ABSTRACT

Title of Document: WHOSE STORY IS IT ANYWAY?:
                                      CONSTRUCTING THE STORIES AND
                                      PATHOLOGY OF MADNESS/MENTAL
                                      ILLNESS IN THE CONTEMPORARY U.S.

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        Personal stories are always told in the context of broader cultural narratives.

Thus, in the contemporary U.S., stories of personal experience of illness and

disability are usually informed by Western notions of health and illness, and a binary

classification system of normative/non-normative bodies and behaviors. The

emerging field of disability studies represents a socially progressive attempt to

interrogate and reconfigure discourses that pathologize and medicalize non-normative

bodies, challenging medical discourses with an alternate framework of evidence that

emphasizes the personal experiences of individuals who have experienced disability

or illness and who conceive of these experiences in different ways.

        Whose Story Is It Anyway? is an interdisciplinary examination of how the

cultural authority of medicine compresses a range of individual experiences into

narrow, standardized narratives of the experience of depression, for instance, or other

phenomena classified as illness. Specifically, my study makes a three-part argument:

first, that biological psychiatry has eclipsed psychoanalysis and that medical definitions of mental illness have become the *culturally* dominant way of determining what kinds of physical or psychological phenomena are classified as bad, e.g., pathological. Second, these definitions then inform and shape stories of personal experience with such phenomena, enough so that standard narrative formats emerge for describing "individual" experiences of both physical disability and madness/mental illness. The personal stories of madness/mental illness then become, in essence, universalized narratives of illness and recovery that reinforce notions of pathology. Third, this standardization of the personal story often aligns with medical narratives in a way that reflects the storytellers' disempowered position in the medical industry, in that telling the "right" story positions them to receive the benefits of working within the medical system, and telling the "wrong" story becomes an act of political activism. Such *de facto* coercion has substantial implications for intellectual projects, such as disability studies, that rely heavily on the articulation of personal experience as evidence for the need for change. Finally, this study argues for a re-examination of experience-based, identity-focused activism, and for an invigorated humanities project in science studies.

WHOSE STORY IS IT ANYWAY?:
CONSTRUCTING THE STORIES AND PATHOLOGY OF MADNESS/MENTAL
ILLNESS IN THE CONTEMPORARY U.S.

By

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Preface

When I began this study, I intended to address the comparative invisibility of madness/mental illness in the contemporary U.S. English-speaking disability rights/disability studies project. I perceived the de-medicalization of disability as one of the primary goals of the disability rights movement, and I saw this study as an opportunity both to make an argument for disability rights to take a more inclusive approach to issues of madness/mental illness and to address an understudied area in disability studies. It was clear at the time that the social/cultural construction of pathology would figure as a central concern in my research, because the approach to both the definition and treatment of mental illnesses had shifted so dramatically in the last fifty years from an emphasis on psychoanalysis to an almost exclusively biologically-based approach. I also wanted to address what I saw as a mis-match between the diagnostic criteria (focused more on measurable standards of socially acceptable behavior rather than on internal states) and suffering. Suffering, too, had its own kind of disappearing act: suffering is hardly ever mentioned in contemporary disability studies except as the result of the pathologization of disability.[1] It seemed to me that somehow suffering must have been at the historical root of the idea of pathology, and perhaps it would be possible to re-link suffering and pathology in a more productive theoretical way, one that would require the application of the idea of pathology to be more attentive to suffering and less focused on the "objective"

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[1] Suffering is often mentioned as a result of the social-cultural consequences of disability, but almost never as a product of what is sometimes distinguished as an "impairment." In other words, one frequently finds references to people having suffered through childhood surgeries to make them appear more "normal," or to people having suffered employment discrimination or similar prejudice. But it is relatively rare to see a reference to physical suffering directly in terms of the course of an illness or physical impairment.

diagnostic criteria, which are focused on the kinds of behavioral criteria that comprise a "productive" citizen (e.g., the ability to get up on time to go to a job, to maintain the "appropriate" social relationships, etc.). I hoped to provide the disability rights/disability studies project with a way to expand the demand for self-determination in health care, but in a way that recognized that some illnesses and disabilities do involve suffering, and that these experiences need a disability rights/disability studies project that encompasses, rather than denies, suffering.

It was clear even several years ago, however, that madness/mental illness would not again be producing a significant civil rights-style movement on its own. The anti-psychiatry movement of the 1960s and 1970s, and the related Mad Pride movement of the 1990s have largely dwindled out. Organizations such as MindFreedom International still exist, usually run by consumer/survivor/ex-patient (C/S/X) volunteers who advocate for increased consumer control and who provide services such as the MFI Shield, described as an "underground railroad" to allow individuals to escape court-ordered psychiatric drugging or electroconvulsive therapy.[2] However, this residual C/S/X movement simply doesn't have the critical mass that the (physical) disability rights movement has, and probably never will, because things have changed. The increasing array of pharmaceutical options has resulted in the discontinuation or decreased use of approaches to treatment (e.g., the induction of diabetic comas or the use of electroconvulsive therapy) that looked brutal and gave the movement some purchase on human rights grounds. Organizations such as the National Alliance on Mental Illness have attempted to remove the stigma of mental illness by portraying it exclusively as a physiological problem—akin to

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[2] MindFreedom International, *Mind Freedom International Website* ([cited September 20 2009]).

diseases such as diabetes—with considerable success. Local public health agencies

and service providers rarely have the funds available to impose mental health services

widely on those who do not want to receive them, and it has often been suggested that

prisons have replaced asylums in terms of keeping troubled individuals out of the

public eye. Though isolated abuses may still occur, people are not usually now

hospitalized as mentally ill on the basis of homosexuality. The advent of direct

advertising of pharmaceuticals in television and magazines caused some to hope that

a meaningful consumer movement might develop—e.g., one in which the commercial

maxim of "the (paying) customer is always right" might be applied to "patients,"

thereby increasing accountability in mental health care—but this kind of movement

never materialized. For whatever reasons, C/S/X activism has not coalesced in the

same way that the physical disability movement has done. While there is certainly

some activity in the spirit of the physical disability rallying cry of "Nothing About

Us, Without Us," any nascent radical social movement rejecting the pathologization

and medicalization of madness has been trampled underfoot by the viewpoint that

mental illness is a physiological disease, which can and should be treated with drugs

to address the "chemical imbalance" in the brain.

I thus find myself obliged to make quite a different argument about strategy.

Although I fervently believe that the issue of suffering *should* be the most important

question in determining what constitutes a "pathological" state, I now see this

particular question, unfortunately, as a moot point. The disability rights/disability

studies project will need to approach the construction of pathology with more

concrete, measurable, and politically leverage-able ammunition than a general

complaint of injustice if the desired outcome is material change. If scholarship is to

better understand the cultural construction of pathology and the ways in which it is

deployed to the disadvantage of people with disabilities, it will need to address how

pathology functions in tangible and material ways, which may be quite different than

the ways that people with disabilities *feel* that it functions. For better or worse, the

disability rights/disability studies project is one with a strong grassroots base. The

"nothing about us, without us" principle has placed great emphasis on the personal

experience of people with disabilities, a philosophy-strategy that is clearly necessary

on an individual basis to permit people with disabilities to retain control over their

lives. However, I have come to understand that emphasis on personal experience, and

the contemporary scholarly preoccupation with identity, as diverting attention from

far more pressing issues in what might be called the "material construction of mental

illness."

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Chapter 1: Introduction

> Hundreds of Harvard Medical School students and faculty members have joined forces to expose ties between industry and researchers that they believe may be tainting the work being done in Harvard's classrooms, laboratories, and 17 affiliated teaching hospitals and institutes, news sources reported last week.
>
> "Before coming here, I had no idea how much influence companies had on medical education," David Tian, a first-year medical student, told *The New York Times*. "And it's something that's purposely meant to be under the table."
>
> A fourth-year student, Matt Zerden, said he felt "violated" when he learned that a professor who was describing the benefits of cholesterol drugs during a first-year pharmacology class was also a paid consultant to 10 drug companies. Five of those made cholesterol drugs.
>
> The medical school has appointed a 19-member committee to re-examine the school's conflict-of-interest policies. David Korn, a former Stanford University medical dean and Harvard's vice provost for research, who last year helped the Association of American Medical Colleges draft a conflict-of-interest policy for medical schools, will advise the group.
>
> School officials point out that corporate support is vital to faculty research at a time when the value of Harvard's endowment has shrunk 22 percent since last July and charitable giving is down. Yet concerns about undisclosed industry ties have prompted federal agencies and Congress to call for a crackdown.
>
> The National Institutes of Health, which has been criticized for failing to adequately police such conflicts, has recently frozen some payments to universities whose researchers have questionable ties.
>
> - from the *Chronicle of Higher Education*[3]

In the contemporary U.S., madness or mental illness—as a subcategory of disability—is largely unlike most other categories used in humanities scholarship. Its boundaries are clearly delineated by an identifiable authority, and regulated and maintained through explicit processes in the form of diagnostic criteria established by the American Psychiatric Association and implemented through clinical use of the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision

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[3] Katherine Mangan, "Harvard Medical Students and Faculty Members Work to Expose Conflicts of Interest," *Chronicle of Higher Education*, March 3 2009.

(DSM-IV-TR).[4] Although certain kinds of cultural definitions can continue to haunt

the popular imagination long after their influence on social policy has waned (such as

the "one drop" rule for defining black racial identity), there are few other cultural

categories for which the boundaries are so explicitly, rigidly, and comprehensively

regulated by a single kind of authority as the category of illness, (inclusive of

disability and particularly madness or mental illness). Whereas understanding the

ways in which the systems of gender or race work to subjugate women or people of

color requires a complex understanding of diffuse and subtle workings of power,

understanding how the category of mental illness functions to establish a binary of

normal/sick is much more straightforward. These boundaries have already been

defined, as clearly as the American Psychiatric Association could make them, and

published and distributed as extensively as possible.

Yet this rather obvious point seems to get lost in scholarship. Disability

studies has often focused on identity and representation—what one might call the

diffuse workings of power—as opposed to more explicit operations such as the DSM-

IV. Disability studies, as a field, has not yet really intersected with what might be

called "science studies" in any consistent way. Though numerous scholars have

identified the medicalization of disability, the argument usually seems to stop once it

identifies that a performative normal/abnormal binary system is dependent upon the

medicalization of illness/disability. In part, this may reflect the dominance of

humanities disciplines within the disability studies project, and the tendency of some

scholars to take for granted that a humanities-style social justice agenda is both

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[4] American Psychiatric Association, *Diagnostic and Statistical Manual of Mental Disorders (DSM-IV-TR)*, Fourth Edition, Text Revision. (Arlington, VA: American Psychiatric Association, 2000).

universally transparent and uncontroversial. However, this seems to me to be an obviously incomplete argument, and one that imposes severe limitations on the argument's efficacy in the long term. If medicalization is part of a performative, normal/abnormal power system, and if these kinds of power systems are hegemonic by nature, then there is little reason to think anything will change without some specific additional steps to clearly identify medicalization as undesirable and to intervene in that portion of the process.

I will argue that the next step, clearly, is to deconstruct how this process of medicalization works, and to that extent, to discredit the medical industry's virtually unfettered authority and privilege in assigning pathology. Medicine enjoys the authority of truth usually attributed to science, and the truths of science are still popularly understood as being somehow *more* true than the truths of the humanities— an issue having to less to do with incontrovertible evidence than the popular perception that medicine works exclusively through incontrovertible evidence. There is some popular understanding that Big Pharma is about Big Dollars, but that popular understanding seems limited to the major drug companies *as companies*, not as entities with the apparatus to strongly inform cultural norms of health and illness. There is very little evidence of any popular understanding that these corporate entities are also directly related to the formation of diagnostic criteria, to medical school training, and to medical practice. It would surely be more accurate to speak of the "medical industry" rather than the "medical profession," yet aside from outrage at the costs of health care, there seems to be little popular inclination for a serious review of how the practice of medicine is conceptualized. Any serious scholarly or activist

interrogation of medicine as an industry will have to contend with several deeply-held

popular convictions: (a) that research in science (and medicine, specifically) is

necessarily objective and true in an absolute sense, and (b) that clinical medicine (and

psychiatry, specifically) is the *application* of scientific knowledge. In other words,

the popular understanding of medical knowledge is that it is "discovered," rather than

"produced."

This study is part of a larger project posing a direct challenge to the narrative

of linear scientific progress. **Specifically, it is an interrogation of how the**

pathology of madness/mental illness is constructed; how it is reproduced (by the

people who are most directly affected by it, in particular), and how this

pathologization of experience is naturalized and made invisible. I seek to

interrogate the ways in which pathology is created from both inside and outside its

formal system. I do not seek to prove or disprove the validity of any particular

classification of disease, which would necessitate working within the functional and

theoretical classification systems of medicine, or to define what depression, for

instance, "really" is; rather I seek to interrogate the system itself. Clearly there is a

something (for example, what we presently call schizophrenia) that causes some

people to experience the world very differently than most other people. It seems to

have existed through at least most of recorded human history, and obviously causes

great suffering to at least many of the people who have experienced it. Equally

clearly, however, the medical-scientific enterprise is able to identify as pathological

some phenomena that do not meet the traditionally narrow sense of the term as

indicating demonstrable, physiological deterioration in tissue. Homosexuality, only

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removed from the DSM in 1980, is perhaps the best example of "modern" medicine

having framed an experience or phenomenon as *medically* pathological, purely on

social and cultural grounds.[5]

      But pathology is not defined exclusively by the medical establishment, though

in many ways such "official" designation remains the one with the greatest practical

impact. The disability rights movement represents a direct challenge to the authority

of medicine to issue absolute decisions on what is or is not pathological, yet

madness/mental illness has not been a part of that project in the same way that

physical disability has. Most obviously, the pathology of mental illness is not

generally now contested in the same way that the pathologization of other

impairments often is.[6] A blind person might reject the pathologization of his

blindness on the grounds that he is neither in pain nor experiences any special

difficulties other than the attitudes of sighted people. Likewise, a person who is Deaf

may not consider herself disabled but rather a member of a cultural and linguistic

minority. People who receive a diagnosis of mental illness have themselves often

sought out or instigated some kind of care or treatment, an action that can be

reasonably understood as indicative of some sort of distress or suffering. Yet even

extreme suffering is not automatically the basis for a diagnosis (e.g., a judgment of

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[5] Ronald Bayer, *Homosexuality and American Psychiatry: The Politics of Diagnosis* (Princeton, NJ: Princeton University Press, 1987).

