, transsexual people's problem would not be solved since the fact that they have a "wrong" sexed body does not change regardless of presence of people around them.

2. Suppose that God suddenly appears and tells FtM transperson that "I will give you a life that everyone thinks that you are a man and you have a happy elite life although your body remains female. Or you can also choose a life that everyone thinks that you are woman and you have to wear skirt and work as an 'Office Lady,' but your body is perfectly male." Transgender people chose the first option while transsexual people choose the later. (p. 14, my translation)

Furthermore, he differentiates transsexual from *onabe* who might or might not have had SRS by stating:

The reason why FtM Transsexual people soon quit a job at *Onabe*-bar is because even if you dress as man and people treat you like a man, they always feel that people do not consider them as "pure male" and dislike the feeling. Once they gain a penis, the situation may change; however, once their mind became congruous with their body to that extent, as a transsexual person, they should get a true man's job. If you have gained a body of the sex you wished for, you should live your life according to the sex. (p. 17, my translation)

According to this explanation, *onabe* individuals are not transsexual if they can continue working in the bar since they are willing to sell their "not-truly-maleness." To summarize his argument, he states that "transsexual people can be satisfied regardless of what others think of them as long as their genitals do not betray them" (Torai, 1996, p. 14).

Although Torai did not illegitimatize transgender and transvestite, the very effort to clearly demarcate the groups in order to justify his transition as a legitimate medical need creates a hierarchy among transvestite, transgender (according to the narrow sense of the term he employs it), and transsexual. Such hierarchy discriminates the groups in terms of who deserve to be "more sympathized" and recognized as a legitimate member of the society. I doubt that putting these groups in hierarchy was Torai's purpose when he was leading the transsexual movement; nevertheless, it resulted in the exclusion of people who did not or could not identify with the idea transsexual fundamentalism had. Although transsexual community included male transvestites and new-half when it first appeared, the emergence of the fundamentalism gradually excluded them from the community. The exclusionary discourse strengthened when the application for SRS for ethical review at Saitama Medical University was announced and the new transsexual community shifted the focus of their activism to legalization of SRS and later to correction of gender on the family register.

The other phenomenon, the shift of the terminologies in the community occurred along with transsexual fundamentalism during this time period. Tsuruta (2009) noted that the terminology the community used to call for equity and recognition gradually shifted from “transgender” to “GID.” Tsuruta asserts that this means that the focus of self-support groups shifted from transgender individuals, who have different needs and identifications and try to change their gender at various levels, to people who wish to gain the approval of their identity from the medical authorities in a form of diagnosis and try to change their gender within the medical framework (p. 225). Symbolic of this change was the formation of the first self-support group whose name contained a word GID instead of transsexual in January 2003. Since then, this trend spread throughout Japan. Tsuruta (2009) asserts that the reason why transsexual activism during the time increasingly focused on GID was because their purpose was legalization of correction of one’s gender on family register (p. 226). Indeed, the year 2003 saw the enactment of the GID Act, and people who enjoyed the benefit of the act were those who were diagnosed and could identify (and met various other criterions the act requires) with GID, not transgender individuals who rejected the pathological definition of their gender identity and those who could not or do not follow the official guidelines of gender reassignment processes.

I argue that these two phenomena – transsexual fundamentalism and terminological shift – are two sides of the same coin which was produced in the unique condition that transgender movement in Japan was situated. As described earlier, the significant emergence of the nonprofessional transsexual community in Japan and the medical community’s initiative toward legal SRS occurred almost at the same time, and these communities have worked closely together to gain social and legal recognition of transsexuality as a form of pathology.

Another important characteristic of the activism in Japan was that they were based on and informed by the precedent studies, activism, and practices developed in Europe and North America. Unlike the Western nations where legal and social recognition of transsexual individuals’ rights came long after intense scientific and philosophical debate over the meaning of non-cisgender,¹⁵ or nonnormative gender, identities, in Japan, the lack of social, medical, and legal support and recognition for transsexual individuals who suffer from horrendous disorder was presented as the backwardness of Japanese society. In his memoir, describing his first attempt (and failure) to have his gender on the family register changed at a court, Torai (1996) states, “the most valuable gain from this experience

[of the lawsuit] might be that, through reading of various materials to prepare for this trial, I learned how backward Japan is in many respects concerning transsexuality” (p. 189, my translation). This is a common sentiment among people with GID, and it is considered that Japanese society should learn from the *progressive* European and North American countries where transsexuality has long been recognized as a form of mental disorder and they enjoy greater access to the medical and social support and even legal protection. When Noono started “GID Study Group” in 2000, Trans-Net Japan¹⁶ made a public comment on the study group, describing how legal obstacles to change one’s gender on official documents have resulted in social sanctioning and suffering of people with GID in Japan. In the comment they compared Japanese situation to that of many European and North American countries where changes on the gender on public documents are permitted by legislation and/or court rulings ([Trans-Net Japan, 2000](#)), implying that they are the models that Japanese should follow.

Having precedents in other countries certainly helped jump-starting the transsexual activism and medical and legal reforms in Japan. However, major source of the power to jump-start the change came from the medical authorities and the mass media which jumped at the sensational nature of the “new disorder” instead of the grassroots transgender activism that works toward the recognition of various gender identities and expressions that do not necessary rely on the medical explanation for different gender identities. This created a situation where there was almost no time and spaces for the society to study and discuss the implication of pathologization of transsexuality and to nurture alternative gender choices and expressions before it became the nationwide human rights issue. Once the issue of GID was recognized as an urgent human rights issue, medical communities and the government moved quickly to recognize some parts of the appeal from GID community. Meanwhile, the alternative discourse of transsexuality and activism struggle to grow. As a result, transsexual came to be equated with GID in the society. In this circumstance, I would argue that it is inevitable that people increasingly identified with GID. As Annemarie [Jutel \(2009\)](#) argues, diagnosis is organizational in a sense that it “provides structure to a narrative of dysfunction, or a picture of disarray, and imposes official order, sorting out the real from the imagined, the valid from the feigned, the significant from the insignificant” (p. 279). GID gives people a “real” name and a space of belonging that has significant social meanings. At the same time, diagnosis is also an important site of contest and compromise, since it is “a relational process with different parties confronting illness with different explanations, understandings, values, and beliefs” ([Jutel, 2009](#),

p. 279). Identification with GID is illustrative of this contesting aspect of diagnosis. Since transsexuality is considered a *disorder* called GID, people could not freely adapt the identity unless they were given the diagnosis or could meet the set of criteria represented by transsexual fundamentalism.

This fusion of diagnosis and identity in which transsexuality is equated with GID and GID became more than a diagnosis but identity, marks the third characteristic phenomenon. Rei Tanaka (2006) asserts that “there is no region in the US, Canada, or European countries where transsexual individuals build their movement by using the medical concept of ‘GID’ as their identity” (p. 85, my translation). The troublesome aspect of this identity–diagnosis fusion is, as discussed earlier, that GID is a diagnosis, which by nature holds a set of criteria that people must meet in order to be identified as such. Analyzing the connection between identity–diagnosis fusion and transsexual fundamentalism, Tsuruta (2009) explains:

GID is a “disorder” which is defined by psychiatry as incongruence between physical gender and psychological gender ... therefore, it is medical doctors who “diagnose.” However, the expansion of the use of “GID” goes beyond the medical site that gives the diagnosis ... Also outside of the medical site, among people in transsexual community, “who is GID” became the locus of dispute and various criteria have been used to categorize people in the community. (p. 127, my translation)

A complicated aspect of the fusion is the emergence of people who identify themselves with GID without actual diagnosis. Tsuruta (2009) notes that particularly after 2003, when the popular television drama series which used a famous young actress to play a role of FtM transsexual character, the reported number of FtM transsexual individuals dramatically increased (p. 178). These “new” transsexual included individuals who had not had counseling or had not started hormone therapy. It is the people in transsexual community who “approve” their transsexual identity until a doctor gives a diagnosis, or “certification.”

The criteria used in this approval process go beyond what is written in a diagnostic manual. Tsuruta (2009) conducted a series of interviews with people in Japanese transsexual communities and noted that those people in the community who are not considered as a “true” transsexual are called *nanchatte* (fake or wannabe). She asserts that the criteria that “true” transsexual individuals use to determine *nanchatte* include: the seriousness for the transition, the readiness to live a life as transsexual, heterosexuality, and morality as a transsexual person (p. 179). If transsexuality is a form of mental disorder, why does morality matter? And what does “morality as

transsexual” mean? In the following section, I analyze the process in which transsexual identity came to require the certain morality and how the process is complicated by GID as a legal and medical concept.

LAW, DIAGNOSIS, AND MORALITY

As described above, the major focus of the transsexual movement in Japan was to legalize SRS and correction of gender on family register based on the notion that transsexuality/GID is a medical condition. In order to achieve this end, it was necessary for them to present themselves differently from people from “older” transgender communities who are often labeled as “perverts.” In order to depart from this old image, simply presenting themselves as GID was no longer enough due to the diagnosis–identity fusion which enabled people without GID diagnosis to take up the identity. Now, transsexual people need to present not only the authenticity of their disorder by having been actually diagnosed and started gender reassignment processes, but also their morality by performing conventional gender roles. Since they are minority, unlike majority, they cannot afford to have “pervert” members – the behavior of an individual minority could affect the image of the entire group. Thus, they constantly need to differentiate themselves from unauthentic/fake transsexuals.

Summarizing the interview with a group of FtM transsexual individuals, *Tsuruta (2009)* states that they consider that identity is, after all, an individual issue. However, because it is also a matter of the image of the whole group, they do not want individuals with “problems” identify themselves as FtM transsexual. They emphasize that they are “different from those who cause the harm to FtM transsexual as a category” (p. 187). Then how do they define the “problematic,” fake transsexuals? What is the morality of true transsexuality?

From the interview data with FtM transsexual individuals, *Tsuruta (2009)* extracted four moral standards used in the FtM transsexual community to distinguish a true transsexual. The first one is coherency as a man. According to this standard, for example, if an FtM transsexual who is hired as a man takes a leave of absence due to menstrual pain or refuse to carry heavy things, this person lacks coherency as a man since true man does not take a leave because of menstrual pain and they should be able to or willing to carry heavy things. Incoherency is, thus, associated with the lack of “the basic

quality as a person” (p. 188). The second standard is “natural masculinity.” If one acts overly masculine, he is considered as mere “wannabe.” This means that a true FtM transsexual should be able to extract and present “natural masculinity” from all qualities and behaviors considered masculine in the society, including exaggerated ones. Furthermore, such “natural masculinity” should be learned by the certain age; and therefore, older FtM transgender who have not acquired the “natural masculinity” are immoral (p. 190). Seriousness to use hormones consists the third standard. Here, “immoral” butch lesbians were used as an example to differentiate themselves from *nanchatte*. They argue that some butch lesbians carelessly use testosterone without meeting the hormone therapy guidelines because they want to be popular among lesbians. On the other hand, “true FtM transsexual” individuals respect the guidelines and carefully consider and plan hormone use. In other words, people who use hormones to gain popularity are immoral and cannot be transsexual (p. 191). The last standard is refusal of dating with lesbians. If one is FtM transsexual, he should not place himself in the position to be treated as a woman by going into lesbian community. Also, it is morally corrupt if an FtM transsexual goes to lesbian community only because it is easy to find a girlfriend there (p. 198).

As these standards demonstrate, legitimacy of transsexuality comes not only from the fact that it is a medical condition but also from the performance of morality based on conventional gender norms and gender roles. In other words, since it is the medicalized condition that provides transsexual individuals some social and legal recognition and legitimacy, transsexual individuals have no choice but to embody the requirements for the diagnosis. Here, law and diagnosis work hand in hand to protect conventional gender order by enclosing transsexual individuals into pathology, their gender reassignment process into medical treatment, and treating them as rightful citizens only on the very condition of pathology. Thus, diagnosis functions as a key element that differentiates rightful citizens from “perverts” whose human rights do not have to be recognized at the same degree.

WHO NEEDS IDENTITY? GID AS BITTERSWEET IDENTIFICATION

Although transsexuality or GID continues to be primarily a medical category, it should be acknowledged that it has provided “livable” identity to those who could identify with it given the lack of alternative identity

categories that have achieved the same degree of social recognition. It has been reported that the number of people who visit psychiatry wondering if they are GID or people who “self-diagnose” and come out as GID without diagnosis have drastically increased particularly after the two popular television dramas featured transsexual characters in 2003 and 2008. Some claim that these “new” transsexual include butch lesbians and transgender individuals who are not necessary needing medical assistance. If such assertion is true, we can then ask why they *had to* identify with GID? What does it mean to identify with GID for those who *could have* had different identifications? In order to answer these questions, I borrow a theoretical framework developed by feminist and post-structuralist scholars who analyzed identity and identification.

Feminist and post-structuralist scholars have revealed that the earlier structuralist theorizations of identity reflected the sociopolitical situation and theoretical needs of their time. For instance, it was Erikson’s theory of identity and lifecycle that popularized the notion of identity as sociological and psychological term and spread it to wider academic fields in the 1960s. Erikson was born in Frankfurt, Germany as a child of Jewish Danish family. Under the Nazi rule he left to the United States and became a history researcher whose analysis was based on psychoanalytic psychology (Komori, 2005, p. 251). He experienced various separations and divides in terms of ethnicity, nationality, language, and religion in his life. Being diasporic himself, it is not difficult to imagine that he might have had numerous occasions in which he had to reflect on who he was. Moreover, when Erikson’s work was published, the United States was experiencing the significant waves of civil rights and human rights movements by various marginalized groups. The United States, for the first time, was also experiencing defeat in the war in Vietnam and the colonized nations were fiercely fighting for their independence. Thus, it was not a historical coincidence that the Erikson’s theorization of identity and identification emerged at that particular point time; rather, it was the sociopolitical environment that necessitated him to conceptualize the notion of identity. In other words, “identity” as we understand today does not *naturally* exist.

Furthermore, the process of acquiring identity is not universal. “Who needs identity?” Stewart Hall (1996) asked in *Question of Cultural Identity*. Raising the example of ID card required and issued by the government, Hall demonstrates that it is power that asks the question of identity, “who are you?” And it is often the marginalized people whose identity comes under scrutiny and forced to answer the question (Ueno, 2005, p. 30). Intersex infants and transgender people, for example, have to face this question far

more often than gender majorities. “Are you female or male?” “If you are neither woman nor man, then who are you?” Answering the question becomes constant effort since their identities could be easily suspected by majority, and failing to provide a *satisfactory* answer often results in a tragic outcome such as being arrested, being forced to have unwanted surgeries, becoming the target of discrimination, ridicule, and even physical violence. Thus, minority subjects are often forced to *choose* a livable identity that brings the least harmful outcome. In this sense, I argue that the quick adaptation of GID as an identity category in Japan was an inevitable outcome provided the social situation in which other identity options were either unavailable or stigmatizing.