[6] I use the term "impairment" cautiously. Some in the disability rights movement have used this term to draw a distinction between physical phenomena (the *impairment* of spina bifida) and the socially constructed *disability* that results from an environment inhospitable to wheelchair users. In some ways, madness/mental illness may indeed be an impairment that can't merely be redefined away inasmuch as people may suffer from something more than social discrimination. At the same time, I am seeking to illustrate that the definition of the category is unstable and what is deemed pathological in one place and time may not be in another. Unfortunately, I fear the impairment/disability model can be easily misused as a more subtle or "polite" way to reinscribe the impairment as pathological.

pathology), nor is it necessarily the central criteria for diagnosis.[7] As I will show, the "subjective" and "objective" criteria for madness/mental illness may overlap, but they do not always align. One of the major concerns of this study is to address the ways in which the supposedly "objective" criteria (e.g., those set by the medical industry) essentially hide behind medical authority, and the ways in which those criteria are made to appear as though they are the indisputable, rational conclusions of a neutral and disinterested expert. A related concern is to examine why and how these criteria are so readily accepted and even reproduced by the very people who, according to a disability rights-style social justice agenda, could be expected to object.

Another major concern is to clarify what kinds of scholarly approaches identify the most productive kinds of questions to ask, and equally, what sorts of questions to leave alone. Determining the terms that govern inquiry into the range of phenomena that have been classed as "madness" or "mental illness" at various times and in various places is no small thing, as it determines a default conceptual position. Whether alcoholism, for instance, is classified as an illness or a moral failing determines whether the subsequent dialogue is framed around treatment or punishment. In a context informed by a "scientific" biological psychiatry, the default inquiry thus tends to become something like "is multiple personality disorder real?" As J.L. Austin points out, a better question would be, "is it a real *what*?" One can't examine a disorder identified by the DSM or ICD *as* a disorder without granting both the terms of discussion and the parameters of what is possible to medical discourse. My response in this study is to focus my inquiry not on any one classification of

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[7] Despair and anguish over the death of a loved one, for instance, is considered normal and explicitly excluded from the diagnostic criteria for depression, unless it extends to an abnormal duration.

experience but to try to look at the process of pathologization from several angles, and in a way that does not privilege medical epistemology or discourse.

Determining the most politically efficacious approaches is also part of identifying the most productive scholarly approaches. I offer a critique of the disability studies project's continued preoccupation with identity and representation (especially in the form of memoir), which, I argue, have ceased to offer substantial new insight. I am concerned that the field's emphases identity and representation may ultimately come to serve more as distractions from (rather than contributions to) either the development of new directions in theory or the advancement of efficacious activism. Although I appreciate that the construction or positioning of disability as another category of identity or a category of analysis is precisely what has made it intelligible to the broader scholarly community, I have some concerns (a detailed discussion of which lies outside the scope of this study) that identity-based theory and practice in general may have serious limitations both theoretically and practically.[8]

Disability studies, as a field, has intentionally positioned disability as a category of identity, so that it could first be detached from medicalized discourses of deformity or deviance, and then examined through the current major theoretical models of normativity and power. Rosemarie Garland-Thomson, for instance, a tremendously important scholar in the establishment the field of disability studies, concludes her influential *Extraordinary Bodies* with an explicit call for disability to

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[8] Briefly put, I am concerned that identity is too often used too crudely, so that an idea cannot be understood as valid unless it can be proved to be common across an ever-increasing list of specificities. More importantly, however, I see it as a comparatively conservative way of thinking that tends to foreclose more radical possibilities. In terms of theory, I worry that it may be too closely aligned with neoliberal ideas of individualism, precluding other kinds of models. In terms of activism, I worry that it can inadvertently promote politics that are too localized and cosmetic at the expense of more materially significant kinds of reforms.

be understood alongside race, gender, ethnicity, sexuality, and class.[9] This formalizes disability as a category of analysis, which on the one hand elevates awareness of disability, but on the other, tends to creates a functional practice model in the humanities that requires scholars to go down a checklist of identity categories to make sure that all the appropriate categories are at least acknowledged. Identity can also become somewhat prescriptive in that certain kinds of identities become simplistically associated with certain kinds of ideas or politics. The fact that a model is often crudely or rotely applied doesn't mean that it's a bad model, but it does make one wonder whether other alternatives might ultimately be more fruitful.

This inquiry thus calls for a redirection of scholarly attention to the construction of the health/illness binary, as well as to the construction of the authority of medicine and science, a project that will require the humanities to re-engage much more actively with other fields. In other words, this study argues for an dynamic, invigorated humanities project that actively engages the sciences and the popular understanding of science. Such a project would serve as a needed balance to the popular perception that science, technology, engineering and mathematics (STEM) activities produce forms of knowledge that are both infallible, uniformly desirable, and of comparatively greater practical use to society than the humanities. The humanities may not presently have adequate theoretical apparatus for addressing these kinds of issues of disciplinary structuring, but I argue that new models of humanities practice are desperately needed. This study is an attempt to begin an

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[9] Rosemarie Garland Thomson, *Extraordinary Bodies: Figuring Physical Disability in American Culture and Literature* (New York: Columbia University Press, 1997), 135.

examination of new ways to find practical means of applying the insights of humanities scholarship, especially science studies, in a broader fashion.

Points of Departure – A Short History and Historiography of Psychiatry

This study begins in the context of the current popular and medical/scientific predisposition to accept contemporary biological psychiatry as the latest step in a linear, if somewhat erratic, development of medical science. The term "biological psychiatry" refers to an approach to madness/mental illness as physiological disorder in the brain. As currently applied, it focuses on psychopharmacology as the primary form of treatment, with psychotherapy considered to be a potentially useful, but decidedly secondary, complementary tactic. The widespread acceptance of the legitimacy of biological psychiatry—by the medical establishment, the general public and by consumers themselves—makes the arena of madness/mental illness fundamentally different from other forms of illness or impairment more visible within the disability rights movement. (The physical disability rights movement had at least one constituency that categorically rejected the pathology of physical disability, and that was the people who had the disabilities.)

Situating this study in the context of biological psychiatry requires a revision of the popular narrative of the history of psychiatry. Psychiatry's own account of itself is the metanarrative of medical progress, a story which is curiously able to acknowledge and include difficult parts of its history at the same time that it can distance itself from it. The metanarrative of scientific progress allows psychiatry to distance itself from therapies now perceived as barbaric or primitive, such as insulin coma therapy or the cold, wet sheet wrap-packs described in *I Never Promised You a*

Rose Garden.[10] In fact, prior barbarity tends to enhance the appearance of dramatic

progress, as the juxtaposition serves to make the "now" appear very humane and

rational indeed. At the same time, however, the inclusion of this kind of history also

serves to establish psychiatry as a field with a substantial lineage.

This study, however, is predicated upon a more scholarly and complicated

understanding of the history of psychiatry in the U.S. The process of assembling a

scholarly understanding of psychiatry requires drawing from sources that are often

contradictory, and it is generally not possible to resolve the contradictions in a

methodical, empirical way and still reach a conclusion. In many ways, these

contradictions are disciplinary scuffles, and unless one has an investment in

maintaining disciplinary boundaries, the resolution of the conflicts can be a red

herring. The impossibility of proving some sorts of questions can effectively result in

paralysis (including not asking certain kinds of questions) unless one cultivates both

the ability to establish provisional assessments and enough tolerance of uncertainty

for such assessments to be merely provisional.[11] Thus, it should be understood that

my primary concern with the history of psychiatry is not really historical at all, in the

sense of being focused on any specific prior period, but is better described as a kind

of myth-symbol analysis located somewhere between political and practical—

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[10] Joanne Greenberg, *I Never Promised You a Rose Garden* (New York: Holt, 1964), 54-55.
[11] Andrew T. Scull, *Social Order/Mental Disorder: Anglo-American Psychiatry in Historical Perspective* (Berkeley: University of California Press, 1989), 5. Scull, a medical sociologist focusing on the history of psychiatry, has repeatedly called historians of psychiatry to task for refusing to draw conclusions—in effect, for refusing to make history useful to people other than historians. He notes, "…historians shy away from making their theoretical assumptions and interpretive frameworks explicit and regard comparative statements with ill-concealed suspicion and distaste—as if attending to such matters might contaminate the attempt 'to understand the past on its own terms.'" Scull also notes the difficulties posed by having so much work in the history of psychiatry written by psychiatrists-turned-historians or historians who have spent so much time working with psychiatrists that they develop a sympathetic bias. Such criticisms serve to illustrate the significance of disciplinary perspectives and what ways of thinking are both enabled and foreclosed by them.

establishing that alternatives to the metanarrative of scientific progress do exist, and that the contradictions between these narratives are in fact useful beyond serving to advance historical study.

So, to acknowledge the specific circumstances that have led to contemporary constructions of pathology, as well as to frame the initial terms of discussion, I offer a contextualization that engages historiography equally with history. I emphasize the historiographical component because, for my purposes, how people assess the significance of what happened is as important as what actually happened. My history of psychiatry portrays the field as shaped by the fits and starts of research, by the limits of the social tolerability of certain diagnoses, by the impact of major historical influences such as social movements and war, and perhaps most important, by the incentive for economic gain. My very brief synopsis of the history and historiography of American psychiatry from 1840 to the late 1980s is intended to provide context in which to understand contemporary biological psychiatry, other than through the metanarrative of scientific progress. Multiple disciplinary perspectives on the history of psychiatry—e.g., histories written by historians, sociologists, psychiatrists, psychiatric epidemiologists, and others—all note marked shifts in the conceptualization of what phenomena could be categorized or interpreted as a psychiatric problem, though there is some variation in how these shifts are described.

By 1840, the idea of the asylum as a (potentially) therapeutic institution was firmly established in the U.S., yet by 1900, asylums had effectively become warehouses and physician's hope of being able to cure inmates was dwindling as

rapidly as the number of inmates was increasing.[12] The increase in the number of

inmates is attributable to a combination of the relocation of mad people from family

homes to asylums, as well as an actual change in the epidemiology of psychiatric

illness, including neurosyphilis, alcoholism and schizophrenia.[13]

According to historian Edward Shorter, the need to understand changes in

epidemiology helped prompt what he refers to as the "first biological psychiatry," a

term I will also employ as a useful way of recognizing that the understanding of

psychiatric illness as physiological is not an invention of the late 20th century and

therefore should not be understood as part of the contemporary narrative of

progress.[14] Nineteenth century psychiatry identified that there were both biological

and hereditary components to major mental illness; yet given the large gaps in

understanding the relationships between bodily phenomena and mental symptoms,

there were limitations as to what this research provided in terms of practical clinical

help. This early research predictably produced a number of false starts, so to speak,

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[12] Edward Shorter, *A History of Psychiatry: From the Era of the Asylum to the Age of Prozac* (New York: John Wiley & Sons, 1997), 46.

[13] Ibid., 48-49 and 55. Ian Hacking, *Mad Travelers: Reflections on the Reality of Transient Mental Illnesses* (Charlottesville, VA: University Press of Virginia, 1998). Unfortunately, the shifts in epidemiology are largely beyond the chronological parameters of this study, though I use the paradigm shift from melancholy to depression as a point of reference. Some epidemiological changes may be easily attributable to social changes, such as the increase in alcoholism. But Shorter's assertion of the increase in schizophrenia—a disorder currently understood to be completely biologically-based— poses a fascinating question when considered alongside Ian Hacking's work on fugue states and the "traveling illness". Shorter refers specifically to increases in neurosyphilis, alcoholism, and schizophrenia, and describes a distinct increase in the epidemiology of these conditions. Neurosyphilis refers to two specific kinds of manifestations of late-stage syphilis affecting the central nervous system, with distinctly psychiatric symptoms, which only began to be described by physicians around 1780.

[14] Shorter's history of psychiatry is probably the most mainstream and widely cited overview of its kind, and represents a very traditional approach to the history of medicine, e.g., a narrative emphasizing the "discoveries" of individuals in a narrative of scientific progress, only somewhat disturbed by other kinds of stories. He is precisely the kind of historian that Andrew Scull criticizes as having a sympathetic bias towards psychiatrists. However, being effectively at the center of the field of the history of psychiatry, I think Shorter provides the most appropriate and accessible starting point for this work.

in terms of scientific research, but the identification of a hereditary component to major mental illness also formed much of the basis for the public support for eugenics. The fear of and social stigma of insanity was so great that it prompted what Shorter refers to as a diagnostic "fig leaf," in the form of a discourse of illness that emphasized variations on the theme of "nerves" as a more useable approach to less severe forms of madness/mental illness.[15] While severely ill individuals were still hidden away in asylums, middle class individuals diagnosed with "neurasthenia" and the like were treated by "neurologists," in private offices and spas. Practicing psychiatrists—those treating the inmates of the asylums—enjoyed little respect, essentially being charged with containing severely ill people more than helping them in any meaningful way.

Yet the basis of the biological psychiatry seen today emerged from the study of psychoses in the asylum, not neuroses seen in private offices. Of particular note for this study is the formation of the "modern" classification of psychiatric illness according to prognosis, effectively fostered by asylum psychiatrist Emil Kraepelin in the 1890s, drawing from the earlier work of Karl Kahlbaum. This classification represented a major change from previous practice, and in Shorter's view, a significant step forward:

> …A half-century of research in neuroanatomy and neuropathology had produced almost nothing in the way of concrete utility to clinical psychiatry beyond a picture of neurosyphilis. The biological psychiatrists had spawned a sprawl of clinical disease labels, each based on the particular circumstances associated with an illness, ("masturbatory insanity," "wedding-night psychosis") or on the particular combination of symptoms ("chronic delusional disorder"), with almost no correlation to brain pathology. Multi-infarct dementia,

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[15] Shorter, *A History of Psychiatry: From the Era of the Asylum to the Age of Prozac*, 113.

neurosyphyilis, thyroid deficiency, and the like were the only exceptions.[16]

Kraepelin had kept data cards on each patient, noting conditions upon admission and discharge that over time showed patterns. Based on specific features of the onset of symptoms, etc., he began to be able to detect a likely prognosis. Kraepelin's classifications of dementia praecox (what later came to be called schizophrenia) and manic-depressive illness as distinct and separate types of illnesses were first published in the sixth edition of his psychiatric textbook in 1899, and prefigured the basic taxonomy of the DSM-I when it was first published in 1952.

Shorter describes the rise and fall of psychoanalysis as a "hiatus" in the history of psychiatry, a characterization that is technically accurate though it also reflects a dismissive attitude towards psychoanalysis as not quite "real" psychiatry. Shorter's portrayal of Freud as merely an opportunist looking for a way to establish a niche market and boost his practice is perhaps overly harsh—not that an economic incentive wasn't there, but an economic incentive is *always* there, to single out Freud for criticism in the whole modern history of psychiatry seems quite hilariously ironic. More reasonable, in my estimation, is sociologist Allan Horwitz' description of "dynamic psychiatry" and its focus on the identification and articulation of feelings as a response to an exceedingly repressive social structure. When psychoanalysis became popular among the middle classes, the practice of psychiatry effectively moved from the asylum to Main Street, and expanded to include neuroses (along with psychoses) as its main concern. Historian Elizabeth Lunbeck, among others, argues that this expansion represented a blurring of the ideas of "normal" and "abnormal"

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[16] Ibid., 103.

and the beginning of the expansion of psychiatry into the realm of what had

previously been considered normal.17 Psychoanalysis was not intrinsically

incompatible with biological psychiatry, because it focused on treatment rather than

causation.   Shorter notes:

> Although there was no good reason why nonphysicians could not
> do analysis just as effectively—there being nothing intrinsically
> medical about plumbing the unconscious mind—American medical
> psychoanalysts had a horror of lay competition. And from their
> viewpoint, rightly so. Given that psychoanalysis had been
> psychiatry's ticket out of the asylum, the last thing the American
> analysts wanted was to break their monopoly by sharing it with
> psychologists and social workers avid to have a go at analysis
> themselves.[18]

Shorter attributes the popularity of psychoanalysis to a multitude of social factors,

among them the positive effects of feeling cared for by a physician, but asserts that it

had been discarded as an effective avenue of treatment by physicians by the mid-

1990s, a position perhaps more widely held by researchers than by clinicians who

continued to recommend therapy in conjunction with pharmacological treatment,

even if they don't propose to administer such therapy themselves.[19]

Meanwhile, in the asylums, some psychiatrists had persisted with research

theorizing that the major mental illnesses had a biological component. In the 1920s

and 1930s it was discovered that extended sleep, fever, and electric current could

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[17] Elizabeth Lunbeck, *The Psychiatric Persuasion: Knowledge, Gender, and Power in Modern America* (Princeton, NJ: Princeton University Press, 1994). Lunbeck places less of an emphasis on a distinction between "psychiatrist" and "psychoanalyst," and focuses instead on the blurring of the normal and the pathological. This results in her placing the expansion of the scope of psychiatry rather earlier (1900-1930) than do those who define "psychiatrist" more narrowly.

[18] Shorter, *A History of Psychiatry: From the Era of the Asylum to the Age of Prozac*, 163.

[19] While I take Shorter's point that psychiatry as a distinct field has now returned to being almost exclusively biologically based, to speak of psychoanalysis as a kind of detour obscures its impact on contemporary mental health care as a whole, which is quite obviously far more dependent on psychologically-based therapy than it would have been without psychoanalysis. Shorter's characterization is perhaps accurate for the field of psychiatry, narrowly defined, but misses the larger point.

have a positive impact on major mental illness. Electroconvulsive therapy (ECT) and insulin coma therapy came into regular usage as a means of managing severely ill patients. Psychiatrists in asylums conducted all kinds of experiments to find ways to improve shock and coma therapies. In 1949, a French navy surgeon began experimenting with synthetic antihistamine compounds to block the autonomic mechanisms involved in shock, thereby improving the chances for success in surgery. Later moved to a physiology unit, he continued these experiments, but with a new phenothiazine compound replacing the synthetic antihistamines, and discovered that in addition to having the desired effect surgically, it also had a profoundly calming effect. Laborit cajoled several psychiatrists to try it on their patients, and by May 1953, it was in use in wards across France. Brought to North America in 1953, chlorpromazine (Thorazine), was hailed as a psychiatric miracle drug, and a slew of related compounds followed quickly. This "discovery," combined with studies of the role of genetics in major mental illness, became the basis for what Shorter describes as the "second biological psychiatry."

At this point, the history becomes more complicated. Psychiatrist turned historian David Healy presents the development of chlorpromazine quite differently, emphasizing the importance of corporate economic interest rather than portraying the development as a series of discoveries by individual doctors.[20] Healy identifies a series of discoveries in organic chemistry that led to the commercial development of dyes, particularly the discovery of methylene blue in Germany in 1876. These dyes were found to be able to stain certain kinds of bacteria and later, certain kinds of cells

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[20] David Healy, *The Creation of Psychopharmacology* (Cambridge, MA: Harvard University Press, 2002).

(in the case of methylene blue, the mycobacterium responsible for causing

tuberculosis, the parasite responsible for malaria, and later, nerve cells). They gave

rise to the idea of the "magic bullet," a drug which would act on only a specific kind

of organism or tissue.[21]   Because methylene blue acted on nerve cells, and because of

the late 19th century (mis)understanding of "nerves" as being the biological

underpinning of psychiatric troubles, the substance was tried as a cure, and indeed it

did seem to calm psychotic agitation to some degree. However, Healy notes, it

generally was replaced after 1903 by the barbiturates, which worked better in support

of the "sleep therapy" that involved putting patients to sleep for days or even weeks

"to give their nervous systems a chance to stabilize," and which actually seemed to

cure catatonic schizophrenia.[22]

The rationale for the use of methylene blue is an important point to Healy,

relative to chlorpromazine, because he finds it illustrative of how much the practice of

psychiatry is influenced by factors other than science.   He notes the "better than

average reason for its [methylene blue's] use" but notes that its disappearance in

clinical practice had to do with timing; first, with the timing of the discovery of

barbiturates, then with the timing of the discovery of convulsive therapies. However,

he argues that the *scientific rationale* for the use of methylene blue remained

unchallenged, and again in the 1970s research studies showed methylene blue to be

have prophylactic properties for manic-depressive (bipolar) disorder. Yet, he

observes,

> "Needless to say, no one uses methylene blue for this purpose today.
> The reason is not competing therapies, although there were many, but

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[21] Ibid., 39-40.
[22] Ibid., 44.

that patents had been obtained on newer agents and no drug company would market an old drug even if it worked. In all three instances, then, there were competing therapies or interest groups likely to make more money out of other therapies than they would from methylene blue. In no case, however, was there any greater theoretical rationale for the use of these other therapies."[23]

Healy emphasizes that chlorpromazine first became widely used because it was an effective sedative, and it was effectively marketed. He continues,

"Methylene blue and other antihistamines had proved to have uses in addition to sedation, and chlorpromazine was to make even more obvious these nonsedative benefits. These benefits, along with commercial support, in due course helped to generate a theoretical rationale for the use of chlorpromazine: the dopamine theory of schizophrenia."[24]

Healy's point is that the theoretical rationale came after clinical usage had been established for reasons entirely different from the basis of the rationale; i.e., financial opportunity.

It would be inappropriate for me to ignore entirely the antipsychiatry movement in this narrative, though as mentioned in the preface it has a tendency to be eclipsed from public memory. The abuses of the asylum and the antipsychiatry movement are woefully understudied areas in the history of medicine; there is relatively little documentation of either in scholarship and even less consensus on the impact or meaning. Both Shorter and Healy acknowledge that psychiatry became very complicated as drugs were administered involuntarily and at large doses to individuals exhibiting merely *deviant* behavior, rather than traditionally psychotic behavior. Shorter, even as he acknowledges the excessive dosages of drugs as a mistake, treats the antipsychiatry movement of the 1960s and 1970s as an unfortunate

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[23] Ibid., 45-46.
[24] Ibid., 46.

reaction of misguided lay people overreacting to popular media such *The Snake Pit* or

One Flew Over the Cuckoo's Nest, or such lofty and theoretical academic arguments

as Foucault's *Madness and Civilization*.[25]   Healy frames antipsychiatry activism

more appropriately, in my estimation, as a response in part to the abuses of

psychopharmacology and psychosurgery, and in part to a general social upheaval with

regard to other social justice movements. Healy identifies texts such as Erving

Goffman's *Asylums*, Thomas Szasz's *The Myth of Mental Ilness*, and Franz Fanon's

Black Skin, White Masks as some of the means by which people came to understand

the expansion of the psychiatric enterprise in a social context.[26]

What both Shorter and Healy agree on, however, is that the discovery of

chlorpromazine began to change psychiatry as an enterprise, to blur the distinctions

between the psychoses of the asylum and the neuroses of the analyst's couch.

Chlorpromazine was considered a tranquilizer at the time, as was Miltown,

introduced in 1955. Although the two drugs worked so differently that a distinction

was established between "major' and "minor" tranquilizers, together they represented

a substantial change in both the scope of psychiatry (now inclusive of less severely ill

people) and the approach to treatment (primarily pharmacological.) The expansion of

the scope of psychiatry is a critical point to a number of scholars: to Shorter, for

whom it represents a boundary issue as to who is included in the category of

"psychiatrist"; to Healy, for whom it represents a new market for both psychiatrists

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[25] Anatole Litvak, in *The Snake Pit* (U.S.A.: 1948)., Milos Forman, in *One Flew Over the Cuckoo's Nest* (U.S.A.: 1976)., Michel Foucault, *Madness and Civilization: A History of Insanity in the Age of Reason* (New York: Pantheon Books, 1965).

[26] Erving Goffman, *Asylums: Essays on the Social Situation of Mental Patients and Other Inmates* (Garden City, NY: Anchor Books, 1961)., Thomas Stephen Szasz, *The Myth of Mental Illness: Foundations of a Theory of Personal Conduct*, Rev. ed. (New York: Harper & Row, 1974)., Frantz Fanon, *Black Skin, White Masks* (New York: Grove Press, 1967).

and drug companies; to Lunbeck, for whom it represents a blurring of the ideas of normal/abnormal and was a means for addressing changing ideas of gender; to Gerald Grob, for whom it was an important part of the mental hygiene movement in the early part of the century. Though scholars interpret and label the specifics of the expansion in different ways, the important points for my purposes are that over the course of the 20th century, psychiatry expanded considerably in terms of who it might reasonably encompass, and that the particular instances of expansion occurred quite rarely as an altruistic response to new scientific discoveries, but quite frequently in response to other kinds of socio-cultural concerns.

Likewise, Shorter and Healy—as well as others—generally frame the publication of the first *Diagnostic and Statistical Manual of Mental Disorders* (DSM) as marking a codification of an approach to psychiatry that did several very important things: it established psychiatric illness as being fundamentally within the scope of medicine; it established psychiatrists as the (only) professionals having the appropriate expertise to oversee treatment; and it provided a standardized scheme for classifying psychiatric illness. The initial 1952 publication and its successor caused relatively little commotion, but the revisions leading to publication in 1980 of the DSM-III were fraught with controversy. Although the public rhetoric for the classification system was to improve the scientific rigor by aligning psychiatry more closely with evidence-based medicine, multiple scholars concur that psychiatry's prestige within medicine (or rather, the lack thereof) was also a motivating factor in the shift towards the classification scheme. Whereas in the early part of the 20th century, the alliance with medicine had served to increase psychiatry's prestige, in the

middle and later parts, comparison with more biologically-based areas of medicine made the field of psychiatry look almost comic.   Multiple scholars have argued that the inability of psychiatry to provide both consistent definitions of disease entities and a capacity for measurement exposed psychiatry to ridicule within medicine.[27]

To the contemporary reader accustomed to the rhetoric of biological psychiatry, the idea of a standardized classification scheme with measurable diagnostic criteria may sound like an appropriate step towards increasing the scientific and intellectual rigor of psychiatry. That, however, is precisely the difficulty: the rhetoric *sounds* good, but in fact merely mimics scientific rigor rather than actually assuming responsibility in that role. One of the intents of this study is to complement and support the scholarship aimed at deconstructing this rhetoric.

David Healy's work, for instance, effectively calls biological psychiatry on its bluff and exposes it for complicated tangle of motivations that it is. Healy's critique of biological psychiatry is multi-pronged but is aimed primarily at the way that drug companies have manipulated the slightest ambiguities for financial gain, to put it mildly. Healy takes particular offense at the way that supposedly objective measures, such as randomized, controlled trials (RCT), have been used in decidedly non-objective ways, i.e., to obscure or replace clinical observation that may help clarify how a drug works, because RCT studies show *associations*, not *causal relationships*. For example, he writes:

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[27] Bayer, *Homosexuality and American Psychiatry: The Politics of Diagnosis*, Nathan G. Hale, *The Rise and Crisis of Psychoanalysis in the United States: Freud and the Americans, 1917-1985* (New York: Oxford University Press, 1995), Healy, *The Creation of Psychopharmacology*, Allan V. Horwitz, *Creating Mental Illness* (Chicago: University of Chicago Press, 2002), Shorter, *A History of Psychiatry: From the Era of the Asylum to the Age of Prozac*.

"Focusing on the RCT evidence that SSRIs can help treat depression, OCD, post-traumatic stress disorder, social phobia, panic disorder and generalized anxiety disorder throws more light on what is actually happening. These positive responses can lead to two hypotheses. One is that there is something wrong with the serotonin system in all these states and that drugs that act on the serotonin system are magic bullets. This is the favored view of pharmaceutical companies. The alternative is that SSRIs heal patients by reducing emotional reactivity, a serenic effect that cuts across a range of nervous conditions. If this is the case, some patients would be expected to respond to such a serenic effect, while others would not respond, with the degree and frequency of response sufficient to distinguish the compound from a placebo. This is exactly the state of affairs that best characterizes trials with SSRIs, which have been shown to have a modest treatment effect across this range of conditions, with striking clinical efficacy in some patients. The clinical trial results are not compatible with the idea of a serotonin lesion or a magic bullet effect in any of these disorders."[28]

Healy also takes aim at the selective distribution of information and the way that insight can be buried:

Consider the classic magic bullet language of main effects and side effects. By convention the main effect of antidepressants is taken to be on mood; other effects, for example on sexual functioning, are designated side effects. But in fact, sexual functioning may be more reliably affected by an SSRI than mood. Where up to two hundred patients may be needed to demonstrate a treatment effect for an SSRI in cases of depression, as few as twelve patients may be needed to demonstrate its efficacy in treating premature ejaculation. Companies kept the evidence of the potentially beneficial effects of SSRI's on aspects of sexual functioning—useful for treating premature ejaculation—out of the public domain for two decades. This example should make it clear that deciding which is the main effect of a compound is essentially an arbitrary decision, related to company economics and far from value free.[29]

The bulk of Healy's work has been directed at what he see as the gross misuse of information with regard to SSRIs, most notably with regard to the expansion of disease categories to create new markets, such as the marketing of fluoxetine

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[28] David Healy, *The Antidepressant Era* (Cambridge, MA: Harvard University Press, 1997), 313.