GID as a mental disorder cannot exist if there is no identity or questioning of “are you man or woman?” However, this question is inevitable in the society where binary gender¹⁷ is the norm. Indeed, one of the very first questions we are asked at birth is “are you a girl or boy?” One’s gender identity is given, affirmed, and reinforced as a child interacts with people (parents, teachers, neighbors, etc.), physical structures (bathrooms, locker rooms, gender segregated schools, etc.), and social systems that repeatedly asks your gender (driver’s license, class rosters, passport, etc.). Through the repetitive affirmation of gender, it becomes “natural” to have a gender identity that is congruent with the one given at birth. Although a structuralist notion of identity leaves a space for different gender identities to emerge, such identification is considered deviant and disintegrated; and therefore, it is unfavorable and pathological, rendering such being partial or unrecognizable for the society and thus unlivable for a person who holds the identity.

Mobilizing Hegel’s work on desire for recognition, Butler (2004) claims that in order for us to persist in one’s own being we must “engage in receiving and offering recognition” (p. 31). When a subject finds that they are outside of the dominant social norm, this is experienced as abjection. If we cannot be recognized as legitimate human being in the terms offered by a society, “if there are no norms of recognition by which we are recognizable, then it is not possible to persist in one’s own being, and we are not possible being” (*ibid.*). In order to avoid this abjection, the desire for recognition is a powerful one, and causes people to subject themselves to existing normative frameworks, even where this subjection is hurtful (Butler, 1993, cited in Kenny, 2010, p. 3). Identification can therefore be bittersweet: “called by an injurious name, I come into social being ... I am led to embrace the terms that injure me because they constitute me socially” (Butler, 1997, p. 104).

This ambivalent identification is demonstrated by Fumino Sugiyama, Japanese FtM transsexual and an author of an autobiographical work,

Double Happiness (2006), whose first chapter is titled “Who Am I?” He structured his story in chronological order starting from his birth. His narrative describes his increasingly disintegrated and incoherent “mind and body,” until he *found* the concept of GID which he could identify with.

Although there are people who do not like the name “disorder,” for the first time in my life I felt that I can affirm who I am by learning what kind of category I belong to, even if it is “disorder.” Until then, I had suffered everyday from the sense of guilt without a reason and I had thought that my existence was wrong and disgusting. Even if the category comes with the word “disorder,” I felt relieved to know the cause of my discomfort and that I was not the only one who had struggled with the mismatch between outside and inside. On the one hand, I think it is not a disorder; but on the other hand, I feel that I can justify myself if categorized as disorder because it means that I cannot do anything about it. (p. 66, my translation)

This statement demonstrates the difficulty or even impossibility of affirming one’s existence without putting oneself into a recognizable category. It also demonstrates the difficult *choice* that marginalized people must make in identification: I do not like the pathological categorization but it is better to have an identity category that is recognizable and not morally deviant (because “I cannot do anything about it”). Thus, Sugiyama made a *choice* to identify himself as a person with GID by self-diagnosing with it. In the preface of his autobiography, he recalled:

Ever since I can remember, my mind was “*boku*”¹⁸ but my body was “female.” Since then, I have spent my entire life feeling as if I am wearing a “female suite.”

“What is this body?”
“Who am I?”

I have struggled and been through a period in which I could not consult with anyone about my gender dysphoria. It is only recently that I can face the reality and express honest self with the support of my wonderful family and friends.

I recently began going to a hospital in order to get a medical certificate of GID diagnosis. Although I could not understand why I have to go to a hospital and even pay money only to be diagnosed with “disorder,” I decided to visit a doctor in order to make it possible to have hormonal therapy and SRS in the future. (p. 2, my translation)

This ambivalent identification is a bargaining. One must choose hurtful identification in order to be recognizable in the normative framework. Only then, one’s life can become livable. Sugiyama’s book, in this sense, is a gesture to the society that he gives in to the normalcy by narrating his life as a coherent moral person within a normative framework: I have always been suffering from the disorder (“ever since I can remember”), it is not my choice, and my very being, my feelings, desires, and behaviors can be fully

explained and legitimized by the name of pathology – I can demonstrate it here by writing an autobiography that shows you my continuity and coherency as a person that is imaginable within the normative framework, *so you recognize me*. Writing an autobiographical narrative as a marginalized and pathologized subject, in effect, answers the question of “who are you?” And as a result, it becomes a part of very discourse that has prevented a sort of queer subjectivity to emerge outside of the pathological framework.

CONCLUSION

I recognize that the introduction of GID to Japanese society contributed to increased social awareness of people whose gender identities do not match with the one given at birth. However, as I discussed above, the sudden release of medicalized gender identity based on GID diagnosis criteria without sufficient history of visible transgender movement resulted in transsexual fundamentalism, which has excluded the transgender individuals who could not or do not want to meet the criteria while reinforcing the conventional binary gender norms and gender roles instead of problematizing them. Furthermore, as Riki Anne Wilchins (2006) convincingly stated, a gender system “tends to enforce monolithic meanings ... [and it provides] us little or no room to construct ourselves and create alternative” (p. 551). GID did provide a new meaning to the body whose gender crosses the sharp line drawn between women and men. Yet, GID fails to capture and represent diverse bodily experiences and identities of transgender people whose bodies are fully capable of experiencing joy, happiness, and excitement as any gender majority subjects do. GID presents the body with a monolithic narrative of mental disorder that makes the body nothing but a source of distress. Worse still, a registration rigidly based on the GID diagnosis has produced two subgroups of gender minorities which places one below the other in Japan: transsexual individuals with GID diagnosis who will be legally and socially recognized as legitimate and those who are not GID and thus undeserving of such social legal recognition – if you are sick, you deserve to be cured, but if you are not sick, you are just perverted. Is this not the very familiar logic we have heard since the time of Krafft-Ebing?

Would it be beneficial or even possible, then to overcome this ingrained fundamentalism while keeping GID as leverage to access the necessary medical assistance? Mitsuhashi would dispute the idea. She asserted that transsexual fundamentalism intrinsically privileges some individuals over others by implying that there is a “true transsexual,” a notion that this study

has attempted to contest. Then why does this kind of elitism attract people? Mitsuhashi asserts that it is precisely because the way in which the current GID medical service restricted by guideline is provided went well along with transsexual fundamentalism. “‘Transsexual fundamentalism’ will never go away unless the medical community stops selecting some patients over others” (Mitsuhashi, 2003c, pp. 126–127).

Diagnosis cannot exist without criteria; therefore, I argue that, by nature, it is impossible for GID to function as an inclusive identity category. Furthermore, by confining transgender identity into medical condition, it focuses the source of the problem in the individual rather than in the social environment; “it calls for individual medical interventions rather than more collective or social solutions” (Conrad, 2007, p. 8). Although I recognize that there are people in need of medical assistance to make their life livable, we must seek a new system to provide medical services that do not necessitate diagnosis. Needless to say, it is also crucial to nurture the social environment where people can freely choose gender identities and expressions that go beyond conventional binary misogynistic gender system so that people do not have to rush for a narrow window of recognition. We must keep insisting on a new gender system that allows plural, fluid, different, and unstable meanings of the body and identity.

NOTES

1. At this meeting, transgender activists protested outside the APA meeting calling for removal of GID from *DSM-V*. See Wingerson (2009) for more detail on the discussion at the meeting.

2. Krafft-Ebing (1965) categorized homosexuals who identify themselves and live as the opposite gender as *Metamorphosis Sexualis Paranoica*. David O. Cauldwell (1949) defined *Psychopathia Transexualis* as individual who is “unfavorably affected psychologically determines to live and appear as a member of the sex to which he or she does not belong.” The current diagnostic category of *Gender Identity Disorder* was placed in *DSM-III* in 1980.

3. This work was originally written as a seminal essay and there are a few versions. The one translated into Japanese with Califia’s (1997) is the version collected in Cartwright, L., Penley, C., & Treichler, P. A. (Eds.) (1998) *The visible woman: Imaging technologies, gender, and science*.

4. There is an important debate against the use of the word “transgender” to refer to all gender practices outside of binary normativity, particularly of those in non-Western societies, in order to avoid conceptual colonization. Towle and Morgan’s (2002) “Romancing the Transgender Narrative” is illustrative of this debate.

5. Year 1868 marked the end of Tokugawa Shogunate, the last feudal regime in Japanese history, and beginning of the Meiji Restoration. The emperor Meiji was

moved from Kyoto to Tokyo which became the new capital and his imperial power was restored. This period from 1868 to the death of Meiji emperor in 1912 is called Meiji Period. Like other Asian nations, Japan was forced to sign unequal treaties with Western powers. These treaties granted the Westerners one-sided economical and legal advantages in Japan. In order to regain independence from the Europeans and Americans and establish itself as a respected nation in the world, Meiji Japan was determined to close the gap to the Western powers economically and militarily. Drastic reforms were carried out in practically all areas as the name of the period “Meiji,” or “enlightened rule,” shows.

6. See Kunio Haruta (1994) for more detail on the purposes of ordinance and its impact on people’s life.

7. See Michel Foucault’s *History of Sexuality: An Introduction*.

8. “Josou” literally means “woman’s dress” but commonly used to refer to a practice of men dress in woman’s attire. “Josouka” refers a person who does “josou.” When women dress in man’s attire, it is called “dansou.”

9. Prior to the appearance of new-half, feminine or androgynous gay men were some sometimes called “gay-boy,” “sister-boy,” “Mr. Lady,” or “okama.” They were considered feminine gay men and not as people with feminine gender identity.

10. The word “transvestite” was introduced on *Kuini* in 1982 but only used in a limited community. In the public, word “*josouka*” still remains in popular use. See Mitsuhashi (2003b) for more detail on the influence and expansion of this word.

11. The first guideline for the diagnosis was crafted based on *Diagnostic and Statistical Manual of Mental Disorders Fourth Edition (DSM-IV)*. The newest edition published in 2006 is based on *DSM-IV-TR* and *International Statistical Classification of Diseases and Related Health Problems, Tenth Revision (ICD-10)*.

12. See *Guidelines for the diagnosis and treatment of Gender Identity Disorder (2nd ed.)* by JSPN for a detailed discussion of the creation and revision of the guidelines.

13. As I have discussed above, this is not the first SRS performed in Japan but it was the first case which followed the guidelines for the diagnosis and treatment of *GID* and thus the first case as a “treatment” of *GID*.

14. Word “transsexuality” and “*GID*” were introduced to Japanese society almost at the same time and the terms have been often used interchangeably. It is safe to say that the most transsexual self-support groups equate transsexuality with *GID* unless they clearly state otherwise.

15. *Cis* is the Latin prefix for “on the same side.” A term “cisgender” refers to individuals who have a match between the gender they were assigned at birth, their bodies, and their personal identity.

16. Trans-Net Japan is a self-support group for people with *GID*, found in 1996.

17. Binary gender: a belief on which social and legal systems are constructed that there are and only two genders, female or male. Kessler and McKenna’s (1978) classic discussion of the gender attribution process and the signs of gender as cultural constructs within a dichotomous gender system illustrates how members of Western reality see someone as either female or male despite the existence of contradicting “gender cues” in a person.

18. “*Boku*” is the first person equivalent of “I” but it is only used by a male subject.

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PART V
SOCIAL CONTROL

DIAGNOSING THE CRIMINAL ADDICT: BIOCHEMISTRY IN THE SERVICE OF THE STATE

Sarah Whetstone and Teresa Gowan

ABSTRACT

Purpose – Since the mid-20th century, drug addiction in America has increasingly been redefined as a disease and diagnosed as a widespread yet treatable disorder. The idiosyncrasies of addiction as a disease, however, have tended to block the journey of the addict from stigmatized moral failure to therapeutic reprieve. Centering in on the process of the “court-led diagnosis” of addiction, this qualitative case study uses ethnography and interviewing at a county drug court and one of its “partner” therapeutic communities to examine the process in detail, from the first negotiations between treatment and court personnel over the eligibility of the client, to the gradual inculcation of an addict identity by means of intensive cognitive education and behavioral modification.

Methodology/approach – Qualitative: ethnography and interviews.

Findings – We demonstrate that a shift from moral judgment to therapeutic sympathy is particularly unlikely for the fast-growing mass of criminal offenders whose diagnosis is spearheaded by the state in the form of the therapeutic jurisprudence of the drug court. For this group, the emphasis on the need for comprehensive resocialization and the close

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cooperation between the intimacies of therapeutic “rehab” and the strong arm of criminal justice “backup” not only maintains, but intensifies, moral tutelage, and stigmatization.

Social implications – The convergence of drug treatment and criminal justice tends to produce yet another stigmatizing biologization of poverty and race, lending scientific validity to new forms of criminalizing and medicalizing social hardship.

Keywords: Drug court; addiction treatment; punishment and social control; biomedicalization; sociology of diagnosis

The Anglo-American struggle to maintain an overblown and fetishized construct of free will has over the centuries developed into a set of dramatized dichotomies. On one hand lies the free-floating agency of possessive individualism. On the other hand, various representations of abject dependence and compulsion (Sedgwick, 1994). These forms – whether gambling obsessions, dependent poverty, or self-indulgent hedonism – have increasingly circled around the trope of addiction. As Timothy Melley and Eve Sedgwick have separately argued, the American fixation on addiction seems to have become a central vehicle for “agency panic” – a broad anxiety about lack of inner control which has developed since World War II (Melley, 2002, 2008; Riesman, Glazer, & Denney, 1961; Sedgwick, 1994).

Within this broadened scope, “addiction” might seem to be losing some of its stigma, opening out again to its earlier definition as any form of overwhelming involvement in a particular pursuit (Alexander, 2008). Addiction has become an omnipresent condition, extending beyond substances to define anything from shopping to vigorous exercising to television viewing (Conrad, 1992, 2007). Whatever the causes of this “proliferation of addictions,” American culture is vigorously developing new tools for understanding these problems through a medical-therapeutic lens (Rose, 1990, 1998, 2003, 2006). Despite the continued stigma attached to substance use, drug addiction is no exception to the medicalization trend. More than ever, Americans are identifying themselves and their family members with the disease of substance abuse, and heading off to self-help groups or “rehab” (SAMHSA, 2010).

The diagnosis and treatment of drug and alcohol addiction presents some complex puzzles for the sociology of health, illness, and medicine. Central to the literature on medicalization is the notion that medical authority has steadily expanded to replace law, religion, and other institutions (Conrad, 1992, 2007; Zola, 2009). Yet before recent developments in neurochemistry,

the role of medical doctors in the research and treatment of addiction has been relatively insignificant. Physicians, traditionally the sole guardians of diagnostic prerogative, were long reluctant to recognize alcoholism as a diagnostic category, partly because they lacked effective strategies to treat it medically (Blaxter, 1978; Conrad & Schneider, 1992). Instead, the main expertise and advocacy offering diagnostic wisdom and legitimating the “disease model” of substance use developed within the self-help movement of Alcoholics Anonymous.

A second complication, more important for this chapter, is that medical interpretations of addictions have always had to work in the shadow of intense moral castigation. According to Parsons’ ideal-type formulation, as well as the more recent work of Conrad and others, a primary benefit of the “sick role” is at least a partial moral reprieve for exhibiting signs of deviant behavior. In the presence of disease, willpower alone cannot prevail, and the sufferer cannot be blamed (Conrad, 1992; Parsons, 1951a, 1951b). And indeed, such redemption constitutes a primary attraction of Alcoholics Anonymous (AA) and the fast-growing web of addiction support groups for gamblers, sex addicts, and codependents. In the case of drug addiction, though, a long succession of moral panics about “hard drugs” has incessantly refreshed fears of drug addicts as possessed monsters or enslaved victims, equally stripped of humanity and free will. From rum and opium scares to reefer madness, from the crack devastation of the 1990s to the current panic over crystal meth, the drug use of the young, people of color, and the poor has been feared and punished (Acker, 2002, 2010; Bourgois & Schonberg, 2009; Keire, 1998; Reinerman, 2008; Reinerman & Levine, 1997). Even for middle-class, white, male alcoholics in AA, or 12-Step based treatment programs, the diagnosis of addiction only represents a moderate reprieve within a healing process aimed at instilling a reinvigorated moral compass and behavioral disposition (Skoll, 1992; Valverde, 1998).