[29] Healy, *The Creation of Psychopharmacology*, 323. I take some issue with Healy here as he does not address that framing of the SSRIs' dampening effect on sexual functioning as a "side effect" also downplayed the efficacy of this phenomenon in other populations.

hydrochloride both as an antidepressant under the trade name Prozac, and as a

treatment for pre-menstrual dysphoric disorder (PMDD) under the trade name

Sarafem. Healy's central concern is that it is drug companies, not clinicians, who are

now driving medicine, through comprehensive marketing to both the public and

doctors, by effectively controlling the research agenda, and by constructing as

"pathological" some phenomena that had previously been understood merely as

"problems."[30]

In some ways, this project continues Healy's interrogation of the factors other

than a scientific rationale that lead to certain phenomena being pathologized,

diagnosed, and treated as illness. But it is equally concerned with how those

processes become entrenched and naturalized, and how pathology is not only

produced but also reproduced and reinforced through other kinds of discourses.

As I outline in Chapter Two, the academic literature review, this project is

best understood as situated between science studies, trauma studies and other

concerned with the meaning of experience, and disability studies. A disability rights

consciousness certainly informs the study's intent and purpose, but through the course

of the investigation, I have come to see the intellectual concerns of science studies

and a certain body of literature focusing on epistemologies of personal experience as

being of equal or perhaps greater importance in shaping the questions I address. In

this chapter I argue that there is an intellectual benefit to focusing on ideas of the

process of the construction, consumption and reproduction of knowledge rather than

becoming overly preoccupied with the specific historical or categorical circumstances

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[30] Sander L. Gilman, *Difference and Pathology: Stereotypes of Sexuality, Race, and Madness* (Ithaca: Cornell University Press, 1985).

to which such ideas have been applied. Because my project is primarily concerned

with opening up new avenues of work in disability studies, it is necessary to avoid

subjecting this study to the same kinds of constraints from which the field suffers.[31]

In other words, to expand disability studies, I am looking beyond its existing borders.

In Chapter Three, I compare two approaches to conceptualizing the

experience of depression.   I contrast Peter Kramer's *Against Depression*, an

argument for considering depression to be exclusively a biological illness, with

Joshua Wolf Shenk's study of Abraham Lincoln's depression, *Lincoln's Melancholy*.

This juxtaposition, at its most obvious level, addresses the absence of madness or

mental illness in the disability rights/disability studies literature, and introduces a

disability rights-style alternative to the dominant medical model approach that

presumes experiences such as depression as solely pathological. Examining the

particular characteristics of Lincoln's melancholy and finding them to be as much

asset as liability, Shenk argues that Lincoln would not have been the man who

became President *without* his depression. Not only is this a more holistic approach to

interpreting a life, it also counters the contemporary (and infuriating) proclivity to

ponder how much more he might have accomplished if only Prozac had been

available to him. Chapter Three also introduces a related argument developed more

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[31] Much of the best scholarship on disability has been done by scholars in the humanities, and has
focused on representations of disability or theorizing how the category of disability has functioned
alongside race and gender, for instance, in systems of power. Though such works represent some
extraordinarily fine scholarship, the field as a whole suffers the absence of a "next step" for translating
these insights into application. Lennard J. Davis, ed., *The Disability Studies Reader* (New York:
Routledge, 1997), Paul K. Longmore and Lauri Umansky, *The New Disability History: American
Perspectives*, *The History of Disability Series* (New York: New York University Press, 2001), Robert
McRuer, *Crip Theory: Cultural Signs of Queerness and Disability* (New York: New York University
Press, 2006), David T. Mitchell and Sharon L. Snyder, *The Body and Physical Difference: Discourses
of Disability* (Ann Arbor: University of Michigan Press, 1997), Sharon L. Snyder and David T.
Mitchell, *Cultural Locations of Disability* (Chicago: University of Chicago Press, 2006), Rosemarie
Garland Thomson, *Extraordinary Bodies: Figuring Physical Disability in American Culture and
Literature* (New York: Columbia University Press, 1997).

fully in the Chapter Five, a revival of Thomas Szasz's 1961 contention that the diagnostic criteria for mental illnesses are not based on an appropriate definition of "pathology"—e.g. demonstrable physiological deterioration of tissue—and reflect at best a well-meaning but intellectually sloppy understanding of these phenomena as "illnesses."

In Chapter Four, I examine what Nancy Mairs has called the "literature of personal disaster," meaning memoirs on the subject of illness and disability, and identify the major ways in which accounts of physical disability are constructed and function differently from accounts of mental illness. Using ten representational examples, I track differences in how the stories are told to create very different kinds of meanings that are made of the experiences. The five memoirs of mental illness share a narrative downspin of worsening illness (or alternately, a progressive deepening of the author's understanding), followed by a crisis in which some sort of therapeutic agent is introduced (psychological therapy, antidepressants, etc.), and the author is ultimately restored to health. Even when the restoration to health is portrayed as an ongoing struggle, the narrative works to identify the experience of illness as pathological and yet simultaneously also works to distance the author from that pathology by positioning him or her as cured (and therefore as a credible witness to the pathological experience).

The five memoirs of physical disability are also structured as journeys, but of a very different kind. In these, management of the author's impairment usually plays a minor role, and the central journey is a psychological process of coming to terms with the oppression faced by people with disabilities, as well as meditation on the

appropriate role to take to resist disabling social and cultural attitudes. Of particular

concern in this chapter is how these meta-narratives (of illness and recovery, and of

oppression and struggle) are in fact extremely limiting in the range of possible

meanings that they present. I question the ways in which the publication market—

e.g., the need for published books to sell—may also serve to limit the range of the

kinds of stories that end up being published into standardized (and possibly also

sanitized) narratives, and in turn, also limit the range of possibilities for *cultural*-level

narratives of illness and disability.

Chapter Five more directly interrogates both the intellectual legitimacy and

social justification of diagnoses made on criteria based on social and cultural values –

specifically, Gender Identity Disorder (GID), the "illness" with which (self-

identified) transgender individuals must be diagnosed in order to obtain legal access

to FDA-regulated hormones or sex reassignment surgery. Unlike many other illness

or disabilities, Gender Identity Disorder is a "top-down" definition; transgendered

individuals may often identify as a "trans woman" (or "trans man), as "men" or

"women" without a prefix, as "transgendered," or perhaps even "queer," or "gay."

Despite the plethora of terms and localized meanings, what is easy to see is that these

identifications are overtly political and drawn along lines of *gender*, not diagnosis.

Yet the American Psychiatric Association includes in the DSM several different types

of gender identity disorders and diagnostic criteria for each.

More specifically, this chapter examines the Standards of Care for Gender

Identity Disorders (6th version), published in 2001 by the Harry Benjamin

International Gender Dysphoria Association (now known as the World Professional

Association for Transgender Health). These standards are the clinical guidelines used by many doctors to determine to whom and how hormones and surgery should be made available. In addition to an examination of the content of the standards, my examination includes a consideration of the professional composition of the committee that authored the sixth version of the Standards. It also includes an assessment of the Standards as a text-object that has a life of its own, owing to its role as the gate through which most transgendered people seeking hormones or surgery must pass to obtain legal supplies and services.

As such, I argue, this very top-down definition of a mental illness offers many interesting opportunities to consider how personal stories relate to the pathologization of the experiences categorized as mental illness. Most obviously, there is the question of whose stories "count" as true: both doctors and patients tell stories about what they see happening in the patient's life, but the doctor's story "counts" in a way that the patient's story does not. There are also stories told in more oblique ways about the larger questions of what is being defined and pathologized as mental illness, about the process of making such decisions and who is authorized to make them, and stories told about how to resist and remodel other stories. This chapter reflects my observations and concerns that while the telling of the personal story may have some usefulness in certain ways, it also has substantial limitations, and in circumstances such as GID, the limitations can raise questions of truthfulness, both in terms of unconscious influence and of outright lying.

The disability rights movement's rallying cry of "nothing about us, without us" made sense, in that at the time of its genesis, it represented a popular demand, in

the 1960s and 70s spirit of direct pickets, sit-ins and boycotts. It insisted on meaningful inclusion of people with disabilities in the decision-making process, and especially emphasized de-medicalizing aspects of disability or illness that did not actively require medical care. But now, when "activism" is more likely to consist of writing a book, a blog, or otherwise "telling one's story," I question whether this is still the most useful approach either for a political disability rights project concerned with the advancement of social justice, or an intellectual project concerned with any sort of anthropological or philosophical inquiry.

Chapter 2: Creating a Context: Interdisciplinary Studies of Science, Experience, and Disability

This chapter outlines a scholarly context for my inquiries into the construction of pathology of madness/mental illness. It examines the scholarly literature that has informed my thinking on the subject and, to a much lesser degree, describes the multiple scholarly contexts in which this study takes place, with a particular eye towards disability studies.

Although people often assume that such an inquiry would begin with the kinds of literature most frequently associated with the *topic* (e.g., psychology, psychiatry, perhaps the history of medicine), my concern in this review is instead on that very process of association between the signifier of the phenomena we call madness or mental illness and the signified category or idea of insanity, and how that association determines the sort of stories that can be told about the experience. This chapter functions as both an intellectual genealogy, connecting the overall project of inquiry to its diverse scholarly roots, and equally, supports one of the project's major threads of argument, that social justice-based humanities projects are strengthened considerably by engaging other types of scholarship (and conversely, are weakened when they do not.)

As befits a question of such an interdisciplinary nature, there are three distinct kinds of scholarly literature from which this project draws. Most important is the scholarly literature in what has come to be called "science studies," the examination of how ideas about what science is or does are of equal importance to what science actually is or does, and how one might be able to imagine the difference. Second,

there is a very loose body of literature concerned with the representation of certain kinds of experience, such as physical sensation or emotion, that are particularly difficult to translate to or "capture" in language. Third, in lieu of a field of "madness studies," there is the literature of disability studies. This literature is predominantly concerned with the experience of physical disabilities, such as polio or blindness, but which nevertheless offers a robust and perhaps the only currently viable socio-cultural model for reassigning the association of disability or illness with medicine. Because this project has its roots in such disparate areas, I will focus on an examination of the scholarly work with the greatest bearing on this project—not always the same as an examination of the most pivotal works within the context of each field.

It is important for me to note that these texts and the others cited in this chapter are primarily those that are pivotal in my own understanding of my project. The assembly of these diverse topics into a coherent whole and an identification of their relationship to my project is necessary both to explain my argument and to clearly justify my logic and rationale. It is more relevant than a literature review of the current work in each discrete area, and reflects a broad argument made in different ways by a number of studies reviewed here, namely that knowledge is always contextual and is constructed in part through the particular situation of the scholar.[32]

I encourage the reader of this chapter to make use of Katie King's idea of "lacquered layerings," which she defines as "layerings of instance, of political

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[32] This idea is engaged indirectly by a number of works here, but is argued most directly by Donna Haraway's concept of "situated knowledges."

meanings constrained in particularity, lacquered over so finely that they are inseparable and mutually constructing while distinct."[33] The term emerged from King's efforts to tease apart the ways in which some kinds of words and ideas developed vastly different meanings and applications in different contexts in U.S. women's movements, particularly over time. This approach to feminist "conversations," as she calls them, is intended to preserve complexity and ambiguities as much as possible, and prevent the term "women's movement" from being compressed into an oversimplified, monolithic idea that privileges the best-funded and most widely distributed perspectives. "Lacquered layerings" is thus a useful technique for holding several differing ideas in mind at once. This project faces similar political challenges—particularly in terms of who understands what as "pathological" and for what reasons—but the idea of "lacquered layerings" is also a way to tolerate uncertainty and contradiction when insisting on a single, fixed definition would prematurely foreclose other intellectual options.

The Construction of Knowledge and the Practice of Science

Science studies is the body of literature most pertinent to this project because it focuses on an examination of the processes by which the idea of science (inclusive of medicine) has become understood as an enterprise that deals with "objective" knowledge, and by which "objective" knowledge has become understood to be more true than other kinds of knowledge. Science studies considers issues such as the

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[33] Katie King, *Theory in Its Feminist Travels: Conversations in U.S. Women's Movements* (Bloomington: Indiana University Press, 1994), 2.

process of classification, the valorization of objectivity, and ways in which "science" has come to have rhetorics and practices that are distinct from each other.[34]

Most fundamentally, this study draws from and expands on the ideas suggested by Geoffrey C. Bowker and Susan Leigh Star in *Sorting Things Out: Classification and its Consequences*, in which the authors in turn expand on ideas introduced in Foucault's *The Order of Things* and *The Archaeology of Knowledge*.[35] Bowker and Star explore how classifications and standards work invisibly to order and structure human interaction, examine how these categories work in the context of the human-built environment (especially in terms of information technology), and consider how the work of such classification is often rendered invisible.

Bowker and Star distinguish between "classifications" and "standards," noting that they are related but not identical. Classification systems are defined as "a set of boxes (metaphorical or literal) into which things can be put to then do some kind of work—bureaucratic or knowledge production."[36] Classification systems are described as having three properties: 1) there are consistent, unique classificatory principles in operation; 2) the categories are mutually exclusive, and overlap is not

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[34] Several distinctions need to be made here. I've heard science studies described as the difference between what scientists say that they do and what they actually do. But equally important to this study is that there is also a difference between what scientists say that they do (and actually do) and what *other* people think that they do. Generally speaking, this study is concerned with the latter, inasmuch as medical authority is a complicated social negotiation. One of the challenges in this project is to retain the understanding that these layers do in fact have some separate characteristics, yet also are conflated in some ways. In other words, I don't think that very many serious research scientists would themselves be quite as cavalier about asserting certainty in their work as non-scientists tend to be.
[35] Geoffrey C. Bowker and Susan Leigh Star, *Sorting Things Out: Classification and Its Consequences*, *Inside Technology* (Cambridge, MA: MIT Press, 1999), Michel Foucault, *The Archaeology of Knowledge* (London: Tavistock Publications, 1972), Michel Foucault, *The Order of Things: An Archaeology of the Human Sciences* (London: Tavistock Publications, 1970).
[36] Bowker and Star, *Sorting Things Out: Classification and Its Consequences*, 10.

permitted; and 3) the system covers the entire world it describes.[37] They note, too,

that classifications can become standardized. Standards, in turn, are defined as:

1. A "standard is any set of agreed-upon rules for the production of (textual or material) objects.
2. A standard spans more than one community of practice (or site of activity). It has temporal reach as well in that it persists over time.
3. Standards are deployed in making things work together over distance and heterogeneous metrics. ...
4. Legal bodies often enforce standards, be these mandated by professional organizations, manufacturers' organizations, or the state. …
5. There is no natural law that the best standard shall win— QWERTY, Lotus 123, DOS and VHS are often cited as examples in this context. …
6. Standards have significant inertia and can be very difficult and expensive to change.[38]

Bowker and Star's meditations on how classifications and standards work is

useful and interesting in its entirety, but their work on the International Classification

of Diseases—used as a major example throughout the book—is of particular

importance, and suggests the kind of approach that I will take in my examinations of

the DSM-IV's definitions of depression and the WPATH Standards of Care for

Gender Identity Disorders. One of the most important insights that Bowker and Star

offer is of the ways in which such classification systems and standards create multiple

and sometimes conflicting lines of pressure on individuals, a process they call

"torque." This idea of torque permits them to trace, in detail, the path from the

classification system or standard to its impact on actual lives.