A third idiosyncrasy of the medicalization of drug addiction, and the primary focus of this chapter, is the increasingly preeminent role in diagnosis taken by the criminal justice system. We argue that the rapid expansion of the drug court system, along with other forms of jail and prison diversion into treatment, is shaping every element of diagnosis. First, the legal system assumes the adjudicator role in identifying large numbers of low-level offenders as addicts, offering them very strong incentives to identify as such. Then, it structures their progress and reifies the diagnosis through an intensive punishment-reward system. Finally, on the aggregate level, the court system is reshaping the definitional category into which these offenders are sorted.

THE RISE OF STRONG-ARM REHAB

Conceived in the late 1980s as a more effective intervention for “high risk, high need” offenders engaged in drug and drug-related crime, drug courts now have widespread popularity and bipartisan political support. Pragmatic politicians welcome court-mandated treatment as a low-cost alternative to the budget drain of the prison boom, alongside public health advocates who see addiction as the hidden root of crime. As a consequence, residential drug treatment is being widely offered to offenders who might not normally have sought treatment on their own. Once-struggling rehabilitation programs have eagerly taken on the charge of correcting the criminal-addict, forging contracts and closer relationships with local court systems. As a result, the drug court and probation processes are now the largest referral sources to publicly-funded drug treatment, funneling more Americans than ever into a “strong-arm” version of rehab (Gowan & Whetstone, 2011), an approach that takes the form of extended residential stays, rigorous cognitive and behavioral modification, and careful criminal justice monitoring both during and after treatment (Gowan & Whetstone, 2011; Marlowe, DeMatteo, & Festinger, 2003; SAMHSA, 2008; Tiger, 2011).¹

The expansion of “strong-arm” rehab has coincided with substantial shifts in the science of addiction. During the past three decades of the 20th century, the developing addiction treatment industry became a primary domain for behavioral therapists, who tugged the language of diagnosis away from the declining “allergen” theory of Alcoholics Anonymous toward a model of addiction as a behavioral disorder. However, recent contributions in the field of neuroscience, aggressively promoted by the National Institute on Drug Abuse (NIDA) have again transformed understandings of the causes of substance abuse. The “biomedical revolution” (Clarke, Mamo, Fosket, Fishman, & Shim, 2010) has transformed the long-held metaphysical commonsense that addiction derives from a weakness of will, replacing it with models of compulsion that are “hard-wired” through molecular processes in the brain (Volkow & Li, 2004). Rapid developments in neurochemistry have confirmed that genetics play a significant role in predisposing individuals to addiction, but they also indicate that long-term drug use fundamentally changes the activity of neurotransmitters, restructuring the brain’s pleasure-reward circuitry so that sufferers continue to relapse long after the cessation of drug use (Weinberg, 2002).

The turn toward biomedicalization has done nothing to simplify the tension between moral castigation and therapeutic registers in addiction treatment. By propagating images of addicted, fundamentally different or

altered brains, neuroscientific understandings of addiction may in fact *increase* the stigma directed toward self and others, rather than offer reprieve (Buchman & Reiner, 2009). The spread of genetic knowledge about illness has not uniformly increased the social tolerance of mental illness, for example – partly due to the perception that an individual with a genetic condition has no opportunity to get better (Phelan, 2005; Schnittker, 2008). Within the process of “strong-arm” rehab, new forms of (bio)medicalization have not mitigated the central project of moral reform so much as buttressed it with the authority of cutting-edge science.

True, for middle-class sufferers, biomedical advances now offer pharmaceuticals which act on neural processes to “cure” addiction. The availability of drugs like buprenorphine, designed to respond to opiate addiction, allow physicians to bypass behavioral therapy altogether, administering neurochemical treatments in their offices and establishing new techniques to shape individual response (Hanson, 2003). The rise of “corporatized medicine” has combined with these new biochemical technologies to undermine more labor-intensive and expensive residential therapies for addiction and other psychological problems (Conrad, 2005, 2007; Rose, 2003). The reluctance of HMOs to pay for residential rehab means that extended in-patient therapy is increasingly proposed only for each end of the American class spectrum. While wealthy adult private payers are sold resort treatment (and out-of-state or offshore boot camps for their troubled teens), a far larger number of working class and poor Americans are coerced into strong-arm rehab by the courts.

SETTING AND METHODS

Arcadia House, the setting for our ethnographic research, was one of a handful of “strong-arm” drug rehabilitation facilities working closely with the drug court of a large American city. A long-standing “therapeutic community,” the institution had built up a close relationship with the criminal justice system since the late 1980s. Arcadia adapted to the steady stream of clientele and funding, regularizing its old Synanon-based therapeutic practice to fit county and criminal court mandates, and building a strong local reputation for dealing effectively with “the worst cases.” The 25% of clientele coming to the facility from drug court referrals represented only the tip of the iceberg – for every drug court client, there were two more “serving time” in treatment on a probation-related sentence, facing sometimes as many as 10 years in prison should they fail to complete the

program. As in the incarcerated population in general, African-Americans were strongly over-represented, making up from two-thirds to three-quarters of the clientele at different points in our two-year study.

Arcadia's 120-day residential program combined elements of intensive behavioral modification, Alcoholics Anonymous meetings, family therapy, and "life skills" development.² According to the phase-step logic of the county drug court, clients had to spend 120 days living in the facility, followed by 6 months of outpatient "aftercare" to complete their legal treatment requirement, although the length of participants' sentences were often increased after sanctions from the drug court judge. After negotiating consent from the Arcadia staff and clientele, our six-person ethnographic team, including the authors, Kristen Haltinner, Tanja Andic, Janelle Rainwater, and Daniel Winchester, conducted over 50 episodes of ethnographic fieldwork in the facility and drug court over a two-year period, much of which took place in classes and therapeutic groups. We also participated in recreational outings, some individual sessions (with the client's consent), staff meetings, regular courtroom visits, and some "hanging out," (especially in the form of smoke breaks!). Eventually, we conducted 60 voluntary interviews with clients who had finished or dropped out of the residential program.

In what follows, we hope to enrich the literature contributing to a sociology of diagnosis by "bringing the structure back" into the largely constructivist paradigm of medical sociology (Brown, 1995; Jutel, 2009). Although diagnosis is generally examined as the province of medical professionals and psychiatric disciplines (Cooksey & Brown, 1998; Kutchins & Kirk, 1997; Mayes & Horwitz, 2005), we focus here on the criminal justice system as a source of diagnostic authority which increasingly shapes the process and character of contemporary medicalization. We examine the process of the "court-led diagnosis" of addiction in detail, from the first negotiations between treatment and court personnel over the eligibility of the client, to the gradual inculcation of an addict identity by means of intensive cognitive education and behavioral modification.

"SENTENCED" TO TREATMENT: DIAGNOSING CRIMINAL-ADDICTS

The court in our study followed a post-adjudication model, in which a drug court team selected eligible clients from offenders recently convicted of drug

and property offences. The team – made up of judge, prosecutor, public defender, probation officer, public safety officer, and senior counselors from partner facilities – reviewed both criminal and treatment records to assess offenders' levels of "criminogenic risk and clinical need." Their diagnostic assessment tool, designed by a prominent academic associated with the therapeutic justice movement, determined those most "at risk" on the basis of high levels of both past criminality and evidence of drug abuse. On the "criminal" side, factors such as youth, early onset of drug use or crime, lack of regular housing or employment, and prior convictions increased the eligibility for diversion into treatment. The key "clinical" criteria, however, were withdrawal problems, loss of control over drug use, cravings or compulsions, or the presence of major mental illness. Offenders were rated across each dimension on a severity index, and the results were scored in relation to a threshold for eligibility, generating a two-by-two table of offender categories across high or low scales of risk and need. Although other offenders were screened out, either incarcerated or put on administrative probation, the "high risk, high need" group required intensive treatment, close surveillance, and enforced accountability for their actions.³ Once in treatment, this hybrid diagnosis was unified into the older construct of the "criminal addict" (Yablonsky, 1962). Conviction became the determining proof of addiction, and conversely, addiction the root cause of all criminal justice problems.

Like the mass incarceration boom in general, the role of drug court in the expansion of criminal surveillance disproportionately affects African-Americans. The massive growth and rapid darkening of America's prison population since the 1970s is due in large part to the steady ramping up of the War on Drugs, and particularly the continued prioritization of aggressive street-level policing strategies (Beckett, Nyrop, & Pflugst, 2006; Beckett, Nyrop, Pflugst, & Bowen, 2005; Duster, 1997; Tonry, 1995; Western, 2007). Since the 1980s, national drug arrests have skyrocketed, and by 2003, African-Americans were 3.4 times more likely to be arrested for a drug offense than whites (King, 2008). In our case study, the racial disparities in the criminal justice system were particularly pronounced. According to 2010 data collected on sentencing outcomes statewide, African-Americans comprised nearly one-third of the state's population of incarcerated drug offenders (and two-thirds of those imprisoned for cocaine offences), but only 4% of the state's population. (Historically, the state we studied has had one of the most racially disproportionate criminal justice populations in the country, at all stages of processing from arrest to sentencing).⁴ These disparities also characterize the diagnosis of criminal-addicts and the application of drug

court's treatment sentence. Recent evaluations of the drug court in our case indicate that over half of the felony drug offenders defined by the court as "high-risk, high-need" and subsequently "sentenced" to treatment were African-American.⁵

THERAPY AND PUNISHMENT MEET AND MESH: "DOSING" LEGAL SURVEILLANCE

Once offenders were "diagnosed" as criminal-addicts, the drug court team applied the "treatment" sentence. The cooperation of court and treatment professionals constantly blurred therapeutic and punitive goals, but staff made considerable effort to separate legal and medical domains conceptually. Donald, the drug court coordinator, asserted that the court always deferred to treatment professionals when it came to making decisions about the content of rehabilitation:

We are minimally involved in structuring their treatment plan, just as we would be minimally involved in structuring the treatment plan for a person who has hypertension. We appropriately defer to the medical professionals to come up with that. Now, we can become very involved in leveraging that plan, to make sure there's sufficient motivation and energy to accomplish it, but we don't shape it. That would be a boundary problem for us.

Yet in practice, the boundaries were less clearly defined. The legal system had substantial influence in structuring treatment from the outset, as they were directly involved in selecting the programs that would best satisfy their needs, affirmed by Donald:

We're looking for programs that have incorporated into their curriculum the stuff that addresses criminogenic needs ... We don't want just a sober crook. We want an offender who is addressing their substance dependence and examining a variety of other variables that get them involved in criminal justice and ongoing criminal behavior ... In order to work with us, we would want them [the treatment provider] to be addressing criminal behavior and criminal thinking.

Donald's admission that drug court seeks reform beyond the "sober crook" further highlights the extent to which addiction and criminality are seen as intertwined, and thus need to be addressed as a joint project of rehabilitation. Rehab staff at Arcadia were equally straightforward about the blending of punishment and therapy, often defending their mission to extend therapeutic logic into the realm of criminal corrections. According to Sylvia, the Arcadia program director, "The next step with drug court is

to take the therapeutic community model and put it into the court system itself. They want to take what we do here and start applying it there.”

The force of law had a constant presence throughout the process of diagnosis and treatment. Clients’ progress in rehab was monitored weekly in public court proceedings which functioned, staff told us, as “staged” reinforcements of Arcadia’s program, rewarding good attitudes and sanctioning lapses and reluctance to “talk the talk” with penalties ranging from community service to prison stays. Within the non-adversarial approach favored by the emerging legal philosophy of “therapeutic justice” (Hora, 2002; Hora, Schma, & Rosenthal, 1999; Nolan, 2001), addicted clients are assumed to be ignorant of their true interests. Rather than arenas for legal debate, therefore, drug court and Arcadia staff understood much of what happened in court as a formal presentation of private agreements earlier that day between court and treatment staff. As Donald put it, “All the disagreements take place behind closed doors, in the staff meetings where they are intended to take place. We go into court with a very unified front, so the defendants can’t triangulate and divide staff, and do what addicts do.” Regular backstage invocations of the sneaky, opportunistic, and ultimately misguided behavior of addicts reinforced the common sense that the protection of basic legal rights within an adversarial system was inappropriate for these clients, and that manipulation was a necessary element of “treatment.”

As many as 100 cases had to be processed during each court session, so the legal team could not reasonably spend more than a few minutes per offender. In most cases, quick progress reports from the treatment staff and probation officer met a standard encouraging remark from the judge. The judicial performances in our site were relatively low-key and dispassionate in relation to the moral dramas played out in some other accounts (Burns & Peyrot, 2003; Mackinem & Higgins, 2007; Nolan, 2001), yet the judge regularly exercised his prerogative to send non-compliant clients back to the city jail. Given the post-adjudication model, the imminent threat of re-incarceration weighed heavily – the court interactions were constant reminders of the prison sentences awaiting those who failed to internalize the treatment philosophy or came up “dirty” on a routine drug test.

In a typical courtroom dialogue, the judge admonished several Arcadia clients accused by treatment staff of being “toxic” during group therapy:

So, I see there has been a big misunderstanding on your part as to why you’re all at Arcadia. You say you don’t belong there and that the only reason you are there is that you lied on your assessment. Is this correct? Let me remind you of how long you all have hanging over your head here. Let’s review that first.

The probation officer recited each client's sentence if they failed to complete treatment.

Now, do you want to go back to prison or do you want to be in treatment?... I'm getting these reports that you're being toxic in the treatment environment. You can either focus on treatment, or go back to prison. It's really all up to you.

By threatening the clients with the "choice" of prison or rehab, the judge leveraged the power of the law as an integral component of the treatment course. Here, the judge also sidestepped the fundamental question of whether the clients "lied on their assessment" or not. A client's biochemical status as addict was taken as given and went unquestioned once they entered the drug court. Indeed, it justified the drug court's project of coercion in the first place. Not only were clients stripped of advocacy within the nonadversarial legal model, but their attempts to speak on their own behalf were often seen as evidence of a lingering addict pathology. Both in the courtroom and in Arcadia's therapeutic groups, self-advocacy that departed significantly from standard recovery mantras was invariably taken as proof that the "disease" was speaking.

The importance of drug court's particular brand of social control was not lost on staff, who frequently used medical metaphors to describe the effect of judicial supervision. Here, Donald tells us how the "dosage frequency" of judge-client interactions is an indispensable factor in clients' success:

One of the things we know from participant surveys and the research is that judicial supervision is among those things that matters most in terms of changing behavior. So we're careful not to change the dose of that thing that we think to be among the most helpful. So we're going to hold to the frequency, or the dosage, of judicial supervision unless the person is doing phenomenally well, and then we might go down to three weeks. But the expectation is every other week. And I think there's an assumption that something substantial, something authentic, is happening in that dialogue – that it's not just talking about the weather.