Bowker and Star's work, although in many ways unique (and, ironically, not

easily classified in a literature review focusing on classification), also fits in with a

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[37] Ibid., 10-11.
[38] Ibid., 13-14.

larger body of scholarship that examines "science" as object of cultural construction.

They acknowledge this connection, aligning their work with science studies, and

specifically Bruno Latour's central argument in *We Have Never Been Modern*.[39]

Bowker and Star interpret Latour as arguing that "we can either look at what

scientists say they are doing (working within a purified realm of knowledge) or at

what they actually are doing (manufacturing hybrids of nature-culture)."[40]   While

I'm not sure that this is the most faithful summary of Latour's argument, it certainly

makes the point that words and deeds are not the same, and sets the stage for Bowker

and Star's own central thesis that there are circumstances in which a system's

description of reality is able to change the world in such a way that the description

becomes true.

Like Bowker and Star, Donna Haraway makes a general argument that cuts

across many topics of scientific inquiry in *Modest_Witness@Second Millennium.*

FemaleMan©Meets_OncoMouse™: Feminism and Technoscience.[41] Haraway's

argument about "situated knowledges" begins with the example of Robert Boyle's

experiments with an air pump in 17th century Scotland. She explicates the idea of

scientific objectivity, noting that the ability to stand up as a "modest witness" in the

attestation of the results of scientific experimentation was limited to men, owing to

women's social status as "covered" persons.[42]   Because it was socially inappropriate

for women to take the public role required in the witnessing and attestation of

scientific experimentation, women were effectively foreclosed from participation in

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[39] Bruno Latour, *We Have Never Been Modern* (Cambridge, MA: Harvard University Press, 1993).
[40] Bowker and Star, *Sorting Things Out: Classification and Its Consequences*, 48.
[41] Donna Jeanne Haraway, *Modest_Witness@Second_Millennium.Femaleman©Meets_Oncomouse™: Feminism and Technoscience* (New York: Routledge, 1997).
[42] Ibid., 27.

science, and this foreclosure was rendered invisible and natural in that cultural context.

Haraway uses this example to frame her rich central argument about "situated knowledges," which contends that science is what it is, in part, through the construction of gender (and other markers of identity), and vice versa. "Situated knowledges" is a way of addressing the idea that knowledge production does not occur in a vacuum, and that the issue of who is doing the asking, as well as what questions are asked and answered, shapes what will be known as "science." Ultimately, Haraway's point is that such issues are not only about the historical exclusion of women from science, for instance, but about a process of the production of knowledge that excludes certain kinds of questions altogether, and that without an understanding of all knowledge as situated within a particular context, a truly reflexive scientific enterprise (or "technoscience") is severely limited. Consideration of the political context of the production of knowledge, she argues, is an essential part of a robust idea of science.

Sorting Things Out and *Modest_Witness* are part of a scholarly metanarrative that argues that processes and outcomes in science are political, and anything but absolute. A similar argument, but focused specifically on contemporary biological psychiatry, can be found in *Pharmaceutical Reason: Knowledge and Value in Global Psychiatry*, in which Andrew Lakoff maps the globalization of biological psychiatry.[43] He examines how a French biotechnology company offered an impoverished Argentine hospital $100,000 for 200 DNA samples from patients

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[43] Andrew Lakoff, *Pharmaceutical Reason: Knowledge and Value in Global Psychiatry*, *Cambridge Studies in Society and the Life Sciences* (Cambridge, UK; New York: Cambridge University Press, 2005).

diagnosed with bipolar disorder, unaware that the dominant therapeutic model in

Argentina is psychoanalysis, and that the diagnosis of bipolar disorder is made

infrequently there. In the samples, the French biotechnology company was hoping to

find genetic markers suggestive of bipolar disorder, with the intent of developing a

drug tailored very specifically to that condition. As Lakoff observes:

> The new biomedical psychiatry seeks to find organic correlates for
> behavioral disorders and hone targeted pharmaceutical interventions
> whose efficacy can be tested through clinical research. Its goal is to
> restore normal psychic functioning by linking intervention—typically,
> but not exclusively through drug therapy—directly to specific brain-
> based disorders. The norm that guides intervention is one of
> "specificity" of effect: thus, for example, "depression" should be
> treatable by an "anti-depressant." However, since both the putative
> effects of a given medication and the characteristics of its target illness
> population are subject to interpretation, the achievement of specificity
> involves a process of mutual adjustment between illness and
> intervention. Illness comes gradually to be defined in terms of that to
> which it "responds."[44]

The conflict between the French biotechnology company's biological psychiatry and

the Argentine hospital's psychoanalytically-based psychiatry thus represented a

challenge to the idea that medical or scientific knowledge is universally valid: how

valid can a *biologically*-aligned model of pathology be if it completely disappears in a

different cultural context?

Similar questions are raised in Ian Hacking's 1998 *Mad Travelers:*

Reflections on the Reality of Transient Mental Illness, in which he examines the

curious historical phenomenon of dissociative fugue states around the turn of the 20th

century, in which urban, working-class men would lose all memory of their regular

lives and go traveling around Europe for months at a time before "waking up."[45]

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[44] Ibid., 7.
[45] Hacking, *Mad Travelers: Reflections on the Reality of Transient Mental Illnesses*.

Hacking, a philosopher, is interested in how the idea of what he calls "transient mental illnesses" are logically possible, and in considering how to move the discussion beyond the simplistic "real" vs. "socially constructed. His *Rewriting the Soul: Multiple Personality and the Sciences of Memory*, published in the same year, examines the debates over the diagnosis of multiple personality disorder (now more frequently known as dissociative disorder) with an eye towards the constitution of the real in a formal philosophical sense.[46]

Turning away from psychiatry and to medicine more generally, there are several important studies in recent years that examine various forms of medical surveillance and the processes by which those observations are imbued with meaning. Joseph Dumit's 2004 *Picturing Personhood: Brain Scans and Biomedical Identity* examines the way that PET scans of the brain come to be understood as signs of disease or disorder to be regulated.[47] Lisa Cartwright's 1995 *Screening the Body: Tracing Medicine's Visual Culture* remains one of the strongest studies of visual surveillance of the body, examining how various sorts of visual imaging techniques from X-rays to film have been used as evidence to "prove" disease or disorder.[48] Likewise, Anne Fausto-Sterling's 2000 *Sexing the Body: Gender Politics and the Construction of Sexuality* confronts a wide range of ways in which bodies are

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[46] Ibid.

[47] Joseph Dumit, *Picturing Personhood: Brain Scans and Biomedical Identity* (Princeton: Princeton University Press, 2004).

[48] Lisa Cartwright, *Screening the Body: Tracing Medicine's Visual Culture* (Minneapolis: University of Minnesota Press, 1995). Also of note is Paula A. Treichler, Lisa Cartwright, and Constance Penley, *The Visible Woman: Imaging Technologies, Gender, and Science* (New York: New York University Press, 1998)..

"sexed," starting from external physical characteristics sexualized into the binary of male/female, and working inwards to similar processes at the cellular level.[49]

The Meaning of Experience

The second area of relevant literature also focuses on ways that meaning is produced, but takes as its subject personal experience. This grouping explores a range of questions about experience, from the ability to represent or understand another person's pain to the importance of establishing scholarly practices for representing and dealing with emotion. Ontological questions also figure prominently here, with a substantial emphasis on the recent literature exploring experiences of trauma.

Elaine Scarry's 1985 *The Body in Pain: The Making and Unmaking of the World* examines the experience of physical pain and what she contends to be the unknowability of another person's pain.[50] Scarry's focus is on how pain can "unmake" a sufferer's world by taking that person to a state of mind without control of language, and in so doing, she argues, effectively dismantling the sufferer's link to any consciousness other than of the experience of pain. Scarry sees the physical, sensory experience of pain as unrepresentable, without fixed points of reference, and therefore understands the pain of another person to be fundamentally unknowable. Scarry's influence on this project is considerable, as I have spent considerable time struggling with her thesis despite my recognition that I begin with the same assumptions that she does. I disagree with Scarry to some extent: her conception of

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[49] Anne Fausto-Sterling, *Sexing the Body: Gender Politics and the Construction of Sexuality*, 1st ed. (New York, NY: Basic Books, 2000).
[50] Elaine Scarry, *The Body in Pain: The Making and Unmaking of the World* (New York: Oxford University Press, 1985).

"knowledge" is a very Western one rooted in Enlightenment thinking, and I do not want to completely foreclose other kinds of conceptualizations of knowledge—even as I find myself imagining the situation with a similar Western idea of knowledge at the center. However, Scarry's points about the difficulty of communicating something complex when language becomes unavailable, or the difficulty of applying language to phenomena that are "prior" to language, are well taken, and are one of the challenges in describing the suffering that can be part of madness/mental illness. I also disagree with Scarry on her distinction between emotional and physical pain, again an issue in which she takes a traditional Western approach with a mind/body split, when perhaps there are other models better capable of representing the simultaneous differentiation and overlap of mind and body.

More recently, a body of literature has grown up around memory and trauma. What is particularly interesting about this literature is that it does not always try to make a firm separation between the experience, and the representation of the experience. In fact, this literature tends to linger on that difficult and unknowable place between experience and representation (including memory) and this approach allows new kinds of questions to be asked.[51]

Kalí Tal's polemic but fascinating study of "the literature of trauma" includes the writings of Holocaust survivors, women and children surviving sexual abuse, and Vietnam-era veterans. She examines three strategies of "cultural coping": mythologization, medicalization, and disappearance:

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[51] Cathy Caruth's work is usually cited as foundational, but I have found other texts to be more useful and relevant. Cathy Caruth, *Trauma: Explorations in Memory* (Baltimore: Johns Hopkins University Press, 1995), Cathy Caruth, *Unclaimed Experience: Trauma, Narrative, and History* (Baltimore: Johns Hopkins University Press, 1996).

Mythologization works by reducing a traumatic event to a set of
standardized narratives (twice- and thrice-told tales that come to
represent "the story" of the trauma) turning it from a frightening and
uncontrollable event into a contained and predictable narrative.
Medicalization focuses our gaze upon the victims of trauma, positing
that they suffer from an "illness" that can be "cured" within existing or
slightly modified structures of institutionalized medicine and
psychiatry. Disappearance – a refusal to admit the existence of a
particular kind of trauma—is usually accomplished by undermining
the credibility of the victim. In the traumas I examine, these strategies
work in combination to effect the cultural codification of the
trauma.52

Tal's description of "mythologization" prefigures my own assessment of the way that

narratives of disability and illness come to be standardized, an issue that is the focus

of Chapter Four. She asserts that "Once codified, the traumatic experience becomes a

weapon in another battle, the struggle for political power."[53] Tal uses the metaphor of

a battle to describe the struggle for the ability to define the meaning of traumatic

experience, and this is a fair description of the kind of crusade that the disability

rights/disability studies project has embarked upon.

However, to speak of illness and disability as trauma is one of the public

relations conundrums of disability studies: on the one hand, the kinds of experiences

we call "madness" or "mental illness" are often of a nature that involves considerable

suffering, and the idea of "trauma" on the basis of those experiences is not, to my

mind, at all far-fetched. On the other hand, this practice reinforces the association of

disability with medicine—exactly as Tal describes in the cultural coping strategy of

"medicalization"—the eradication of which is one of the major emphases of the

disability rights/disability studies project.

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[52] Kalí Tal, *Worlds of Hurt: Reading the Literatures of Trauma* (Cambridge [England]; New York:
Cambridge University Press, 1996), 6.
[53] Ibid.

Tal focuses on the relationships between personal stories and community-

level stories (e.g., of Jews in the Holocaust), especially the urge to "bear witness" and

the process by which testimony becomes political action:

> Each of the traumas discussed has as its victims a certain group of
> persons definable by characteristics of race, sex, religion and/or
> geographical location. If the members of a persecuted group define
> themselves as a community, as part of a common plight, then (and
> only then) will the urge to bear witness be present. If a trauma victim
> perceives herself as suffering alone, and has no sense of belonging to a
> community of victims, she will remain silent, imagining that her pain
> has no relevance to the larger society.[54]

Assuming that a survivor of a traumatic experience can imagine herself as part of a

larger community, the impulse to bear witness materializes in the literature of trauma.

Noting that "survival literature" tends to appear at least ten years after the traumatic

experience occurs, Tal argues:

> As the years pass and the immediacy of the event fades into
> memory the process of revision begins to occur in the mind of each
> survivor. The dislocation of trauma, which removed meaning from the
> world, is gradually replaced by new stories about the past that can
> support a rewritten personal myth. The survivor's perception of
> community is a crucial element in the shaping of her new myth.[55]

In Tal's description of the rewritten personal myth, however, I hear an echo of

Andrew Lakoff's notion of the gradual adjustment of the idea of illness becoming

defined by that to which it "responds,"—a gradual, constantly cycling adjustment of

meaning. However, I also hear questions hearkening back to Elaine Scarry's

observations about the difficulty of representing the experience of physical pain. Tal

also notes:

> But the task of the traumatized author is an impossible one. For if the
> goal is to convey the traumatic experience, no second-hand rendering

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[54] Ibid., 124.
[55] Ibid., 125.