Mobilizing Biochemical Knowledge in State-Mandated Rehab

Crucial though the "dose" of court visits might be, the truth of the addiction diagnosis was established not in court, but in the interaction with staff and other drug court clients in the highly structured programming of the therapeutic community. In Arcadia, group therapy was an all-consuming activity. Clients attended a minimum of six sessions every day, often conducted in the same cramped room, breaking only for a quick lunch in the facility's basement. As in other therapeutic communities, the staff's primary

training was in behavioral modification and life skills development. With sessions like the “Criminal Thinking” class and the “Log Group,” an intensely confrontational interaction where embarrassing sanctions for noncompliance were publicly applied, Arcadia pursued its mission to install self-discipline and cultivate specific lifestyle change. Elements reminiscent of talk therapy surfaced in the treatment process, as some counselors encouraged their clients to explore their histories of trauma or abuse, but the dominant engine of the program was the reward-punishment system framed around the central project of client “accountability” for each and every statement or action. This emphasis on round-the-clock behavior modification was designed to reorient a range of “dysfunctional” behaviors and “habilitate” fully functioning adults who could abstain from drugs and lead self-sufficient lives after graduation. The overwhelming badges of transformation were making beds, completing chores, tucking in shirts, refraining from cursing or speaking out of turn, and in turn holding others accountable to the same goals. Needless to say, this treatment philosophy, despite its origins in the California counterculture, shares a natural affinity with the state’s goals of criminal correction.

Despite a seeming disjuncture between the brain scans of addiction science and Arcadia’s brand of behavioral modification, the biochemical model of addiction appeared often. Environment and biography are increasingly understood and articulated in American popular culture in terms of neurochemical brain functions (Rose, 2003), no doubt shaping the therapeutic content mobilized in the everyday spaces of drug rehab, and the up-to-date addiction science now standard in counselor education and licensing requirements has strongly reinforced this trend. The Arcadia staff thus officially defined addiction according to the guidelines of NIDA: as a biochemical brain difference. Scientific understandings of addiction featured prominently in many of the educational materials, like the HBO documentary produced in cooperation with NIDA that was required viewing for new clients, *Addiction: Why Can’t They Just Stop?* (Quasarman, 2007). The film explained how drug use alters brain function, how genetics play a role in predisposition, and how dangerous “high risk environments” increase the likelihood of addiction, ending with the bold assertion that “addiction is not a choice, but a disease.”

Yet the talk of faulty brain chemistry rarely made its way beyond worksheets and videos into treatments designed to directly address that issue. The pharmacotherapies with which the rest of us manage our lives were generally off-limits at Arcadia. One of our informants went through the program on Xanax, which he found extremely helpful, but this

prescription was only permitted because he had recently survived a suicide attempt. Another more typical case involved a client who was denied medication and hospitalization for severe alcohol withdrawal, on the premise that he was not to leave the building for anything during the first week of the program. Staff was finally convinced he required medical attention after he experienced a minor seizure.

It was clear that biochemical understandings lay very lightly on the actual practice of administering the “cure” for addiction, and yet, the availability and dissemination of these frameworks accomplished important discursive work. Unlike the “allergen” theory of AA, an earlier medical notion of addiction which granted the addict reprieve from responsibility for their condition, the biochemical theories of addiction now disseminated by NIDA still allow plenty of room for individual accountability. The notion of brain plasticity – that individuals are not just predisposed to addiction genetically, but can transform their brain structure through repeated use – complements drug court’s project of moral accountability and offender reform quite well. That is, (bio)medical models can now be mobilized without jeopardizing the fundamental legal principle of the free-willed, rational individual. It is through the *choice* to use drugs that we reset our addictions, and are given over to irrationality, leaving personal responsibility fully intact. Nuanced understandings of *how* addiction gets hard-wired in the brain have thus made it possible for treatment staff and clients to mobilize the biochemical model alongside seemingly contradictory frameworks, and in the process, to exploit the authority of brain science to support a project of behavioral, moral, and even racial-cultural reform.

As clients negotiated their status in the program, challenges to accepted addiction science were often heard, and in these interactions, the biochemical diagnosis served as an authoritative “final arbiter” on the matter in the face of lingering questions about whether a client truly had an addiction problem. Paralleling the “first step” in the AA tradition, Arcadia clients were required to publicly accept their addiction as proof of program compliance. Despite drug court’s stated mission to target only the high risk-high need offenders with severe addictions, we met many young men who reported they accepted an addict identity and a treatment “sentence” only to avoid more serious penalties for small-scale dealing. In many cases, these younger men had consumed little beyond marijuana and alcohol, and had experienced limited or no negative psychological or physiological effects as a result of their drug use. For these clients who were less comfortable seeing themselves as addicts, or who directly challenged prevailing commonsense constructions of addiction, staff could always trump their protests by

appealing to the brain science that underlie their purported pathologies, claiming legitimacy through the medical connotations of their legal-therapeutic diagnoses as “high risk, high need.” In this passage extracted from a larger discussion in which several clients openly disputed their addiction diagnoses, counselor Silas mobilizes brain science to buttress client Damon’s objections:

Silas: To review from yesterday, the hypothalamus is what controls our brain chemistry. It sets up all of our natural responses to life like being hungry, having an appetite, or being tired. We have all these natural drives and our body keeps our chemistry in balance. For example, using meth or crack will imbalance your sleeping habits. Using substances like this messes up our natural chemistry ... It’s like a key and a lock – drugs will release some of our natural chemicals, but deplete them too. Something happens when you use drugs. At some point, at a line we can’t really pinpoint, something happens and the blood-brain barrier is crossed. Using a substance again will reactivate this whole process and reset our addiction, and we don’t think rationally when it pops up –

Damon: But I just smoke weed! I’m not, like, some crack addict.

Silas: But what’s your chemistry? Your chemistry is wired for dependency. Something happens to us, and we each have our own relationship to some chemical. The basic, bottom line is that your drug use is a medical issue. Now, your behaviors, that’s what we need to focus on to fix it.

Although Silas draws on biochemical explanations of addiction in this group therapy session to silence clients’ dissension, the real disconnect between emerging addiction science and on-the-ground practice here comes to the surface, as he is unable to impart a clear understanding of the science with his loose account, evidenced by his confusing admission that “something happens” when drugs are consumed. The passage also demonstrates how counselors quickly set brain science aside for a curriculum of moral re-education that aligns with the traditional therapeutic community approach – “focusing on behaviors” (Leon, 2000; McKim, 2008; Weinberg, 2005). Indeed, treatment staff did not address addictions at the level of brain chemistry at all, but rather worked to install functional blueprints for “right living” within each client, accomplished through strict scheduling, bodily discipline, mutual surveillance, and adoption of individual accountability, upon which the biochemical discourse of addiction was only a superficial overlay. Despite its lack of coherence, mobilizing a biochemical frame worked successfully for Silas in this interaction, and often worked to convince clients that their brains set them apart, warranting the intervention in which they found themselves. The alliance of brain science with behavioral modification is made possible here because the explanation leaves room for personal culpability – the “behaviors” remained front and center, and the core project of the therapeutic community was not challenged. Thus, we

observed an underlying tension between the (bio)medicalization of addiction and the decreased blame and shame thought to accompany that process. In the spaces of “strong-arm” rehab, at least, biomedical notions of addiction not only worked alongside calls for personal responsibility, but lent a new sense of legitimacy to its project of moral reform.

Racial-Cultural Disease

Although biomedical discourses were mobilized in the therapeutic community at particular moments and for particular ends, behavioral modification was the “medicine” upon which staff and clients focused their energies. Evidence that recovery was working was found not in brain chemistry, but in the adoption of the “right attitude” – assessed through dress, speech, movement, and the acceptance of normative value systems. Clients were often “called out” by staff and by each other for failing to assume the comportment associated with the truly recovered. Baggy pants; aggressive posturing; the use of slang terminology; and signs of “addict values” such as selfishness, idleness, inability to delay gratification, and pride, were collapsed into one problematic “street” subculture which had to be eradicated for full recovery. The court’s requirement that criminal-addicts undergo an explicit moral transformation complemented the traditions of moral reeducation already in place in the therapeutic community to produce the unique “strong-arm” process, informed by the popular “criminal thinking” prison curriculum developed in the 1970s by forensic psychologists Yochelson and Samenow (Broekaert, Vandeveld, Schuyten, Erauw, & Bracke, 2004; De Leon, 2000; Yochelson & Samenow, 1976).

A recent NIDA publication outlining the latest addiction science for the criminal justice system reiterated the importance of the “criminal thinking” approach:

Criminal thinking is a combination of attitudes and beliefs that support a criminal lifestyle ... which includes feeling entitled to have things one’s own way and failing to be responsible for one’s actions ... This pattern of thinking often contributes to drug use and criminal behavior. Treatment that provides specific cognitive skills training to help individuals recognize errors in judgment that lead to drug abuse and criminal behavior may improve outcomes. (NIDA, 2007)

Once the biochemical narrative of “hardwiring” had demonstrated the objective, “color-blind” character of the diagnosis, a far more decisive role in both past and future behavior was attributed to criminal thinking. Just as pathological “pathways in the brain” had been created by the deviant

practices of the past, the key to a drug-free future lay not on the level of brain chemistry, but on a radical modification of “behaviors” and “criminal thinking.” The causal relationship between drug use and criminality was thus defined fuzzily. Although NIDA maintains that criminal thinking can lead to drug use, an easy slippage resulted in staff and clients oftentimes claiming that drug use also gave rise to criminality, reconstructing the single choice to use drugs as the dramatic moment upon which clients’ “dysfunctional” fates hinged.

One illustration of this dynamic is Ricardo, an African-American male in his mid-20s, who learned to express that his drug use was the cause of his frustrations with lifelong poverty. “Arcadia taught me that my drug use was the cause of my criminal thinking,” he told us. “Sometimes, you know, I get to thinking that I’m broke and that I really need more money. But here, I learned I don’t have to *act* on that criminal thinking anymore.”

Given the highly racially disproportionate context in which many offenders entered the criminal justice system and the drug court program, the program’s aggressive attack on the purported “street mentality” and “criminal lifestyle” that underlay or generated their addiction firmed up existing associations between blackness, criminality, and degeneracy. The content of much of the behavioral modification seemed designed to erase the cultural practices and styles associated with African-Americans, constantly reinforcing the dual “addict-criminal” characterization of the clients, and offering a cure which was not only moral but ultimately cultural. “Criminal Thinking” participants were encouraged to accept that their addictive disorders either produced – or were produced by – a range of different “criminal lifestyles,” which included everything from reciting rap lyrics to hanging on the street to selling illicit drugs to avoiding responsibility for parental care. The goal, often reiterated by Sylvia, the men’s program’s enthusiastic director, was to join the mainstream, to become “Joe taxpayer.” “When we go to the bowling alley,” Sylvia remarked, “and people see you with your baggy pants, prison tattoos, and do-rags, they get worried. Your average Joe is a taxpayer. He’s a contributing member of society. That’s what you guys should be striving to be.” As Sylvia’s comment illustrates, the moral and cultural makeover project was strongly racialized – “negativity” and “addictive” street culture were marked by baggy pants, Black English, and listening to rap, and house sanctions for “bad attitude” were applied much more vigorously to African-American clients. In a lecture we became very familiar with over the course of our fieldwork, counselor Mike tried to convince Jermaine, an African-American client in his early 20s who had just entered the program after

being convicted of selling marijuana, that the roots of his purported addiction lay in his dysfunctional “street mentality”:

I had a street mentality and street values, just like you. It's a cycle we get caught up in which is made up of sex, drugs, fast money, criminal thinking, rap music ... If you don't break this cycle and beat the streets, then you will have worse consequences. But the system says, 'Wait, maybe there is something in you that really wants to change. Deep down, maybe you really want to be a better person,' and so we send you to treatment ... I'm appealing to the basic core of you now, the part of you that says, 'I want a better life, I want to be something, I want to stay out of prison.' ... All your excuse-making keeps the cycle going, and that's insanity ... You have to break ties with all those street urchins you're hanging with ... I don't know if you've had serious gang involvement or whatever, but you have to break the cycle. You've developed irresponsible, undisciplined, irrational ways of thinking. You've developed the 'I don't give a fuck' attitude that the world owes you something ...

Mike's words demonstrate that beneath the biochemical “front,” a rhetoric of personal responsibility and cultural pathology was alive and well. Mike's characterization of Jermaine's problems surely overemphasize the power of personal desire for change, turning a blind eye not only to biochemical etiology, but more appropriately for Jermaine, the impact of racial and economic constraints on his life chances. Though Mike in fact knew nothing about Jermaine beyond his age and race, he pursued the standard one-size-fits-all narrative designed to neutralize “excuses” in service of the central project of (racialized) moral reform.

Despite the abysmal failure of these institutions, the notion of a racial-cultural pathology seemed to stick to some extent, at least in the sense that Mike's characterizations were frequently echoed in our interviews with clients, whether they had graduated or dropped out of the institution. Our attempts to create discursive openings outside the stock narratives constructed in treatment did not resonate with most of our interviewees, who seemed determined to attribute their addiction to their own irresponsible behavior, and often to their susceptibility to a particular “lifestyle” of street culture. In fact, the African-American clients were less likely than whites to touch on the official biochemical diagnosis, instead reiterating their own moral failings within the context of a toxic street life.

Jesse, a 42-year-old African-American male, started selling drugs for survival after becoming homeless as a teen and suffering a bout of severe health problems, eventually progressing to using large amounts of alcohol and marijuana. Jesse reinterpreted his street hustling and drug use as part of an addictive package:

I call myself a criminal, and I call myself an addict. I don't call myself a drug user, because I'm not addicted to drugs, I'm addicted to the lifestyle, because I love that

lifestyle. In the past, that was my bread – kept me with clothes, kept me with money, kept me with weed, kept me with the lifestyle I wanted to live, so I didn't feel that weed was a problem. I didn't feel that hustling on the street was a problem. I felt it was a part of me surviving. I realize now that weed is the problem and that my lifestyle is going down in a spiral to the point where it will eventually kill me ... As addicts, we always depend on somebody else to take care of us. And I'm an addict, and I know that much. But if I get out there and do it on my own, it means I become a responsible adult who is not dependent on somebody ... Recovery means I can live a normal life without drugs or the lifestyle.

In a stunning echo of the neo-liberal reading of everyday economic need as addiction, this penniless, traumatized, and sick man set himself the Herculean task of “doing it on his own.”

Like Jesse, many of the other African-American dealers learned to articulate their lives in terms of addiction, despite skepticism about their relationship to substances. Instead, these clients saw themselves as addicted to the unproductive, “negative” street culture pathologized in treatment. Curtis, an African counselor who often led the “Criminal Thinking” class, epitomized the atomized, neoliberal interpretation of sober lifestyle at Arcadia, as he exhorted the men to struggle for survival against the odds:

Commitment is important. It's the only way to be successful in recovery. Even when we show commitment, there is still a struggle because we are fighting back against that old self ... Yeah, we have all these problems – homelessness, addiction, someone might have a legal problem, an employment problem, yeah ... But you have to separate yourself from all those problems and then take proactive steps to address them. See, you are really the problem, because you fail to live a sober life.