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of it is adequate. The horrific events that have reshaped the author's construction of reality can only be described in the literature, not recreated. Only the experience of trauma has the traumatizing effect.[56]

Taken at face value, this is probably true, to some extent at least, in describing most kinds of experiences. An exceptionally fine writer may be able to craft a story that allows the reader to feel as though he or she were there—but, as Scarry notes, there is a difference between empathy and knowing. But what happens when "meaning" is partially pre-ordained through a diagnosis? If, as will be discussed throughout this project but especially in Chapter Three, biological psychiatry decrees the suffering associated with experiences of madness/mental illness meaningless, then it also forecloses the process of political awareness and empowerment through bearing witness. If, however, the suffering or trauma can be aligned with certain practices and named, then the seeds of community have been sown.

Tal observes, "On a social as well as an individual psychological level, the penalty for repression is repetition."[57] To suggest a relationship between suffering as it is often felt in madness/mental illness (e.g., anxiety, or post-traumatic stress disorder, in which sufferers relive traumatic experiences) and the proverb that those who do not learn history are doomed to repeat it is provocative to me. While perhaps not a completely defensible theoretical principle for scholarship, it is an interesting idea in considering how political projects based on identity-related issues may want to formulate and deploy their arguments and activities, an idea to which I will return in the conclusion.

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[56] Ibid., 121.
[57] Ibid., 7.

Other feminist scholars dealing with trauma of various kinds have grappled

with the complex challenges of using the representation of experience as scholarly

evidence in a way that is both respectful and productive. Wendy Hesford and Wendy

Kozol's essay collection, *Haunting Violations: Feminist Criticism and the Crisis of*

the "Real," focuses on the challenges of teaching about profoundly traumatic events,

such as rape, in a way that neither re-traumatizes the victim by asking her to relive

her experience in the retelling of her story, nor erases her perspective altogether by

requiring positivist, "objective" evidence. The act of representation thus becomes a

central focus, and they note:

> Contributors to *Haunting Violations* are concerned with how subject
> positions are constituted through and within historically located
> discourses. The emphasis on history stems from the belief that the
> "real is not a fixed essence but a historically formulated epistemology
> that responds to localized needs and expectations. Much attention is
> therefore paid to the material body, which is one of the most privileged
> sites for the production of reality claims because of the presumption
> that one is one's body, that identity is expressed through the body.
> Thus definitions of experience and authenticity frequently presume a
> coherence between subjectivity and the material body. This is most
> apparent at moments of crisis, for pain occurs not in the abstract but on
> or in particular bodies. "Haunting violations" refers to both the
> belatedness of trauma and how representation recasts those
> violations."[58]

What is useful here is the idea that the act of representing a physical experience

assumes coherence between subjectivity and the material body, and that the act of

representation "recasts" those relationships. Recall Scarry's assertion of the

incommunicability of pain (which I extrapolate here to include other kinds of bodily

sensation); recall Tal's and Lakoff's assertion of stories gradually changing in the

telling of them. What we are left with is a "hot mess," so to speak—a provocative

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[58] Wendy S. Hesford and Wendy Kozol, *Haunting Violations: Feminist Criticism and the Crisis of the "Real"* (Urbana: University of Illinois Press, 2001), 7.

and intriguing intersection of assumptions and assertions that refuse tidy resolutions

or conclusions. Put another way, this constellation of issues (the challenges of

communicating bodily knowledge, the complicated relationship of body to identity,

and the way in which that relationship necessarily changes over time in response to a

multitude of factors), means that using personal experience (especially that in which

the body figures prominently) as evidence is extremely complex and challenging.

Also writing in the context of feminist theory, Joan W. Scott acknowledges

the necessity and desirability for historians to find ways to incorporate the

perspectives of those who have traditionally been excluded from history, and the

utility of the incorporation of such perspectives and narratives of experience.

However, Scott contends, there are serious problems with the tendency to treat

experience as uncontestable evidence:

> …The evidence of experience, whether conceived through a metaphor
> of visibility or in any other way that takes meaning as transparent,
> reproduces rather than contests given ideological systems—those that
> assume the facts of history speak for themselves and, in the case of
> histories of gender, those that rest on notions of a natural or
> established opposition between sexual practices and social
> conventions, and between homosexuality and heterosexuality.
> Histories that document the 'hidden' world of homosexuality, for
> example, show the impact of silence and repression on the lives of
> those affected by it and bring to light the history of their suppression
> and exploitation. But the project of making experience visible
> precludes the critical examination of the workings of the ideological
> system itself, as categories of representation
> (homosexual/heterosexual, man/woman, black/white as fixed
> immutable identities), its premises about what these categories mean
> and how they operate, its notions of subjects, origin, and cause. [59]

Scott observes that experience tends to have a "foundational" status in terms of its

access to authority, by establishing a "prediscursive authority" and "indisputable

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[59] Joan Wallach Scott, "'Experience'," in *Feminists Theorize the Political*, ed. Judith Butler and Joan Wallach Scott (New York: Routledge, 1992).

authenticity," but that this authenticity is established in a logical action that serves to universalize the category of identity and to legitimize the link between the personal and the political. Scott sums up her logic:

> "Subjects are constituted discursively, experience is a linguistic event (it doesn't happen outside established meanings), but neither is it confined to a fixed order of meaning. Since discourse is by definition shared, experience is a collective as well as individual. Experience is a subject's history. Language is the site of history's enactment. Historical explanation cannot, therefore, separate the two."[60]

Instead, Scott suggests a more "literary" reading of personal experience, one that constitutively links the fact of the experience with the telling of it—a suggestion that would seem like a curious sort of déjà vu, were it not that "experience" has in fact become so uncontestably authoritative.

However, the utility of Scott's point—for my purposes, anyway—lies in her identification of the way that the authority of experience has been understood as epistemologically transparent, and that the elision of the role of discourse is a function of the political work that the evidence of experience must do. Disability studies, like the women's studies project of which Scott writes, has an investment in establishing the authority of experience as incontrovertible evidence, and like Scott, I am concerned that the political utility is allowing a lack of interrogation of the terms under which the evidence of experience comes into being. Although it is tempting to allow what could be described as a lack of rigor to pass undisturbed in the service of an undeniably well-intentioned project, to do so ultimately reduces the intellectual integrity of the project and, for those comfortable enough with postmodernism to be

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[60] Ibid., 28.

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untroubled by this as an ethical issue, can also produce unintended consequences with potentially deleterious effects for disability studies.

Disability Studies

The third major body of literature that informs this project is disability studies, which can be defined officially as scholarship concerned with the explication of dis/ability and non/normative bodies as a category of analysis alongside gender, race, etc. Equally important to a functioning definition, however, is understanding the pronounced activist motivation behind much of the enterprise, a feature certainly evident within the formal scholarship but which reveals itself best in the textures of informal conversations and discussions in the hallways at the Society for Disability Studies annual conference.[61] This makes for something of a difference between the *scholarship of disability studies*—which I see, generally speaking, as larger and more inclusive of studies of illness, and often written by scholars (e.g., Sontag) who have not explicitly identified themselves as disabled or part of a disability studies community—and the *disability studies project,* which tends to operate, politically speaking, in much smaller circles and have a much more explicitly activist agenda.[62]

There is certainly much common ground, but there are intellectual differences as well, primarily attributable to the activist agenda. For example, Sander Gilman prefaced *Difference and Pathology*, which could be understood as one of the early works in the scholarship of disability studies, with an observation that "every group has laws, taboos, and diagnoses distinguishing the 'healthy' from the "sick. The very

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[61] This is, to my mind, one of the particular features of the Society for Disability Studies annual conference compared to other national conferences.

[62] In the rest of the dissertation, when I refer to the disability studies project, or the disability rights/disability studies project, I am referring to this activist component.

concept of pathology is a line drawn between the 'good' and the 'bad.'"[63] Gilman

sought to explain how stereotypes of particular kinds of sexuality and race become

associated with or understood as pathological. While Gilman clearly has an

investment in examining injustice, the study is better described as an intellectual

history of the process by which these kinds of categories are constructed and

reproduced. In contrast, *Why I Burned My Book and Other Essays on Disability*,

written by an equally fine historian, Paul Longmore (and lavishly praised on the back

cover by Gilman), is built around an argument that scholars have an ethical obligation

to perform scholarship explicitly in support of social justice activities, culminating in

an essay describing a protest in which Longmore burned his own tenure book.[64]

There is a small body of (contemporary) work that is explicitly concerned

with handling issues of madness/mental illness in a disability studies project

framework.[65]   Stuart A. Kirk and Herb Kutchins co-authored two early examples of

studies on the expansion of psychiatric authority. *The Selling of DSM: The Rhetoric*

of Science in Psychiatry, published in 1992, is a compelling study of how the

administrative need to measure and code the diagnostic categories of mental illness

shaped the DSM.[66]   While it remains a very clear explanation of how standardization

in diagnosis has replaced individual autonomy in assessment, it is also dated

inasmuch as it represents a 1970's antipsychiatry mindset and does not really engage

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[63] Gilman, *Difference and Pathology: Stereotypes of Sexuality, Race, and Madness*, 23.

[64] Paul K. Longmore, *Why I Burned My Book and Other Essays on Disability*, *American Subjects* (Philadelphia: Temple University Press, 2003).

[65] There are a good many other interesting and useful studies on the topic of madness/mental illness that do not take an explicitly disability studies-style approach. However, because it is the urgency and the coherence of the activist disability studies agenda that really shaped this inquiry, it is appropriate to recognize the contours of the field and not reproduce associations simply by subject matter.

[66] Stuart A. Kirk and Herb Kutchins, *The Selling of DSM: The Rhetoric of Science in Psychiatry* (New York: A. de Gruyter, 1992).

the biological psychiatry that has become the standard today. The pair again analyze

the psychiatric authority in their 1997 *Making Us Crazy: DSM: The Psychiatric Bible*

and the Creation of Mental Disorders, and in this volume focus on the ways in which

diagnostic criteria work to expand the category of mental illness along the lines of

normative identity, e.g., particularly for women, people of color, non-heterosexual

people, etc.[67] The central argument of the book is that the pathologization of

behavior mirrors certain demographic positions—true enough, but again feeling

somewhat dated because the argument is rooted in a very civil rights era-style

assumption that the mere identification of such inequities is adequate to spur action.

In 2000, Dwight Fee's edited collection of essays, *Pathology and the*

Postmodern: Mental Illness as Discourse and Experience, explicitly engaged the

difficulties of pursuing postmodern conceptualizations of madness as hegemonic

oppression in the face of the (modernist?) practical problems of illness. Although the

essays are somewhat uneven, Fee's examination of Elizabeth Wurtzel's *Prozac*

Nation (which I too will discuss in Chapter Four) is a serious engagement with the

ontology of depression.[68] Fee also identifies the difficulties of constructing personal

stories in a context in which expectations of what such stories should look like have

already been established, and discusses this in terms of the problem of reflexivity.

Likewise, in another essay, Vivien Burr and Trevor Butt consider the

"pathologization of everyday life," specifically with the "psychologization" inherent

in the process. Burr and Butt are interested in defending the potential usefulness of

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[67] Herb Kutchins and Stuart A. Kirk, *Making Us Crazy: DSM: The Psychiatric Bible and the Creation of Mental Disorders* (New York: Free Press, 1997).

[68] Dwight Fee, "The Project of Pathology: Reflexivity and Depression in Elizabeth Wurtzel's *Prozac Nation*," in *Pathology and the Postmodern: Mental Illness as Discourse and Experience*, ed. Dwight Fee (London; Thousand Oaks, CA: SAGE Publications, 2000).

therapeutic practices against what they believe a strictly Foucauldian social constructionist perspective would require, namely that the "psy-complex" (of psychology, psychiatry, etc.) as be understood exclusively as a disciplinary project. As neither psychology nor psychiatry seem to be in any danger of imminent eclipse by social constructionism, their concern may be overstated, but their insight that the problems of everyday life are increasingly pathologized at an individual level is important. Burr and Butt argue:

> "We are now used to feeling and expressing doubt about our performance as parents, as lovers, as workers, and we scrutinize our thoughts and feelings for signs of some developmental flaw, perversion, or personal inadequacy. …An important feature of this process of pathologizing is its inherent 'psychologization'—that is, the casting of difficulties and problems into psychological frameworks and therefore locating them at the level of the individual."[69]

Overall, the volume represented one of the first efforts to try to engage a disability studies project-type approach to mental illness. Although the volume seems to have faded from view a bit, to my mind it remains an important collection because it seriously engaged (and then ultimately illustrated) some of the problems with trying to approach madness/mental illness in the same ways as physical disabilities, e.g., the difficulty in simply identifying the "problem" as socially constructed, because it demonstrated that this kind of approach would be plagued by problems of defining the "real."[70]

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[69] Trevor Butt and Vivien Burr, "Psychological Distress and Postmodern Thought," in *Pathology and the Postmodern: Mental Illness as Discourse and Experience*, ed. Dwight Fee (London; Thousand Oaks, CA: SAGE Publications, 2000), 186.

[70] Of course I do not mean to imply that "socially constructed" problems are not "real." But there are some kinds of problems (stairs, for instance) that have fairly simple solutions (requiring wheelchair ramps). In contrast, the phenomena of madness/mental illness can cause difficulties for those who experience them that are far more difficult to reject exclusively as prejudiced and discriminatory.

Emily Martin's 2007 *Bipolar Expeditions* examines mania as a component both of bipolar disorder (formerly known as manic-depressive disorder) and contemporary culture in general.[71] She argues that mania, though as significant a component of bipolar disorder as depression, has a dramatically different cultural meaning. Martin argues that mania is closely associated with ideas of financial and personal success—i.e., sleeping very little, thinking at a breakneck speed, and having grandiose ideas are considered desirable traits in corporate executives—and that such behaviors (and a manic style) are actively cultivated as desirable characteristics. She notes:

> "Peter Kramer warns us not to romanticize depression as a form of 'heroic melancholy,' but instead treat it as a disease we can cure. …I want to call attention to the socially based reasons why we want to eliminate some moods but keep others. Kramer exempts mania and hypomania from elimination because 'they drive productivity in many fields." Once again, mania is valuable because of its association with motivation and productivity."[72]

Whereas depression is pathologized precisely because its features typically make it an undesirable characteristic in a capitalist society, Martin argues that mania is valued precisely because of its support of capitalist culture.

Martin's examination of mania's "good reputation" in cultural terms provides a compelling (and refreshing) counterpoint to the usual argument that X, Y, or Z set of characteristics is pathologized through systematic and intentional discrimination. The characterization of mania as a "style," the evidence of the cultural preference for manic behavior, and the description of the substantial lengths to which people must

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[71] Emily Martin, *Bipolar Expeditions: Mania and Depression in American Culture* (Princeton: Princeton University Press, 2007).