BIOCHEMISTRY IN THE SERVICE OF THE STATE

The national expansion of the diagnosis of addiction through the court-led constitution of a “high risk, high need” population must be interpreted within the context of persisting mass incarceration. Although diverting drug offenders out of costly prisons into cheaper treatment facilities, drug courts have steadily expanded state surveillance by increasing prosecutions for low level drug offences (Hostetler, 2002; Nolan, 1998, 2001). As treatment becomes widely available as an alternative to incarceration, police and court professionals have redefined their roles as “helpers” or social workers, eager to reform without overburdening the strained correctional system (Tiger, 2011). In our case, only a year after its 1997 drug court implementation, the county's drug crime prosecutions rose by 50% county-wide, and have continued to increase in the decade since.⁶

Despite the halo effect around drug court expansion, strong-arm rehabilitation represents neither moral reprieve nor any significant reduction of the criminalization process. The now-widespread intimacy between therapeutic rehab and the criminal sentencing process not only maintains, but also intensifies the place of moral supervision and evaluation in addiction diagnoses. NIDA may be guiding addiction research toward the biochemical frontier (Courtwright, 2010), but in practice, our case suggests that on-the-ground treatment interventions are still fundamentally oriented toward the cognitive transformation and behavioral re-education of the morally culpable. In this context, the biochemical component of the diagnosis is paradoxically both etiologically superficial and discursively foundational. On the one hand, addiction-as-brain-disease serves as a shallow scientific façade, a class and color-blind medicalized label disguising a moral crusade to reform the badly behaved poor. Yet at the same time, the causal touchstone of the individual “hardwired” for dysfunction at the molecular level is extraordinarily successful at closing down discussions of the clustering of “addicts” at the bottom of race and class hierarchies. The diagnosis thus ultimately serves as a “device of purification,” a crucial de-contextualizing spotlight (Mackenzie, 2008). With this construct in place, therapeutic jurisprudence can bypass lingering questions of social justice (or indeed of due process), and instead harness the truths of cutting edge science in service of a Victorian rhetoric of salvation.

The Biomedicalization of Poverty and its Limits

In his landmark discussion of the relationship between medicalization and social control, Peter Conrad (1992) asked, “What is the impact of the dismantling of the welfare state? Will this engender a redefinition to ‘badness’ rather than sickness?” Our investigation of how the criminal-addict diagnosis is produced in “strong-arm” rehab suggests that the criminalization of poverty via mass incarceration has not *suppressed* but *incorporated* the neurochemical interpretation of human behavior in the biomedical era, producing a powerful hybrid of brain dysfunction and moral culpability (Zola, 2009). Court-led diagnosis erases poverty, social suffering, and institutional racism by attributing failure to thrive in the legal economy to brain damage and cognitive weakness at the individual level. Yet both drug court and “strong-arm” rehab immediately re-collectivize the problem in the form of a crusade to quarantine the individual from “negative” neighborhoods, people, cultural tastes, and styles. The special

vulnerability of the high-risk, high-need individual paradoxically justifies the amplification of the taint of addiction to cover clients' families, entire communities, and, at least in our case, African-Americans as a whole. Reviving the old connection between cultural pathologies and biological difference, the therapeutic jurisprudence of the drug court system is producing a refreshed (bio)medicalization of poverty and race for the 21st century.

NOTES

1. Approximately 70% of clients admitted to the residential program we studied were fulfilling a treatment order mandated by criminal court, risking re-incarceration or other sanctions if discharged from the program.
2. Arcadia also had a separate women's program, but our observations were confined to the men's unit.
3. The ambiguity of "at-risk" in this formulation supports Rose's argument that the focus of the notion "at-risk" has migrated from the dangers posed *to* vulnerable clients to the risk of danger *from* the labeled person to the public (Rose, 2010).
4. We disguise this source, and all other county and state statistical data we cite, to protect the anonymity of our case.
5. All of the 20% of offenders entering the drug court with private insurance were white. Offenders with private insurance have more choice within the process, whereas the treatment options of the uninsured are directly decided by the criminal justice system. Although we did not observe the treatment of drug court clients outside Arcadia, we heard about middle-upper class white drug offenders who attended expensive resort-like facilities in other states, and even interviewed one man who had been released by the court to attend a facility run by Scientologists.
6. Source disguised to protect anonymity of the case.

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TROUBLING DIAGNOSES

PJ McGann

ABSTRACT

Purpose – To explore the ideological effects and social control potential of diagnostic biopsychiatry and encourage the sociology of diagnosis to retain key insights of early medicalization scholarship.

Methodology – As the sociology of diagnosis emerges from medicalization, it is imperative that the new sub-specialty retains the critical edge of the early scholarship. With this in mind the paper reviews key aspects of the medicalization thesis, emphasizing the links between medical definitions and social control processes (e.g. Conrad, 1992; Conrad & Schneider, 1992; Zola, 1972). Based on this review scholars are urged to be mindful of the “diagnostic imaginary” – a way of thinking that conceals the presence of the social in diagnoses, and which closes off critical analysis of the existential-connectedness and political nature of diagnoses.

Findings – The paradigm shift from dynamic to diagnostic psychiatry in DSM-III opened the door to a new biomedical model that has enhanced American psychiatry’s scientific aura and prestige. With the increased presence and ordinariness of diagnoses in everyday life, an illusory view of diagnoses as scientific entities free of cultural ties has emerged, intensifying the dangers of medical social control.

Social implications – By illustrating that diagnoses are cultural objects imbued with political meaning, the ideological effects and social control potential of diagnostic biopsychiatry may be mitigated.

Sociology of Diagnosis

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TROUBLING DIAGNOSES

Diagnosis is the centerpiece of scientific medicine. Yet, despite its centrality, a clear sociology of diagnosis has yet to cohere. Even so, sociologists have produced a large body of scholarship concerned with diagnosis and diagnoses, especially under the aegis of medicalization (Jutel, 2009). In what came to be known as the “medicalization thesis,” early scholars of the approach focused almost exclusively on the negative consequences of redefining previously nonmedical phenomena in medical terms (Ballard & Elston, 2005; Lock, 2004; Riska, 2003). They warned of the encroachment of medicine into new areas of social life and pointed to the social control possibilities that medical definitions and diagnoses might engender (Conrad, 1992; Conrad & Schneider, 1992; Zola, 1972).

The “anti-psychiatry movement” of the late 1960s and 1970s raised similar themes. Critics such as Szasz (1970, 1974), Laing (1960, 1967), Goffman (1961), and Scheff (1966) drew attention to unreliable diagnostic practices and potentially abusive treatment protocols based on those diagnoses, and shared the medicalization scholars’ insight that diagnoses are matters of definition. They questioned the validity of psychiatric categories, arguing that many supposed disease states were instead disguised moral judgments. Together the medicalization thesis and the anti-psychiatry movement provided a clear sense that diagnoses are cultural constructs infused with political meaning, and that action based on these constructs could have ominous consequences.

As medicalization scholarship developed it turned away from some of the early work, becoming more balanced and nuanced in the process. Scholars are now as likely to stress the positive results of medicalization and diagnosis as the negative. The initial concern with medical expansion has given way to the recognition that multiple “engines” drive medicalization processes (Conrad, 2005). In fact, with “medicalization from below” (Furedi, 2006), we see that patients and advocates sometimes seek diagnosis and work to increase medicalization rather than resist it. There have been changes on the psychiatry front, as well. In contrast to the early 1970s when psychiatry faced a crisis of legitimacy, today the widespread – and often successful – use of pharmaceutical treatments supports a growing sense among many that

mental disorder is biologically based. Psychiatry and its categories have a more “scientific” feel as a result. Between the embrace of pharmaceuticals and the naturalization of diagnoses in everyday life, the public seems relatively unconcerned with the possible excesses of psychiatry.

These are positive developments in many respects. But neither the public acceptance of psychiatric diagnoses nor the increased scholarly attention to their many positive consequences is without problems. As the sociology of diagnosis emerges from the “folds of medicalization” (Jutel, 2009, p. 285) and matures into a subspecialty in its own right, it is important that we not throw out the early critical insights with the medicalization bathwater. Particularly in a social context where the biomedical model has renewed the scientific legitimacy of psychiatry and medicalization is increasingly normalized (Conrad, 2007), we should be mindful that diagnoses are cultural constructs marked by history, politics, and social currents. Indeed, the recent success of scientific biopsychiatry may have intensified the very dynamics that so alarmed the medicalization scholars in the first place. Thus, whereas concern with medical social control is not new – and may even be out of fashion – in light of recent developments, it is time to renew some of the central insights of medicalization, even as we turn to diagnosis.

With this in mind, I gather together diverse lines of thought that draw attention to the existentiality of diagnoses and survey the sorts of troubles these connections engender. I argue that the emergence of diagnostic biopsychiatry and the normalization of diagnoses in everyday life have created an illusory relationship to diagnoses that obscures their real, material conditions. This “diagnostic imaginary” disguises the presence of the social in diagnoses, construing them as neutral, scientific entities rather than cultural constructs imbued with moral judgment. The result is an insouciance that intensifies the danger of medical social control.

In what follows, I revisit key insights of the medicalization thesis and consider how medicalization studies have been moving toward a sociology of diagnosis. Next I explore how psychiatry and everyday life exhibit their own “turns” to diagnosis – for the former, the embrace of diagnosis in *DSM-III* (APA, 1980); for the latter, the increased presence and ordinariness of diagnoses. The convergence of these developments naturalizes diagnostic categories, making it difficult to think critically about them and their social control potential. As antidote, I consider how sexual diagnoses illustrate the historicity and cultural situatedness of psychiatric categories. I conclude by returning to medical social control and consider how ideological elements of biopsychiatry obscure the politicality of diagnosis.

MEDICALIZATION REVISITED

The theme of this essay is that medicine is becoming a major institution of social control, nudging aside, if not incorporating, the more traditional institutions of religion and law. It is becoming the new repository of truth, the place where absolute and often final judgments are made by supposedly morally neutral and objective experts. (Zola, 1972, p. 487)

So begins Irv Zola's classic analysis of medicine as an institution of social control. The essay, along with writings by Conrad and Schneider (1992), Conrad (1992), and Riessman (1983), formed the core of what came to be known as the "medicalization thesis." The concept refers to the process whereby previously nonmedical things come to be seen (and perhaps responded to) in medical terms. As noted, early work in the area was overwhelmingly critical of the creation of new medical categories and the concomitant expansion of medical jurisdiction such redefinition might entail (Davis, 2006, 2010; Dingwall, 2006; Furedi, 2006). Writers were particularly alarmed by the potential for medical social control and its insidious, pernicious quality. Whereas the repressive aspects of some forms of social control is clear – religion condemns the sinner and law deprives the criminal of liberty (and sometimes life) – medicine's regulatory dynamics are opaque, disguised by a scientific veneer and therapeutic ethos. As Zola explained, "not only is the process masked as a technical, scientific, objective one, but one done for our own good" (Zola, 1972, p. 502).

Peter Conrad systematized and elaborated these points in a series of publications, underscoring in each that questions of meaning and culture are the heart of medicalization (1979, 1992, 2004, 2007; Conrad & Schneider, 1992). In an oft-cited 1992 paper, for example, he argued "the key to medicalization is the definitional issue. Medicalization consists of defining a problem in medical terms, using medical language to describe a problem, adopting a medical framework to understand a problem, or using medical intervention to 'treat' it" (p. 211). The central book length monograph in the tradition, *Deviance and Medicalization* (first published in 1980), drew attention to the political nature of definitions and the multiple uses to which they might be put. Central was the insight that "any given 'problem' can be viewed by different eyes and thus may be defined and analyzed in different ways" (Conrad & Schneider, 1992, p. 8). Depending on how the problem is defined, both it and the "deviant" will be in the jurisdiction of a institution authorized to respond in a particular way, with potent and far-reaching consequences for the person (Gusfield, 1967). People seen responsible for

their acts are deserving of punishment; illness mitigates culpability and therapeutic intervention, if not compassion, is warranted.

In this spirit, [Conrad and Schneider \(1992, p. 8\)](#) argued that the authority to define a problem is the “greatest social control power.” Nearly 30 years later Conrad reiterated this position in his second book length treatment of medicalization: “in general, the key issue remains definitional – the power to have a particular set of (medical) definitions realized in both spirit and practice” ([2007, p. 8](#)). Medical intervention is ostensibly therapeutic rather than punitive, taken on behalf of the sick rather than against them. The would-be patient, however, might not see it that way. As [Zola \(1972, p. 489\)](#) pointed out: “punishment cannot be seen in merely physical terms, nor only from the perspective of the giver.” The “medicalization thesis” thus underscored the centrality of meaning and linked medical definitions to social control. As medicalization scholarship developed, other foci came to the fore.

From Medicalization to Diagnosis

Although it was not the central claim of the approach, some writers seized on medical imperialism ([Illich, 1976](#)) – the idea that physicians were initiating and imposing medicalization processes – to question the medicalization thesis¹ (e.g., [Strong, 1979](#)). This critique prompted further refinements, such as description of “levels” of medicalization ([Conrad & Schneider, 1980, 1992](#)) and attention to patient-driven medicalization ([Dumit, 2006; Furedi, 2006](#)). As scholarship progressed, it branched in many directions and, although it was not a self-conscious “sociology of diagnosis,” diagnoses were often an analytic focal point. Many medicalization case studies, for example, recount the extra-scientific dynamics behind the creation of new diagnosis (e.g., [Bryant, 2006; Crisler & Caplan, 2002; S. Scott, 2006; W. Scott, 1990](#)). “Contested illnesses” ([Dumit, 2006](#)), are also skirmishes over diagnosis – but they involve struggles *for* increased medical involvement rather than struggle *against* the encroachment of medicine ([Conrad & Stults, 2008](#)).

These and other insights complicated the medicalization picture considerably. Even though diagnosis was identified as both a starting point of medical social control ([Brown, 1990, 1995](#)) and a way to legitimate it ([Conrad & Schneider, 1992](#)), it became clear that diagnosis was also linked to potentially positive dynamics. Diagnosis organizes and legitimates suffering and illness, directs treatment, facilitates, and organizes medical research ([Balint, 1964; Jutel, 2009; Mischler, 1981a, 1981b](#)). Diagnosis triggers the sick role, facilitates disability accommodation and legal protection, and serves as

medical explanation of poor performance (Conrad, 2007; Conrad & Potter, 2000; Parsons, 1951). Diagnosis provides an account of deviance that mitigates responsibility and moral approbation – or is supposed to at least (Conrad & Schneider, 1992). Diagnoses are linked to identity and community (Klawiter, 2004; Singh, 2011), and can even be a rallying point for collective action that contests the category (Bryant, 2011). Thus far sociological consideration of diagnosis has been fruitful. And now, at long last, Brown's (1990) call for a sociology of diagnosis has been answered.

Jutel's (2009) survey of the literature is both erudite exegesis of what the sociology of diagnosis might entail and call to scholarly arms. In her conclusion, she reminds readers that most have

gone to the see the doctor to “find out what’s wrong.” Some will go with trepidation wondering if they’re wasting the doctor’s time – “It’s probably nothing” – while others will leave with even more unease than when they went in – “If nothing’s wrong with me, why do I feel this way?”. Yet a third group will leave a consultation with a clear sense of what is amiss, instructions about treatment, and with some luck, an anticipation of when and how the ailment will be resolved. (p. 293)

What has not been considered is a fourth group, those who do their best to evade both doctor and diagnosis. Those who, when they go to the doctor are dragged there kicking and screaming. Those who resent, resist, and refuse diagnosis. Those who worry a diagnosis might apply, who fret – and rightly so – the consequence of diagnosis not (only) because it means they’re “sick,” but because diagnosis means medical intervention is forthcoming – whether they want it or not.

If psychiatric diagnoses were neutral descriptions, this omission might not be so troubling. But aside from a few disorders – schizophrenia, bipolar, psychotic depression – most *DSM-IV* diagnoses do not fit “disease model” criteria (Horwitz, 2002), as both socially inappropriate *and* harmful dysfunctions of inner systems (Horwitz & Wakefield, 2007; Wakefield & First, 2003). Nonpsychotic disorders also show tremendous cross-cultural and historical variability. All told, given the interest politics and advocacy behind disorders such as PTSD (DeGloma, 2011; W. Scott, 1990), female sexual dysfunction (FSD) (Hartley & Tiefer, 2003; Moynihan, 2003; Tiefer, 1994), and shyness (Lane, 2007; S. Scott, 2006), to name but a few, some diagnoses are better seen as sociopolitical rather than scientific achievements.

The adoption of a medical framework is a political decision. Securing the right to define a given problem as medical is the result of collective “enterprise, strategy, and struggle” (Conrad & Schneider, 1992, p. 8). Although it isn’t always the case, diagnostic categories are a potential

product of these processes.² Conrad and Schneider (1992) made precisely this point when they identified the official codification of diagnosis as the culmination of a medicalization sequence. However, even though diagnoses and medicalization are related, they are clearly not the same (Jutel, 2009). For one, medicalization can occur in the absence of diagnosis, making medicalization the broader process (also see Jutel, 2009). Diagnoses though, mobilize medical response and therefore can be the starting point for medical social control (Brown, 1990). But medical categorization does more than provide the fulcrum for medical social control – it fundamentally alters its quality. In a word, diagnosis *authorizes* medical social control; it legitimates it, while disguising the fact of having done so. Diagnoses thus do important “cultural work,” providing “seemingly value-free frameworks about the normal and deviant” (Rosenberg, 2002, p. 246). Yet we lose sight of this dynamic time and again.

The Diagnostic Imaginary

Building on Althusser’s discussion of an “imaginary” as an image of reality that masks historical and material conditions, Ingraham (1994) argued that the “heterosexual imaginary” closes off critical analysis of heterosexuality as a fundamental organizing principle of social relations. Heterosexuality consequently seems natural rather than historically contingent, and we are left with an illusory relationship to heterosexuality that foregrounds beauty and romance at the expense of the multiple relations of inequality that uphold the illusion (Ingraham, 2002).

Following Ingraham, I posit the diagnostic imaginary as a way of thinking which conceals the presence of the social in diagnoses, closing off critical analysis of the complex ways they are structured by history, culture, politics, and value judgments.³ Diagnoses thus appear to be morally neutral, scientifically valid, ontologically real “things” rather than sociopolitical achievements. Codification of medical categories and their embeddedness in clinical practice, research, training, and elsewhere reifies diagnoses, making it difficult to see and think critically about their existentiality. Developments in psychiatry over the last 30 years have fostered the diagnostic imaginary, in particular the embrace of diagnosis in the *DSM-III* revolution and the subsequent rise of biopsychiatry. Accompanying this shift is a new “ordinariness” of diagnoses in everyday life. The convergence of these developments has naturalized diagnoses such that we lose sight of their role

in upholding normative standards. In this context, revealing the diagnostic imaginary is all the more urgent.

THE DIAGNOSTIC TURNS

For most of the 19th-century American psychiatry was more interested in understanding the dynamics of the mind than it was in applying specific diagnoses to its abnormalities. This changed dramatically in 1980 when the field turned away from the complexities of cognition and mind functioning toward a symptom-based diagnostic approach.⁴ The shift had far-reaching implications for mental health practice and scientific stature of psychiatry, and created the conditions within which the diagnostic imaginary flourished.

By the mid-1970s, psychiatry was in a state of “serious disarray” (Lane, 2007, p. 40). In addition to the stinging critiques by the anti-psychiatry movement, studies documenting low diagnostic reliability endangered third-party reimbursement for psychiatric care (Cooksey & Brown, 1998; Lane, 2007; Mayes & Horwitz, 2005). Worse, Rosenhan’s (1973) pseudo-patient study suggested that mental patients might be better arbiters of normality than psychiatrists. In the wake of the demedicalization of homosexuality in 1973–1974 psychiatry was seen as unscientific, having given in to outside political pressure; putting the matter to a vote subjected the APA to open ridicule (Bayer, 1987; Kirk & Kutchins, 1992; Mayes & Horwitz, 2005). In the midst of the tumult, the World Health Organization was due to update the International Classification of Diseases. Since *DSM* had not been revised since 1968, it seemed an ideal time for a new edition of *DSM* (Lane, 2007).

In this context, the developers of *DSM-III* sought to revolutionize psychiatric practice and raise the status of psychiatry within medicine (Kirk & Kutchins, 1992). Robert Spitzer was appointed to shepherd the transformation. With his dual expertise in neuropsychiatry and psychodynamic thought, Spitzer seemed “neutral” (Lane, 2007). Yet he showed a clear preference for medically oriented researchers rather than clinical practitioners when populating the nomenclature committee (Mayes & Horwitz, 2005). The product, *DSM-III*, is widely viewed as both response to the crisis of legitimacy and psychiatric paradigm shift (Brown, 1990; Cooksey & Brown, 1998; Horwitz, 2002; Horwitz & Wakefield, 2007; Lane, 2007; Mayes & Horwitz, 2005; Reuter, 2007; Wakefield & First, 2003).

DSMs I and *II* (APA, 1952, 1968) were underpinned by psychoanalytic thought, a dynamic approach to the mind that saw the difference between mental health and illness as more a matter of degree than clear, categorical

difference. Dynamic psychiatry was thus more focused on etiology than specifying diagnosis (Cooksey & Brown, 1998; Horwitz, 2002; Mayes & Horwitz, 2005). As the psychoanalytic paradigm receded in the 1970s, debate ensued among multiple schools of thought and psychiatry splintered (Horwitz, 2002; Lane, 2007). To quell dissent and make the manual useful for practitioners of diverse training and theoretical commitments, *DSM-III* was purged of psychoanalytic language and reference to etiology in favor of an atheoretical, symptom-based approach Horwitz calls “diagnostic psychiatry” (2002).

The move from dynamic to diagnostic psychiatry was a response to concerns over the scientific status of psychiatry, the poor reliability of psychiatric categories, and the “embarrassing public debate over homosexuality’s status” (Mayes & Horwitz, 2005, p. 258). With its propensity for diagnostic boundary disputes (Rosenberg, 2006) and lacking a classificatory system similar to that for physical disorders (Tausig, Michelo, & Subedi, 2004), psychiatry has long had “second class citizenship” within medicine. The new structure of *DSM* provided a solution, complete with symptom checklists designed to improve reliability. For *DSM-III*, patterns already being treated by dynamic psychiatrists were broken into discrete entities comprised of symptom clusters (Horwitz, 2002; Mayes & Horwitz, 2005). The focus on decontextualized symptoms – the hallmark of diagnostic psychiatry – was seen as an objective stance that “replicated the positivistic drive in behavioral sciences toward operational definitions” (Mayes & Horwitz, 2005, p. 260). Improving reliability was similarly “seen as a way to silence the critics who claimed that psychiatry was not even able to measure the entities it claimed to study and treat” (Grob & Horwitz, 2010, p. 30). Other aspects of *DSM-III*, such as the V-Code⁵ system, directly addressed anti-psychiatry movement concerns that psychiatry was diagnosing deviance rather than dysfunction (Wakefield & First, 2003).

The emphasis on operational definitions, symptoms, and reliable diagnoses paid off. *DSM*’s coding system rationalized health-care coverage and reimbursement (Mayes & Horwitz, 2005), and its shared language facilitates communication among diverse mental health-care professionals (McGann, 2006). *DSM* is now hegemonic in the mental health field (Brown, 1990). Although it was not the intent of the symptom-based approach, the diagnostic revolution has become central to the “professional project of biopsychiatry” (Cooksey & Brown, 1998). The new *DSM* categories helped broker links to the pharmaceutical industry, leading to a “recent explosion of research on empirically based psychological and pharmaceutical treatments” (Phillips, First, & Pincus, 2003, p. xxv). No doubt these are important

instrumental effects of psychiatry's embrace of diagnosis. But the symbolic effect of the diagnostic turn is equally significant: it confers the appearance of science and the cultural authority that comes with it (Horwitz, 2002).

Its centrality in Western medicine is relatively new, but diagnosis has become a core component of the biomedical model (Jutel, 2009; Mishler, 1981a, 1981b). The iconic symbol of the "scientific aspect of medicine" (Rosenberg, 2002, p. 244), diagnosis embodies medical authority (Friedson, 1972; Jutel, 2009; Pescosolido, 2006). No surprise, then, that the embrace of diagnosis enhanced psychiatry's status and "medical credentials" (Moncrieff, 2010, p. 372; Tausig et al., 2004), or that *DSM* has become the symbol of psychiatry as science. With its size and emphasis on reliability, *DSM* provides an "aura of scientific precision" (Crisler & Caplan, 2002, p. 291) – which might explain the sometimes effusive support it receives: "by allowing diagnoses to be made in a reliable way, [DSM] has brought a great deal of order out of chaos and has fostered groundbreaking advances in both research and clinical care ... without the ability to make reliable diagnoses – without *DSM* – such work would be severely hampered, if not impossible" (Phillips et al. (2003, p. xxv). Even psychiatrists who question *DSM*'s validity or who "workaround" its nosology support the manual as a public demonstration of psychiatry's scientific expertise (Kirk & Kutchins, 1992; Whooley, 2010). Pilgrim thus aptly describes *DSM* as a "revisable political manifesto for the psychiatric profession" (2007, p. 538).

The *DSM-III* revolution addressed psychiatry's "recurrent status anxiety" – "its inability to call upon a repertoire of tightly bounded, seemingly objective, and generally agreed-upon diagnostic categories firmly based on biopathological mechanisms" (Rosenberg, 2002, p. 411). The biopsychiatric model has since achieved cultural legitimacy and become the dominant way mental illness is understood (Brown, 1990; Horwitz, 2002; Mayes & Horwitz, 2005; Whooley, 2010). *DSM* is not without its problems, however. Foregrounding reliability resuscitated psychiatry's standing, but it left questions of validity gasping for air. In this, *DSM* embodies the diagnostic imaginary and feeds the illusion that psychiatric categories are scientifically supported, objectively real disease entities untouched by the culture within which they are delineated and described.

The Omnipresence of Diagnoses in Everyday Life

The diagnostic imaginary has also taken hold in everyday life. Although the power of medicine has diminished a bit, physicians retain their monopolies

on the right to perform surgery, write prescriptions, and define “official” diagnoses (Hughes, 2000; Pescosolido, 2006). Somewhat curious, then, is the degree to which diagnoses have filtered out of medicine and taken up residence in everyday life. Numerous authors have noted the increased role of medical frameworks and “discourse” in Western culture, documenting how medical “surveillance” and the “medical gaze” shape how we think about and even inhabit our bodies (Armstrong, 1995; Lupton, 1997, 2003; Simon, 2003; Turner, 1995). Medicalization “resonates” with contemporary cultural dynamics (Furedi 2006) and medical frameworks “have become a part of our culture” (Conrad, 2006, p. 20).

What seems different, though, is the increased actual and symbolic presence of *specific* diagnoses. Whether shyness, shopping, or sexual indulgence more and more areas of social life are now not only understood via medical frameworks, but through the prism of specific diagnosis. The result is a public increasingly conversant – and comfortable – with diagnoses. Diagnoses are commonplace, so matter of fact, that they’ve become seemingly real and increasingly normalized “things.” A few diagnoses are even routinized in the day-to-day functioning of nonmedical venues.⁶ ADHD medication lines are commonplace in many schools, for example, and accommodation forms have standardized (and legitimated) requests for extended exam time and flexible deadlines in colleges and universities. Gender-neutral bathrooms are not yet as plentiful as “family restrooms,” but are growing more common in high schools, colleges, the workplace, and some public settings. In addition to ADHD and gender identity disorder (GID), other diagnoses that have recently stepped out of *DSM* into high public profile are PTSD, obsessive-compulsive disorder (OCD), bipolar disorder, Tourette’s syndrome, Asperger’s, autism, depression, social anxiety disorder (SAD), generalized anxiety disorder (GAD), premenstrual dysphoric disorder (PMDD), and erectile dysfunction. Proto-disorders such as sexual addiction/compulsion (SA/C), FSD, and a wealth of would-be addictions (e.g., gambling and Internet) are also part of the public proliferation.

We need empirical analyses detailing how this omnipresence has come about, as well as investigations of how categories penetrate consciousness (Horwitz, 2002). Here I am interested in the fact that this has occurred, so I only sketch the breadth of the phenomenon. Certainly the mass media, direct-to-consumer (DTC) advertising in particular, top the list. Also important are increasing rates of diagnosis for many everyday difficulties of living (Conrad, 2007), and the new willingness of many to be “out” about such diagnoses. The widespread and increasing availability of medical information on the web, typically organized by diagnoses, is important, as is

the emergence and increased visibility of patient groups and health social movements (Brown & Zavestoski, 2004), again organized by diagnoses. Diagnosis-centered (and often celebratory) public events such as fund-raising walks, runs, and bike tours bring diagnoses to attention, as does diagnostic “branding” of commodities. To wit, the dizzying array of pink goods linked to breast cancer awareness.

DTC adverts are perhaps most responsible for the increased visibility of diagnoses. DTC ads pitch drugs, but they “sell” diagnoses in the process (Conrad, 2007; Conrad & Leiter, 2004; Healy, 2006). The number of such ads has increased tremendously since the FDA Modernization Act of 1997. One year after its passage, pharmaceutical company advertising budgets increased by 400% as drug companies “redirected their marketing efforts from doctors to their patients” (Cole, 2007, p. 101). TV spending alone increased six times from 1996 to 2000 (Conrad & Leiter, 2004). DTC marketing reframes drugs and diagnoses by linking them to nonmedical venues and persons. One example is erectile dysfunction, rebranded from “impotence” by systematic associations with virility and sporting masculinity (Loe, 2004). Eli Lilly, for example, sponsored pro golf, and sports luminaries such as Mike Ditka advocated Levitra (Cole, 2007). In 2004, Levitra became both an official NFL sponsor and the first pharmaceutical ad to air during the Super Bowl (Conrad & Leiter, 2008). NASCAR’s “Viagra car” likewise helped make the drug “part of everyday discussions” (Conrad & Leiter, 2004, p. 163; also see Loe, 2004). Here again it is important to note that DTC drug ads bring diagnoses “into the minds of many” (Feinberg, 2005, p. 868). SAD and GAD, for instance, were “fairly obscure diagnoses” until GlaxoSmithKline spent millions to raise their “public visibility” (Conrad & Leiter, 2004, p. 163). The medical director of UCLA’s Neuropsychiatric and Behavioral Health Services concurs, noting that by raising awareness that DTC ads “authenticate” and “legitimize” specific diagnoses (Feinberg, 2005, pp. 867 and 868).