[72] Ibid., 190. Martin cites Peter D. Kramer, "There's Nothing Deep About Depression," *New York Times Magazine*, April 17 2005.

go to maintain firm distinctions between the "healthy" and the "sick" certainly serves

as compelling evidence that this medical diagnostic category is deeply informed by

cultural and capitalist values. But it also is a useful reminder that sometimes a

reverse direction—in this case, looking at what considered "healthy" in cultural

terms—is just as useful in establishing the contours of what is considered "sick."

One of Martin's most methodologically useful insights is in how people who

have been diagnosed with bipolar disorder themselves use the medical discourse—or

don't. She was surprised and disappointed to find that many of the individuals she

met in bipolar support groups used "standard medical terms without further

elaboration, frustrating my hopes of finding a rich, individually and culturally

nuanced language about interior states."[73] Eventually Martin realized that people

were not describing their emotional states experientially but rather drawing from the

conventional discourse. She realized that "the pervasive use of the DSM categories

might work to prevent people from realizing the social importance of exploring their

inner states"—and, one might add, the importance of seeing their diagnosis as

culturally constructed.[74]

> A chart on a Web site published by Jinnah Mohammed includes large
> amounts of information about his particular life, undercutting the
> depersonalized and abstract qualities of most charts. The more
> specific his information is, the less readily it can be reduced to a
> number and compared to information from others. Jinnah's chart also
> separates measures of mood from measures of functionality, opening
> multiple axes on which he can compare different aspects of his
> condition. The additional axis has the potential to increase the
> surveillance over Jinnah's life, but at the same time it opens the
> possibility of challenging how standard DSM categories link moods
> and productivity. In the DSM, moods on either end of the manic
> depression scale are abnormal. By charting functionality as well as

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[73] Martin, *Bipolar Expeditions: Mania and Depression in American Culture*, 134.
[74] Ibid., 142.

moods, Jinnah discovers that he can be functional while his moods are abnormal, thus opening the possibility that he could reject the DSM's assumptions. However, he does not go this way. Instead, he concludes that he is never normal: "I have used the charts to show my family that when they thought I was normal (i.e., functional), I wasn't emotionally stable. It came as quite a shock to them often because they couldn't detect anything wrong with me… [The chart allowed me] to realize I had no periods of normality."[75]

The idea of the existence of a hegemonic discourse that prevents alternate interpretations is nothing new, but Martin makes a very helpful contribution in recording her surprise, clarifying the expectation that interior states would be described experientially and in terms that would provide a discursive resistance. Martin's surprise at Jinnah Mohammed's chart is also interesting; her expectation is that his chart would provide a space of discursive resistance by challenging the assumption that mood and functionality are parallel. She sees his response as a failure to resist the DSM's assumptions. Within the context of a disability studies sensibility, this is certainly a reasonable argument to make, but I think it exposes a tendency among those inculturated in disability studies (and its counterparts in other social justice projects) to see things in terms of a binary of the authoritative discourse or resistance to it. I would instead propose that Jinnah's chart be seen as a site in which the meanings of "normal" (and "pathological") are in contest, but also one in which "authority" and "resistance" are in play.

Moving beyond madness/mental illness to illness more generally, Lisa Diedrich also explores ways in which our understanding of the "experience" of illness becomes indistinguishable from the narrative in which it is represented. Diedrich's

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[75] Ibid., 194. Martin cites Jinnah Mohammed, *Living Manic Depressive: Coping with Bipolar Disorder and Depression* ([cited November 16 2009]); available from http://www.livingmanicdepressive.com/index.htm.

Treatments, which teases apart the differences between experience, identity and representation, questions how memoirs, specifically autobiographical and biographical accounts of illness, are read, and how those readings become common cultural meanings. Diedrich explicates several illness narratives in considerable detail and identifies ways in which specific narratives reinforce or complicate the idea of the (singular) "experience of illness" by examining how such experiences are also shaped by race, class, gender, and sexuality. Overall, Diedrich is concerned with the ways in which the narrative boundaries between "illness" and "the rest of life" become blurred. However, one particular example effectively illuminates the gist of her insight and argument. She describes critic Arlene Croce's emphatic condemnation of Bill T. Jones's dance piece on the subject of AIDS, *Still/Here,* which she refers to disparagingly as "victim art." Diedrich notes that Croce slips from talking about reviewing a *performance* into talking (literally) about reviewing a *person*. Diedrich contends that this slippage is revealing of at least one way in which meanings can be compressed in the mind of the reader, so to speak. She argues that the slippage shows the layers of illness, identity, and a particular form of representation being compressed into one entity, at least in Croce's mind.

Diedrich provides compelling arguments for complicating the cultural and literary expectations of what an "illness narrative" should look like. Her purpose is to identify and map the meanings of illness inscribed by the authors of illness narratives—something suggestive and yet distinctly different from identifying and mapping the meanings that readers take from them. Diedrich's explication of how illness narratives could be read in a more complicated way is helpful, yet is also

distinctly limited. Diedrich certainly presents compelling evidence for the idea of an

illness narrative form to be understood as perpetuating itself even as its authors

complicate what we can understand illness to be. However, aside from the

Croce/Jones example, without getting outside the world of the illness narrative, she

can offer little evidence of how these narratives shape larger cultural forces.

Other important work in the scholarship of disability studies has focused on

the meaning of illness, and specific cultural meanings of specific illnesses. Susan

Sontag's *Illness as Metaphor and AIDS and Its Metaphors*, which is often praised for

unpacking the accusatory subtext of medical discourse, also suggested to me that if

illnesses could have specific kinds of metaphors that worked to give the illness

specific kinds of cultural meanings, then perhaps all discourses about illness would be

constrained in these ways as well, regardless of the intent of the writer.[76] For

instance, to use an example outside of medicine: practically no American reader

could read a novel that uses the date of September 11, for any reason (for a first kiss,

the day a cure for cancer is discovered, for any event, no matter how wonderful)

without making some sort of reference to the events of September 11, 2001—even if

the novel predated 2001. September 11 might be seen as being used in "reverse," in

an intentional effort to replace the meaning of the date, but it will not be free from the

association for a very long time.

Annemarie Mol uses a similar tactic in the "pivoting" of the meaning of

illness in her ethnographic study of the meanings of atherosclerosis in a Dutch

university hospital. Alongside her ethnography of patients, doctors and others, she

includes a parallel meditation on relevant scholarly work, an approach that while

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[76] Susan Sontag, *Illness as Metaphor; and, AIDS and Its Metaphors* (New York: Picador USA, 1990).

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distracting to read is interesting for the ways in which it interrupts one's line of thought in productive ways. Mol's contribution, as pertains to this project, is a short discussion about the idea of distinguishing the "normal" and the "pathological," in which she reviews the relevant scholarly literature that documents a shift away from a "where does it hurt?" framework to a "what is your problem?" framework, meaning that the patient has become a participant in the identification of pathology inasmuch as only the patient can articulate whether a particular phenomenon is a *problem* in the context of the patient's life, clearly a completely subjective assessment.[77] Mol concludes that this shift does not replace but rather coexists with previous conceptions of pathology, which were based on both quantitative deviance and qualitative judgments. This is not a lengthy meditation, and it is perhaps too general to interrogate very seriously, but the differences in the ways that pathology is constituted in atherosclerosis vs. madness/mental illness are interesting.[78]

While several scholars, most notably Georges Canguilhem and Lennard Davis, have discussed the relationship between the notions of statistical deviance and pathology, the most recent and most comprehensive major study on how notions of difference and pathology became so embedded in a pseudo-scientific discourse was done by Sharon Snyder and David Mitchell in *Cultural Locations of Disability*, published in 2006.[79] One of the central arguments in this study of eugenics is that talking about disability in terms of a social model is inadequate because it fails to

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[77] Annemarie Mol, *The Body Multiple: Ontology in Medical Practice*, *Science and Cultural Theory* (Durham: Duke University Press, 2002), 120-28.
[78] On the one hand, biological psychiatry could be seen to contest this shift as it places authority with the doctor to treat a biological illness; on the other, the pathologizing of everyday life discussed elsewhere could be argued to be as much a "bottom-up" phenomenon as a "top down" phenomenon.
[79] Snyder and Mitchell, *Cultural Locations of Disability*.

address the ways in which the idea of disability is produced and constructed not only

through discursive practices of documentation and surveillance but also through

medical practices such as sterilization and other kinds of "public hygiene" activities.

What is particularly relevant to this project is their nuanced treatment of how

comprehensively eugenics-based thinking became embedded in "scientific" practice

and naturalized; it is useful to consider in reference to the ways in which

madness/mental illness is pathologized through biological psychiatry now. It also

represents the kind of engagement with "science"—albeit an engagement with a

specific historical moment—that I have argued is so essential to a vibrant humanities

project.

Obviously, this study engages disability studies very broadly and engages

scholarly conversations beyond those specifically described in this chapter. Among

these, there are several studies that stand out as important texts in shaping the field of

disability studies as I understand it, including (in chronological order): *Disability*

Studies Reader, edited by Lennard Davis (1997); *Extraordinary Bodies: Figuring*

Physical Disability in American Culture and Literature, by Rosemarie Garland-

Thomson (1997); *Diagnosis: Difference: The Moral Authority of Medicine*, by Abby

Wilkerson (1998); *The New Disability History: American Perspectives*, edited by

Paul Longmore and Lauri Umanski (2001); *Disability Studies: Enabling the*

Humanities, edited by Sharon Snyder, Brenda Jo Brueggemann and Rosemarie

Garland-Thomson (2002); *Crip Theory: Cultural Signs of Queerness and Disability*,

by Robert McRuer (2003); and *Desiring Disability: Queer Theory Meets Disability*

Studies (special issue of *GLQ*), edited by Robert McRuer and Abby Wilkerson

(2003).[80]

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[80] Davis, ed., *The Disability Studies Reader*, Longmore and Umansky, *The New Disability History: American Perspectives*, McRuer, *Crip Theory: Cultural Signs of Queerness and Disability*, Robert McRuer and Abby L. Wilkerson, "Desiring Disability: Queer Theory Meets Disability Studies," *GLQ: A Journal of Lesbian and Gay Studies (special edition)* 9, no. 1-2 (2003), Sharon L. Snyder, Brenda Jo Brueggemann, and Rosemarie Garland Thomson, *Disability Studies: Enabling the Humanities* (New York: Modern Language Association of America, 2002), Garland Thomson, *Extraordinary Bodies: Figuring Physical Disability in American Culture and Literature*, Abby L. Wilkerson, *Diagnosis: Difference: The Moral Authority of Medicine* (Ithaca, NY: Cornell University Press, 1998).

Chapter 3: Depression and the Instability of Pathology

> How many legs does a dog have, if you call the tail a leg? Four.
> Calling the tail a leg doesn't make it a leg. – Abraham Lincoln*
>
> [*Note: Lincoln never said this. He liked a similar, more long-winded
> anecdote about a cow, but the dog version? Nope. Still, the quote is
> credited to Abe on some 11,000 different Web pages, including quote
> resources Brainy Quote and World of Quotes…]
>
> - From a feature story about truth in *The Washington Post*[81]

In 1621, Robert Burton first published *The Anatomy of Melancholy*, under the

pseudonym Democritus Junior and with the impressive full title of *The Anatomy of*

Melancholy, What it is: With all the Kinds, Causes, Symptomes, Prognostickes, and

Several Cures of it. In Three Maine Partitions with their several Sections, Members,

and Subsections. Philosophically, Medicinally, Historically, Opened and Cut Up.

Burton's purpose was nearly as ambitious as his title; he sought to understand

melancholy, and to figure out how control might be regained over an unruly mind and

soul. He portrays melancholy as an surreptitious misery, one which gradually seeps

into all aspects of his consciousness, displacing all other thoughts and feelings.

Burton's description of melancholy is surprisingly similar to contemporary

descriptions of the experiences of depression:

> …When I lie waking all alone,
> Recounting what I have ill done,
> My thoughts on me then tyrannise,
> Fear and sorrow me surprise,

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[81] Monica Hesse, "Truth: Can You Handle It? Better Yet: Do You Know It When You See It?" *The Washington Post*, April 25 2008.

> Whether I tarry still or go,
> Methinks the time moves very slow.[82]

Burton's references to insomnia ("waking all alone"), feelings of worthlessness or guilt ("things ill done"), depressed mood ("fear and sorrow") and a loss of interest or pleasure ("the time moves very slow"), if experienced frequently enough, would be quite sufficient to earn him a diagnosis of depression by the current DSM criteria for depression (cited in their entirety later in this chapter). Yet the melancholy of which Burton wrote is not entirely interchangeable with the contemporary concept of depression as a biological illness. Burton's melancholy was surely an affliction, but it was not so clearly an "illness"—nor Burton so clearly a "doctor" in the contemporary sense of the term either, for that matter, as he was a scholar and cleric who held the post of librarian at Christ's Church College, Oxford. Rather, Burton's melancholy might be better thought of as one of the "wicked problems" of his day, suitable for contemplation using the entire range of intellectual tools available. Philosopher Jennifer Radden, who compiled an anthology of writings on melancholia covering a time span of more than two thousand years, notes that "The subject of melancholy in Western traditions is one whose appeal reaches well beyond any particular disciplinary division, and indeed, the study of melancholy long antecedes the study of such disciplinary boundaries."[83]

Melancholy might be thought of as a "wicked problem" in this study, too, as it poses a thorny question. Burton's description of melancholy remains immediately

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[82]Robert Burton, "The Author's Abstract of Melancholy," in *The Anatomy of Melancholy* (New York: New York Review Books, 2001).

[83] Jennifer Radden, *Moody Minds Distempered: Essays on Melancholy and Depression* (Oxford; New York: Oxford University Press, 2009), Jennifer Radden, *The Nature of Melancholy: From Aristotle to Kristeva* (Oxford; New York: Oxford University Press, 2000).

recognizable, but it is not the same; context, meaning, nearly everything is different, just as "melancholy" was a substantively different thing to Galen, Avicenna, and Burton. Yet to insist on examining "melancholy" and "depression" only in historical specificity is to miss the intellectual opportunity to take a longer view of a vexing kind of human experience, and effectively to limit the imagination of "depression" to the current conceptualization of the experience as purely a disease. As will be discussed extensively in the following chapter, there really is no active practice in re-imagining the pathology of depression in the contemporary disability rights/disability studies project; instead, activities have focused primarily on providing accommodations (such as flexible work hours) and access to services.