In addition to the exponential increase in the amount of drug/diagnosis advertising is the way it now pops up so routinely, sometimes where one might least expect it. We’ve grown accustomed to the ubiquity of DTC advertising in mass media and routinely flip through pages upon pages of drug/diagnosis ads in magazines. Drug ads slip past email filters to make their way into the daily dispatch of personal and professional communication. Television pitches are so commonplace that their typical tagline – “ask your doctor if blank is right for you” – has become a running joke in some quarters.⁷ But baseball games? In 2002, Viagra’s sponsorship of Major League Baseball made erectile dysfunction a “familiar part of baseball

through ballpark signage” and “sponsorship of plays of the game and year” (Cole, 2007, p. 101). The surprise afternoon appearance of one such ad required at least one father to talk “about grown-up issues” with his 10-year-old son instead of enjoying the game they were watching in the privacy of the family living room (Feinberg, 2005, p. 866).

DTC advertising is clearly leading the way, but other manifestations of the diagnostic turn abound. Diagnoses appear in newspaper headlines, grace the covers of *Newsweek* and *Time* (Healy, 2004, 2006), are featured on the nightly news (Blum & Stracuzzi, 2004), and are the subject of in-depth investigative journalism (e.g., *Nightline* on ABC and *This American Life* on NPR). Diagnoses have wandered into childcare advice books (Bryant, 2006; Martin, 2005) and even appear in greeting cards (Crisler & Caplan, 2002). Diagnosis-centered memoirs are common enough to be a genre (e.g., Dully, 2008; Grandin, 2010; Kaysen, 1994; Scholinski, 1997; Wurtzel, 2002). On television, diagnosis has moved from plot element to central aspect of the main character’s character, shifting some diagnoses from something one *has* to something one *is*. One such “diagnosis-person” fusion is *Monk*; supporting characters on *Boston Legal* are others. Films such as *A Beautiful Mind*, *Rain Man*, *Shine*, *The Fisher King*, and *Boys Don’t Cry* show a similar trend.⁸

With the increased visibility, public debates have erupted about the ontological status and “social legitimacy” of diagnoses such as GID, chronic fatigue, road rage, and addictions to gambling and sex (Rosenberg, 2006, p. 409). In the process, diagnoses have become part of how we make sense of ourselves, each other, and the world. Formal *DSM* concepts like ADHD, depression and bipolar disorder “have been incorporated into lay language and understandings” (Moncrieff, 2010, p. 370). Some diagnoses have entered the vernacular so deeply and are so widely understood that they’ve transitioned from nouns to adjectives (“anorexic”; Paul Westerberg’s song “Dyslexic Heart”) to metaphors (“I was like, all, OCD about it, organizing everything” or “He was going all ADD, jumping from one thing to the next.”), some to the point of cliché (“I’m addicted to ...”). More troubling is that DTC ads “may well shape the way the public conceptualize problems” (Conrad & Leiter, 2004, p. 162). PMS imagery, for example, is so commonplace that the sexist images and the diagnosis “are easily absorbed into a kind of folk wisdom” (Crisler & Caplan, 2002, p. 286). Healy (2004) attributes the decreased prevalence of anxiety disorders and increased prevalence of depression to pharmaceutical marketing. Autism provides another example of the relationship between experience and the proliferation of diagnosis. According to Liu, King, and Bearman, “people now think

about autism as part of the developmental landscape” (2010, p. 1390). One result is a diagnostic “proximity effect” wherein talk of autism diffuses through local networks leading to pockets of increased incidence.

As diagnoses become more commonplace, they also become more ordinary. To be sure, diagnoses still demarcate departure from health ideals. But a subtle shift in meaning might be underway. We already know that diagnoses are sometimes sought rather than avoided due to their pragmatic value (e.g., Dumit, 2006). With our decreased tolerance of mild symptoms, the line between correcting dysfunction and providing advantage has blurred (Conrad, 2007; Marshall, 2002). As medicalization shifts from sickness and deviance to wellness (Lock, 2004), might diagnoses be acquiring a benevolent valence? In an era of enhancement and biomedicalization (Clarke, Shim, Mamo, Fosket, & Fishman, 2003; Conrad & Potter, 2004), securing diagnosis allows access to lifestyle drugs that promise to render us “better than well” (Kramer, 1993 as quoted in Conrad, 2007, p. 71). In times such as these, it is difficult indeed to conceive of diagnoses as (also) being “about” social control.

Convergence

Diagnoses emerge at particular historical, cultural, technological, and political junctures (Jutel, 2009). Yet they have a “naturalistic feel” (Summerfield, 2001) – a facticity due in part to their new ordinariness. We tend to be unaware of classification schemes when they surround us in everyday life (Schutz, 1962, 1976). Although we are surrounded by classification schemes, we often aren’t aware of them. Scientific classifications are typically more visible (Berger & Luckman, 1967). When science and everyday life converge, it can be particularly difficult to see that a classification system is in place (Bowker & Star, 1999, p. 33). The objective character of diagnoses is an effect of their presence in dense networks of activity across multiple institutional settings. In-depth analysis of the reification process is beyond the scope of this chapter. However, since disappearance of social relations is central to the “thing-ness” of diagnoses and the diagnostic imaginary, a few points warrant mention.

By facilitating the sense that its categories refer to “naturally occurring phenomena” (Pilgrim, 2007, p. 539), *DSM* does ontological work. *DSM* establishes “what it is possible to suffer in the way of problems psychiatrists recognize and treat” (W. Scott, 1990, p. 294), which helps convince psychotherapists, self-help authors, patients, and insurance companies that diagnoses are real (Crisler & Caplan, 2002; Dumit, 2006). Codification also

makes possible the interconnected practices that reify *DSM* categories, creating supportive constituencies along the way. Some sequences are teleological: bipolar disorder is defined by responding to lithium, for example, and “depression is legitimated ontologically by the drugs that treat it” (Rosenberg, 2006, p. 418). Whether clinical application, compensation claim, or research publication, every instance of diagnosis reaffirms its “apparently free standing existence” (Summerfield, 2001, p. 97; also see W. Scott, 1990). Diagnoses are thus “institutionalized in a literal way” every time they are used (Whooley, 2010, p. 458). Embedding a diagnosis in large-scale bureaucracies such as NIMH, insurance companies, or treatment centers anchors it by creating “vested interests” (Conrad & Schneider, 1992, p. 270). The “always-already-there object in the world” feel (W. Scott, 1990, p. 295) of diagnoses is thus a collective production. Multiple groups have stakes in and “promote the view that the various categories of mental disorder in the *DSM* are ‘real’ diagnoses” (Horwitz, 2007b, p. 2) Once codified, embedded in webs of practice, and built into institutions and bureaucracies, diagnoses crystallize as objects in the world and become difficult to dislodge. As their constructedness fades, we are left with an illusory sense of diagnoses as obdurate things free of existential ties.

THE EXISTENTIALITY OF PSYCHIATRIC CATEGORIES

As the history of *DSM-III* illustrates, diagnoses and nosological systems are influenced by sociopolitical dynamics (Cooksey & Brown, 1998; Kirk & Kutchins, 1992). Advocacy, interest politics, and intentional political manipulation are important aspects of diagnostic existentiality (e.g., Conrad & Schneider, 1992; Hartley & Tiefer, 2003; Loe, 2004; Munro, 2002; Pfohl, 1977; W. Scott, 1990). However, less obvious encroachments of the social – as when diagnoses resonate with social trends and cultural anxieties – illustrate the foundational presence of cultural values in medical knowledge.

Formal institutionalization of knowledge creates the “apparent objectivity of the world we inhabit” (Swidler & Arditti, 1994, p. 314). Knowledge, though, develops in historically situated cultural configurations (Seidman, 1997; Turner, 1995). The classic, historicist approach to the sociology of knowledge exempted science from social conditioning (Mannheim, 1936), but as Kuhn’s (1970) work demonstrates, science is not a hermetically sealed realm of truth. And as science goes, so goes medicine.

Classification schemes are not given in nature, but are a mixture of the natural world and social concerns (Berger & Luckman, 1967; Bowker & Star, 1999; Douglas, 1973; Kuhn, 1970, Rosenberg, 2002; Swidler & Arditti, 1994). The empirical world provides limits, but the process of “lumping” some things together while “splitting” them from others is profoundly social (Zerubavel, 1996). As Gould (1990) explains, it is a

false premise that our categories are given by nature and ascertained by simple, direct observation. Nature is full of facts ... so nature does provide some hints about divisions. But our classifications are human impositions, or at least culturally based decisions on what to stress among a plethora of viable alternatives. (p. 73)

Since diagnoses are categories, we should not be surprised that they are marked by their origins. Like any cultural object, diagnoses reflect the larger symbolic system of which they're a part (Geertz, 1973). Indeed, diagnoses are bound to culture and history such that “we are not dealing merely with different interpretations of ‘the same’ natural phenomena, but with differently constituted phenomena” (Atkinson & Gregory, 2008, p. 594).⁹ The point is not that mental disorders are complete fabrications, but the intimacy of culture and categories, in particular, how ostensibly neutral diagnoses reflect and symbolize other aspects of culture. As illustration, I consider a few sexual diagnoses, beginning at the beginning of medicalized sex – the emergence of sexology.

Diagnosing Sex

With the birth of sexual science in the mid to late 1800s, an entire realm of human experience shifted from religious and legal control to medical regulation (Foucault, 1978; Hekma, 1991; Irvine, 1995b; Weeks, 1979). “Classic” sexology is a paradigmatic instance of medicalization, the moment when many of our contemporary sexual diagnoses were first “put into cultural play” as disease entities (Rosenberg, 2006, p. 413). More profound is sexology’s link to the ontological centerpiece of our sexual universe – the idea of sexual types. In this, sexology exemplifies Bowker and Star’s (1999) point that categories do not merely reflect the world, they shape it.

The notion that sexual activity is indicative of sexual personhood is a relatively recent invention.¹⁰ Prior to the 1800s, what one did sexually was simply that: an act. But as lust “differentiated,” it became indicative of specific sexual types of people (Katz, 1996; Weeks, 1979) – types the sexologists dutifully described and catalogued (e.g., Ellis, 1908; Kiernan,

1911; Krafft-Ebing, 1899). However, rather than merely describing a sexual nature that was always, already “out there,” sexology was part of the process of sexual “speciation” that brought new forms of sexual personhood into being (Foucault, 1978). In so doing, sexology helped consolidate, reify, and naturalize the sexual ontology that underpins modern sexuality.

Although we don’t typically think of our contemporary “sexualities” as diagnoses, homosexuality was a recognized mental disorder as recently as 1973. Heterosexuality was likewise once a diagnosis: “abnormal or perverted sexual appetite toward the opposite sex” (Dorland, 1900, p. 300). Like fetishism [sic], masochism, sadism, homosexuality, and pederasty, heterosexuality was an unnatural “turning aside from the normal course” (p. 497) of the procreative sexual instinct (Kiernan, 1892; Krafft-Ebing, 1899). All such forms of sexual activity oriented to pleasure rather than reproduction – including standard, missionary-style coitus – were violations of the normal sexual instinct. However, with the emergence of companionate marriage, the meaning of some forms of nonprocreative sexual desire and activity changed (D’Emilio, 1983; Seidman, 1991) and heterosexual attraction was recast from perversion to normality. The transformation was so thorough that heterosexual attraction is now seen as wholly “natural,” the very standard of sexual normality (Ingraham, 1994; Rubin, 1993).

As others have noted, diagnoses sometimes reflect and reproduce meanings of race, class, and gender (Brown, 1990; Cooksey & Brown, 1998; Lupton, 2003). The preoccupations of nation-states also influence nosology. For years analysts across Europe and North America had noted the existence of and described in detail actions eventually identified as fetishism. None though, was sufficiently concerned so as to sequester the behavior as a unique category. Only the French conceptualized fetishism as a discrete disease entity – and they did so for distinctly social rather than scientific reasons. In the mid-1800s, France’s geopolitical standing was severely diminished, and the nation was befuddled by fears of depopulation. In this context, French psychiatrists were especially concerned with nonprocreative sexual acts. According to historian Robert Nye (1993, p. 14), it was cultural anxiety about the health and size of their population that “provoked the French to consider how and why fetishistic deflections of the sexual instinct occurred.”¹¹ The category was then quickly incorporated into other sexual nosologies of the time (e.g., Ellis, 1908; Freud, 1962; Krafft-Ebing, 1899).

Whereas some diagnoses reflect broad social dynamics, others encapsulate specific cultural concerns (Atkinson & Gregory, 2008; Bowker & Star, 1999; Busfield, 1996; Conrad, 2007; Rosenberg, 2006; Turner, 1995). Hysteria is a

well known and “clear example of the manner in which medically defined and documented illnesses are embedded in social, political, and historical conditions” (Lupton, 2003, p. 147). A female disease of the mid to late 1800s, hysteria is typically understood as a reflection of patriarchal power relations and androcentric understandings of sex (e.g., Maines, 1999; Turner, 1995). Less commented upon is the diagnosis that emerged at the end of the 1800s, in the context of shifting sexual mores and increased independence for women. At the time, social and sexual autonomy were transgressions of women’s “natural” roles of wife and mother (Groneman, 1994; Lunbeck, 1987). The psychopathic hypersexuality diagnosis “embodied Victorian fears of the dangers of even the smallest transgressions, particularly among middle-class women whose conventional roles as daughters, wives, and mothers, were perceived as a necessary bastion against the uncertainties of a changing society” (Groneman, 1994, p. 342).

Hypersexual women earned and spent their own money, lived on their own, and enjoyed city life (Lunbeck, 1987). Even minor violations of feminine modesty, including flirting, adultery, divorce, and “feeling more passionate than their husbands” led to diagnosis (Groneman, 1994, p. 341). In severe cases, women with “boundless desires” victimized men: “Invigorated by overwhelming desire, a young woman could haul through the windows of her residence or accost an innocent man on the street and force him to submit” (Lunbeck, 1987, p. 535). Such passion was not always pathologized, however. “Hypersexuality” in Black women was seen as an expression of the “natural immorality of the race” (p. 535), and white prostitutes presumably pursued sex for an intelligible motive – money – rather than pleasure.

A more recent diagnosis “thinkable” in one time period but not another is SA/C. Not (yet) a formal *DSM* category, SA/C is diagnosable using *DSM-IV*’s “not otherwise specified” option for either “sexual disorders,” or “impulse control disorders.”¹² The SA/C idea emerged out of the addiction movement of the 1970s, and by the late 1980s the “sex addict” was a well-known popular figure (Irvine, 1995a, 1995b). Given the sexual revolution of the late 1960s and related counter-cultural changes, this is a rather surprising turnaround. However, “disease metaphors flourish when they resonate with broader cultural trends and anxieties” (Irvine 1995b, p. 431).

Sexual mores changed rapidly in the late 1960s and early 1970s. With advances in birth control and new treatments for STDs, a new sexual ethic emerged that prioritized pleasure (Levine & Troiden, 1988). “Too much” sex was unthinkable at the time. Fitting, then, that the diseases of the sexually permissive 1970s, hypoactive desire and anorgasmia, focused on

“not having enough sex” (Edwards, 1986, p. 1). Too much sex was a disease for the 1980s, a period marked by an intensely conservative political climate and widespread AIDS-inspired sexual fear (Irvine, 1995a, 1995b; Levine & Troiden, 1988). Palpable Cold War-related nuclear anxiety added to the sense of menace. In this context the “rhetoric of danger and chaos” (Irvine, 1995b, p. 443) easily took hold, raising the stakes of the on-going clash of sexual norms. SA/C thus represents an attempt to repathologize conduct that had become acceptable in the 1960s and 1970s (Levine & Troiden, 1988) that signified “powerful cultural anxieties about sexuality and desire” (Irvine, 1995a, p. 315).

With that said, some people do experience anxiety, fear, and a sense of lost control in the sexual realm. Even so, SA/C seems a rather straightforward instance of “pathologizing behavior that offends traditional sensibilities” (Rust, 1996, p. 138). Levine & Troiden (1988) put it more sharply, calling SA/C “pseudoscientific codifications of prevailing erotic values rather than bona fide clinical entities” (p. 349). At the time, some observers noted that the sex addict pattern was stereotypically associated with gay male subculture, and characterized the would-be diagnosis as a “new way to express homophobia” (Rowland, 1986, p. 43). Others worried the category could be used to oppress anyone whose sexual tastes strayed from the straight and narrow. Either way, the point is clear. Intended or not, diagnoses are cultural objects useful for political purposes – including social control.

MEDICAL SOCIAL CONTROL

Medical social control refers to “the ways in which medicine functions (wittingly or unwittingly) to secure adherence to social norms” (Conrad, 1979, p. 1). The actual medical means vary but include technologies such as drugs, surgery, or behavioral modification, as well as medical ideology and “surveillance” (Armstrong, 1995). Medical social control can also take the form of collaboration with other institutional authorities, such as court-ordered sterilization, forced medication of inmates (Conrad, 1979, 2004; Conrad & Schneider, 1992), or “strong-arm” rehab (Whetstone & Gowan, 2011).¹³ Importantly, all such acts are done not as punishment, but “in the name of health and illness” (Zola, 1983, p. 269). The resulting regulatory effects may be disguised by therapeutic language or intent. Medical intervention enforces normative conduct nonetheless, by repressive and discursive means (McGann, 2006).¹⁴

Whereas other forms of social control are more obviously punitive, with medical social control power is disguised, hidden by the supposed moral neutrality of medicine. The neutrality is illusory, however, an ideological effect of medicine's allegiance to science. Illness is by definition social judgment, an assessment that form, function, or conduct departs from socially meaningful standards (Brown, 1990; Conrad, 1992, 2007; Cooksey & Brown, 1998; Jutel, 2009; Rosenberg, 2006). As Engelhardt (1974, p. 248) put it, "the notion of 'deviant' structures the concept of disease." Yet, when yoked to science the moral aspects of diagnosis and diagnoses are camouflaged by the methods and language of scientific rationality. Diagnoses thus seem "descriptive" rather than "prescriptive" (Blaxter, 1978), but their judgment is but a "pinprick below the surface" (Zola, 1972, p. 248). Medicine's therapeutic ethos finishes the disappearing act, not so much by hiding judgment from view as recasting it as something else: compassionate assistance. But one woman's "treatment" for sexual impropriety is another woman's denial of liberty (McGann, 2006). In a different register, the question would be one of politics. But in the medical realm expert authority rules the day, and critique of doctor's orders is rendered ignorance, noncompliance, or evidence of pathology (or all three).

Early medicalization writings articulated these dangers with moral clarity (Davis, 2006). Today though, changes in clinical practice, efforts to increase diagnostic reliability, and new pharmaceutical treatments "have pretty much put the psychiatry critiques to rest" (Wakefield & First, 2003, p. 29). However, we have been lulled into complacency precisely when we should be alarmed. The troubles of medical social control have been exacerbated by the very developments that created the insouciance. Psychiatry's scientific aura, the prestige of its expert knowledge, and the decontextualizing, depoliticizing effects of the medical model are stronger than ever.

Psychiatry, like medicine more broadly, directs its diagnostic gaze at the individual rather than, say, the relationship of the individual to society. This was true of the dynamic approach that imbued *DSMs I and II* but the individualistic focus has intensified significantly since 1980. Some of the problem stems from the switch to symptom checklists. Checklists strip conduct from context, restricting clinical judgment and making it difficult to distinguish contextually understandable distress from more pathological forms (Whooley, 2010). The line between ordinary sadness and depressive disorder, for example, has been blurred (Horwitz & Wakefield, 2007; Grob & Horwitz, 2010), as has that between normal and pathological gender variance (McGann, 1999, 2006), and between standard shyness and social phobia (S. Scott, 2006). The erosion leads to overdiagnosis (Wakefield &

First, 2003). By narrowing of “the range of what is considered acceptable” (Conrad, 2007, p. 7), the “social space of pathology” is enlarged (Horwitz, 2007a, p. 217).

Psychiatry has long considered mental illness as disease entities independent of culture and history (American Medico-Psychological Association, 1918; Bleuler, 1924; Kraepelin, 1904). Since *DSM-III*, these illnesses have increasingly been seen in biological terms (Brown, 1990; Horwitz, 2002; Mayes & Horwitz, 2005; Whooley, 2010), a trend that has turbo-charged the reductionism of the medical model by shifting attention from the individual to the individual’s neurochemistry. Brain-based diseases can even be abstracted from the brains that presumably “have” them (Horwitz, 2002). This mechanistic approach is antagonistic to questions of social relations, values, or politics but amenable to drug-centered treatment protocols that reinforce the very assumptions that authorize medication.

The majority of the functional disorders have “at best questionable physiological evidence” (Conrad, 2004, p. 106). Still, many people are convinced that “mental illness is a purely biological phenomenon” (Brown, 1990, p. 46). The increased use of psychotropic drugs fuels this belief and cements “the centrality of diagnosis” (Cooksey & Brown, 1998, p. 529). Drugs certainly “work,” in the sense that they lessen symptoms (or at least make people easier to manage (cf. Conrad, 2004)). The presumed biological basis is immaterial; drugs work because they are powerful psychotropic agents (Moncrieff, 2010) and can alleviate symptoms without removing their cause (Mirowsky & Ross, 1989). However laudable, the effectiveness of drug treatments is not necessarily evidence of biophysiological causation (Conrad, 2004). Even so, use of pharmaceuticals reinforces the biological view and adds to psychiatric prestige (Horwitz, 2002). The apparent “confirmation” of the biomedical model has recast psychiatry’s scientific veneer as “hard” science. Manifestly biological phenomena seem less subject to social influence (Conrad, 2004), which makes diagnostic biopsychiatry an especially effective depoliticizer.

“Scientific” (Seidman, 1997) language and methods further shores up psychiatry’s scientific aura. The narrowness of *DSM* categories makes them seem more objective (Mayes & Horwitz, 2005), and standardized methodology likewise seems neutral (Bowker & Star, 1999; Conrad, 2004; Moncrieff, 2010; Rosenberg, 2002; W. Scott, 1990). Overall the new focus on reliability “confers the appearance of a more scientific approach” (Horwitz, 2007a, p. 218), but the seeming precision obscures basic problems of validity (Bowker & Star, 1999; Kirk & Kutchins, 1992; Mischler, 1981b). In reality, most *DSM* categories are recent inventions embraced for their

pragmatic value rather than their scientific adequacy (Horwitz, 2002). And yet, the scientific aura provides cover. The initial critiques of medical social control drew attention to expert knowledge and medical prestige in deflecting criticism (Conrad, 1992; Conrad & Schneider, 1992; Zola, 1972). Biopsychiatry's association with neuroscience and pharmacology augments this effect. Both are highly prestigious fields bodies of knowledge controlled by extensive training and credentialing processes – exactly the sort of professionalization dynamic that consolidates expert power in relation to lay people, making it extremely difficult for the latter to challenge the former.

However, even thorough critiques of *DSM* categories by prominent scholars have yet to gain significant traction in psychiatry (cf. Horwitz, 2002; Grob & Horwitz, 2010; Horwitz & Wakefield, 2007; Wakefield, 1992; Wakefield & First, 2003). Since *DSM-III* American psychiatry has purported to distinguish dysfunction from deviance, noting that conflict between individual and society is “social deviance, which may or may not be commendable, but is not by itself mental disorder” (APA, 1980, p. 6). The distinction was reiterated in *DSM-IV*: “Neither deviant behavior (e.g., political, religious, or sexual) nor conflicts that are primarily between the individual and society are mental disorders unless the deviance or conflict is a symptom or a dysfunction in the individual” (APA, 1994, p. xxii). Yet, as Wakefield and Horwitz point out, most psychiatric categories do not fit the disease model's dual criteria of social inappropriateness *and* harmful dysfunction. In the absence of dysfunction, the disorder-deviance distinction collapses. All that remains is judgment of inappropriateness. Such judgment is – or rather should be – the province of politics, not medicine.

CONCLUSION

When scientists adopt the myth that theories rise solely from observation, and do not grasp the personal and social influences acting on their thinking, they not only miss the causes of their changed opinions; they may even fail to comprehend the deep shift encoded by the new theory (Gould, 1994, p. 68).

American psychiatry was once the focus of vibrant (and at times vehement) critique. Sociological voices were among those who charged psychiatry with “medically labeling socially devalued nondisorder conditions for purposes of social control” (Wakefield & First, 2003, p. 29). Early medicalization theorists were wary of psychiatry, alarmed by the expansion

of medical jurisdiction, and deeply skeptical that therapeutic intervention was more humane than other forms of social control. Now though, “categories of diagnostic psychiatry have gained broad acceptance in educational, occupational, political, and cultural institutions” (Horwitz, 2002, p. 214). In a context where psychiatry’s scientific sheen shines brightly and its diagnostic categories are increasingly commonplace, it is vital we not forget our medicalization past as we turn toward the sociology of diagnosis future. Medical definitions remain definitions and the choice to use medical frameworks still poses political consequences. Construing an act as illness confers a different status than sin or crime. Diagnosis thus has implications not only for health but also for knowledge, power, and personal liberty.

Over time, cultural constructions lose their constructedness and come to be experienced as natural; they seem to *be* reality rather than a *version* of it. The same is true of diagnoses. By bracketing their existentiality, we run the risk of perpetuating normative standards that may have to do with psychological distress but that have little to do with real psychological dysfunction. A sociology of diagnosis that leaves the diagnostic imaginary undisturbed risks reinforcing “the current social order and its values by participating in the production of ‘acceptable’ knowledges and ideologies” (Ingraham, 1994, p. 209). Diagnoses are central to medicine and medical practice. Their critique should be central to sociology.

NOTES

1. Early work highlighted inappropriate or undesirable medicalization, but the tendency wasn’t as uniform as some might suggest (Lupton, 1997). Conrad & Schneider’s chapter on “Medicine as an institution of social control,” theorized multiple consequences, including medicalization’s “bright side,” and Riessman (1983) described medicalization as a “two-edged sword.” The medical imperialism charge also seems a bit overdrawn (so much so that Riska (2003)) calls it “vulgar medicalization.”) Zola noted several times that societal demand was an important part of the “medicalization of life” (cf. pp. 487 and 500). Conrad & Schneider demonstrated that medicalization could proceed without the involvement of physicians. Conrad restated this point many times (e.g., Conrad, 2004, 2005, 2006, 2007; McGann & Conrad, 2007). For the early debate, see Strong (1979) and Conrad and Schneider (1980, 1992).

2. Here I sidestep an important question the sociology of diagnosis will need to take up: when exactly is a diagnosis a diagnosis? See Bryant (2011) for an exploration of the relationship between diagnosis and medicalization.

3. This isn’t the only way our illusory relationship to psychiatric diagnosis manifests. As diagnoses become more commonplace and their potential pragmatic value comes to the fore, we risk overlooking or dismissing the pain and suffering that

can be caused by serious mental disorder, continuing problems with the availability and quality of care, potential abuses of medical authority, and the like.

4. The diagnostic imaginary has not taken hold in France. As Vallée (2011) explains, French psychiatry is more likely to consider sociocultural aspects of diagnosis and resist the pharmacological imperative.

5. V-Codes are “conditions not attributable to a mental disorder that are a focus of attention or treatment.”

6. This distinction of normalization and routinization is indebted to Seidman, Meeks, and Traschen’s (2002) analysis of the changing status of homosexuality in the United States

7. The Saturday Night Live “Queer-loss” gags comes to mind (see Lane, 2007 for a description).

8. Mental disorder has long been a subject of popular film (e.g., *One Flew Over the Cuckoo’s Nest*, *Sybil*). Livingston (2004) provides an impressive listing and helpful categorization.

9. On diagnoses as symbols, see Comaroff (1982). Anthropologist and psychiatrist Arthur Kleinman (1988) provides a classic discussion of “culture-bound” syndromes, but the approach dates to Benedict (1934). Historians and sociologists also explore disease categories as culturally contingent, for example, agoraphobia (Reuter, 2007), anorexia (Bordo, 1993; Brumberg, 2000), chlorosis (Brumberg, 1982), gambling (Lee & Mysyk, 2004), neurasthenia (Kleinman, 1994), PMDD (Crisler & Caplan, 2002), PTSD (W. Scott, 1990; Summerfield, 2001), and shyness (S. Scott, 1990). Systematization and conceptualization of the interdisciplinary work is needed.

10. It is now widely accepted by scholars of sexuality that contemporary sexual types – hetero-, homo-, and bisexuals – are historically and socially contingent constructions rather than entities given in nature. Scholars debate both when the shift began and sexology’s precise role in the process, but agree that sexology was part of a seismic change in the 19th century sexual landscape. The debate turns on whether the sexologists created the diagnostic categories themselves or merely named and catalogued already extant or emerging types. The answer depends in part on what sort of evidence is used to advance one’s claim. Trumbach (2003), for example, anchors his analysis in what might be called folk knowledge of the behavior patterns of effeminate “mollies.” Similarly, Weeks (1979, p. 4) notes “there are signs of the emergence from at least the seventeenth century in Britain.” Like Foucault (1978), Weeks points to the importance of formal medical-scientific knowledge in codifying and consolidating the shift (also see Chauncey, 1989, 1994; Rubin, 1993; Seidman, 2010).

11. Jean-Martin Charcot and Valentin Mangan described the behaviors in 1882, but it was Charcot’s student, Alfred Binet, who bestowed the moniker “fetishism” in 1887 (Nye, 1993).

12. SA/C might become a “real” disorder under the rubric of “hypersexuality,” proposed for DSM-V. See <http://www.dsm5.org/ProposedRevisions/Pages>

13. As Rubin (1993) points out, the stigma provided by medicine legitimates state regulation of sex.

14. Literal (White & Thomas, 1905) or chemical castration via Depo-Provera (Conrad, 2004) are examples of the repressive mode. The symbolic effects of diagnoses as markers of normality illustrate the discursive, as does the disciplinary

dynamic diagnoses elicit whereby subjects attempt to embody the normal (McGann, 2006). The latter illustrates the “consonant vision” of medicalization and Foucaultian thought (Lupton, 1997).

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