Thus, the purpose of this chapter is to try to imagine what a more productive overall view of the experience of depression might look like. The reimagining of physical disability as part of the spectrum of human variation has yielded not only a promising approach in terms of social justice concerns, but has also spawned some extremely interesting, to my mind at least, studies in intellectual history.[84] This chapter is a "what happens if…" experiment in trying on a model of depression that de-pathologizes the experience; it seeks to determine whether de-pathologizing depression might be a viable goal or strategy for the disability rights/disability studies project, and it seeks to determine what sorts of epistemological insights, if any, might be gained in doing so.

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[84] For instance, see Lennard Davis' discussion of the manipulation of statistics to reflect judgment. Lennard J. Davis, "Constructing Normalcy: The Bell Curve, the Novel, and the Invention of the Disabled Body in the Nineteenth Century," in *The Disability Studies Reader*, ed. Lennard J. Davis (New York: Routledge, 1997).

However, it isn't easy to re-imagine an idea as deeply ingrained as the model of depression-as-illness. For help, I turn to Avery Gordon's twin concepts of "haunting" and of "complex personhood," which she uses to describe both lingering traces of historical forces and social figures and the continuing effects of their influences in the production of knowledge.[85] Gordon's concept of haunting is similar to King's notion of "lacquered layerings," in that both ideas are ways of trying to deal with complexity and the simultaneous presence of consistency and contradiction. Gordon's description of complex personhood is useful as a way of imagining lacquered layerings in a dynamic form, as an active process in the experience and representation of a person's life. Gordon states:

> Complex personhood means that all people (albeit in specific forms whose specificity is sometimes everything) remember and forget, are beset by contradiction, and recognize and misrecognize themselves and others. Complex personhood means that people suffer graciously and selfishly too, get stuck in the symptoms of their troubles, and also transform themselves. Complex personhood means that even those called "Other" are never never that. Complex personhood means that the stories that people tell about themselves, about their troubles, about their social worlds, and about society's problems are entangled and weave between what is immediately available as a story and what their imaginations are reaching toward… Complex personhood means that even those who haunt our dominant institutions and their systems of value are haunted too by things they sometimes have names for and sometimes do not. At the very least, complex personhood is about conferring respect on others that comes from presuming that life and people's lives are simultaneously straightforward and full of enormously subtle meaning.[86]

Complex personhood inspires my use of the term "depression" in this chapter despite its linguistic ambiguity because the most often suggested alternative— "melancholy"—feels too mild and too removed in its contemporary usage, and too

[85] Avery F. Gordon, *Ghostly Matters: Haunting and the Sociological Imagination* (Minneapolis: University of Minnesota Press, 1997).
[86] Ibid., 4-5.

hard to imagine as being the same kind of experience. "Melancholy" is complicated, not only because is it many different things in historical context, but also because the word lingers on today with a peculiarly anachronistic flavor, e.g., it conjures up images of heartbroken heroines in movies based on Jane Austen novels. Equally, however, I have tried to replace the word "depression" with the phrase "the experience of depression" to try to detach it from the objectifying clinical perspective and resituate its primacy as an experience constituted through a variety of factors. Where I have used the word on its own, it should be understood to refer to the broader sense of the term except where it is explicitly or contextually indicating the narrow, clinical sense. Such complications exist at every stage of the process of knowledge production: there are conflicts in the conception and representation of the experience by the person who experiences it, in the valuation of the experience by others, and in the (presumptive or consequent) placement of the experience in one philosophical framework or another.[87]

Overall, for my purposes, "complex personhood" offers a provisional methodology that will allow me to discuss the experience of depression as an entity that exists reasonably consistently across different cultural contexts, yet also in historical specificity. Its ability to "create" a kind of depression/melancholia that can exist reasonably consistently across different cultural contexts is important, because it allows a comparison of different cultural meanings in the different contexts, and that comparison of different cultural meanings forms the focus for this chapter.

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[87] Throughout this chapter, I often refer to "the experience of depression" in the singular. This linguistic construction is in no way intended to erase differences in experience relating to differences in social location.

Specifically, this chapter will establish a conversation between two trade press nonfiction books with opposing views on the meaning of depression: Peter D. Kramer's *Against Depression* and Joshua Wolf Shenk's *Lincoln's Melancholy: How Depression Challenged a President and Fueled His Greatness*.[88] I have chosen these two volumes as representatives not because they are the most typical, but because they are very clear embodiments of their respective theoretical approaches, and make the intellectual architecture easily visible. *Against Depression* represents the medical model of depression as a biological illness, the dominant understanding of depression in both the general public. *Lincoln's Melancholy*, while not necessarily written and certainly not marketed explicitly as part of the explicit disability studies project, is consistent with praxis often found in (physical) disability studies and represents a cultural studies approach that envisions the phenomenon as inherently shaped by its historical, social and cultural contexts.

I have chosen volumes that are easily available in bookstores, are aimed at an educated general public, and were at the time of publication reasonably visible. Both volumes were published by major trade presses (*Against Depression* by Viking and *Lincoln's Melancholy* by Houghton-Mifflin) in 2005, and both have received considerable mainstream media attention in the form of reviews, newspaper articles and author interviews. Kramer's 1993 book, *Listening to Prozac*, was successful and well-known, and he now hosts a weekly public radio show, *The Infinite Mind*.[89] Although Shenk is less well known, Lincoln is a popular subject matter and *Lincoln's*

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[88] Peter D. Kramer, *Against Depression* (New York: Viking, 2005), Joshua Wolf Shenk, *Lincoln's Melancholy: How Depression Challenged a President and Fueled His Greatness* (Boston: Houghton Mifflin Co., 2005).
[89] Peter D. Kramer, *Listening to Prozac: A Psychiatrist Explores Antidepressant Drugs and the Remaking of the Self* (New York: Viking, 1993).

Melancholy has also received considerable mainstream media attention, including the 2005 notable book lists of the *New York Times* and *Washington Post*, a slew of reviews, and an interview on NPR's *All Things Considered*.[90] Shenk has taught writing at Washington College in Chestertown, MD, the New School, and New York University, but is primarily a professional journalist and essayist, whose articles have appeared in *The Atlantic Monthly, Harper's Magazine,* and *The New York Times.* He has also held writing or editing positions at *U.S. News & World Report, The Economist, The Washington Monthly,* and *The New Republic.*

In addition to the potential value of a model for de-pathologizing depression (and mental illness in general), I believe there is also value in examining the circumstances that have led to the question of the judgment of pathology becoming such a central one in characterizing the experience of depression. In part, this question foreshadows my examination in Chapter 5 of the substantial effort invested in delineating the "medical professional" from the "patient" in the context of another phenomenon classed as pathological, Gender Identity Disorder. But this is also a question about what disability studies as a field has chosen to engage, or not. Thus far, disability studies has largely avoided both the subject of madness/mental illness and the conceptual problem of suffering. It may be that this particular gap currently exists because disability studies is such a new field, and scholars may be reluctant to argue amongst each other when there is so much work to do in areas of general consensus. Given the many other obstacles that lay in the path of both the field and

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[90] Joshua Wolf Shenk, *Website Describing Press Coverage of Lincoln's Melancholy.* ([cited June 4 2007]); available from http://www.lincolnsmelancholy.com/press_articles.html.

individual researchers, one could see how a gap could grow as individual researchers repeatedly choose other projects equally necessary but far less contentious in nature.

Additionally, it should be remembered that the nature of madness/mental illness (and in many cases, illness in general) can be quite substantively different from other kinds of disabilities, in terms of its relation to medicine and health care providers, and this may also account for the scarcity of certain kinds of scholarship and activist work. Some people with disabilities can make a meaningful distinction between an *impairment* such as blindness, for example, and the *disability* created by discrimination and physical environments designed for sighted people. Others, however, may find their situations more ambiguous. Certainly, people exist who disagree with a medicalized understanding of depression as a pathology, yet find antidepressants to be useful tools for daily life, as others use reading glasses. Such individuals would obviously find themselves in a more complicated relationship with their health care providers than a rigid politics of demedicalization could encompass, and this may account for why the occasional activist group that attempts to tackle the concept of mental illness as primarily an issue of prejudice and discrimination never lasts very long.

Against Depression

The first of the two books to be examined, *Against Depression,* is used here to represent the basic premise underlying the "medical model" approach, which understands depression as an illness or pathology to be treated.

Against Depression follows Kramer's 1993 bestseller, *Listening to Prozac*, in

which he examines what he terms the "cosmetic psychopharmacology" of Prozac.[91]

After treating patients with Prozac for clinical depression, Kramer began to notice

that in many instances people experienced such dramatic changes in both mood and

personality that he felt these experiences could be accurately described as

"transformations." As Kramer expands the circle of patients treated with Prozac to

include those with sub-clinical conditions (e.g., with signs and symptoms of the same

sort, though not as severe, as those that would qualify for a clinical diagnosis), he

reflects upon the ethical considerations involved in the use of drugs to make

somebody "better than well." He notes:

> Psychotherapeutic medication is both instructive and problematic for a
> liberal society. It leads us to focus on biological difference, whereas
> for years our culture has chosen to biologically based characteristics
> that, in Carl Degler's words, 'might serve as an obstacle to an
> individual's self-realization.' Emphasis on temperament could be
> divisive and oppressive, if a culture too strongly favors one
> temperament over another—traditionally masculine over traditionally
> feminine traits, for example. Or awareness of temperament can be
> inspiring, leading perhaps to efforts to minimize psychological harm to
> children, or to foster a social environment welcoming to
> constitutionally diverse adults.[92]

Although most of Kramer's concerns about the use of Prozac to effect personality

changes have to do with the potential to rob humanity of what is "uniquely human:

anxiety, guilt, shame, grief, self-consciousness," he concludes that constitutional

differences have a biological base.[93]

Kramer opens his 2005 *Against Depression* by noting the exponential growth

of depression memoirs since the publication of *Listening to Prozac* in 1993. As a

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[91] Kramer, *Against Depression.*
[92] Ibid., 298.
[93] Ibid., 299.

popular authority on the subject, Kramer is often asked to read the manuscripts and is

impressed by the variety of individuals who have penned such "autopathographies."

Kramer notes, "There were accounts by sexually depleted depressives, promiscuous

depressives, urban single mothers, small-town family men, femmes fatales, gay

lotharios, celebrities, journalists, ministers, and psychologists."[94] Although pleased,

as a psychiatrist, "to see a mental illness shed some of its stigma," Kramer notices

that "despite the superficial variety, the memoirs of depression struck me as

surprisingly uniform."

Although the accounts would nominally frame depression as an illness and

advise depressed readers to seek treatment, he also noticed a tendency to attribute an

ennobling character to depression, "as if affliction with depression might after all be

more enriching than, say, a painful and discouraging encounter with kidney failure."[95]

He acknowledges that different perspectives on depression do allow placing a

positive value on the experience, (such as a "left wing" perspective which views it as

a moral distancing from the culture, "minimalism in contrast to mercantilism," or a

"right wing" perspective that views it as a character-building enterprise to tough it

out), but is disturbed that he also sees traces of a positive valuation of depression

creep into memoirs and professional thought. The conflict seemed particularly

obvious when he attended a professional conference and listened to a psychoanalyst's

presentation:

> He described his treatment of a middle-aged patient who had come
> for help with depression that had arisen out of the blue. The main
> features were leaden paralysis, obsessive self-doubt, and low self-
> regard. The analyst had the impression that for the whole of his life,

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[94] Ibid., 5.
[95] Ibid.

the patient had been self-centered, blandly confident, and lacking in insight. So the doctor allowed the episode to continue. He hoped that the loss of confidence in particular would motivate the patient to engage in a psychotherapy that would make inroads against the narcissism.

I might once have considered this presentation unremarkable—an example of a psychoanalyst 'optimizing' a patient's level of discomfort in the service of a process of self-exploration. But now—with my own patients' mood disorders so clearly in mind—I was seething. Is there another disease with which a doctor would make this choice? If a patient had cancer or diabetes and seemed psychologically the better for it—humbled, taken down a notch—still, we would treat the condition vigorously. Nor would a comparable argument, to let the syndrome be, arise in a discussion of other mental illnesses, such as anorexia or paranoia.

I found myself thinking about the particulars of depression in this patient, the one who turned to the psychoanalyst for help. What do we make of its unexplained appearance at midlife in a previously confident man? Perhaps the mood disorder resulted from a specific medical condition, outside the brain. Anemia can cause depression. If it did here, would the analyst tolerate a blood disorder, to provide the benefit of low self-worth? If the patient recovered spontaneously, might the doctor recommend therapeutic bloodletting? The thought was an angry one, I knew but I was familiar enough with the brutality of depression to feel riled by the pride the speaker took in his choice, to let the patient flounder.[96]

This anecdote effectively captures Kramer's central argument in a nutshell: any lingering ideas that depression is an indicator of special sensitivity or provides particular insight should be ferreted out and obliterated, because depression is a bodily disease like any other, and should be treated as such.

Kramer divides the book into three sections, "What It Is to Us," "What It Is," and "What it Will Be," to emphasize the disjuncture he sees between cultural understandings of depression and scientific evidence, and emphasizing a "modernist" sort of certainty that there is a distinct and absolute difference between what we think

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[96] Ibid., 8-9. I, too, find myself seething, but on the grounds that a doctor—any doctor, treating any kind of condition—would feel so entitled to decide what is best for a patient/client on the basis of his/her own ideas of an ideal psychological state, and that Kramer would find *that* unremarkable.

depression is and what it *really* is. However, Kramer's argument doesn't correspond

to this structure past the major divisions, and chapters appear to be arranged more

with an eye to rhythm and illustration than structure per se. As a result, my

examination of his argument will remain at the level of the major structure.

Kramer contends that "What It Is to Us" is a virtue born of necessity. Two

stories form the core argument of the section. One centers on his patient Margaret,

whom he treated for depression with medication and therapy. Her therapy explored

personal relationships and career issues with which she expressed dissatisfaction or

unhappiness, in accordance with his training in "depth therapies" or resolving

unconscious conflicts.[97] Margaret suddenly (and somewhat inexplicably) emerged

from her depression, and, as a healthy individual, was a person quite unlike the one

Kramer knew when she was depressed. The feelings she reported during the therapy

were not really *hers*, she asserted; they belonged to the *illness*, and they were largely

foreign to the healthy Margaret, who chastised Kramer for not recognizing the

difference between Margaret's "real" feelings and the depression.   Kramer takes

from this a lesson to be careful in assuming the significance of negative feelings.

> Superficially, depression sometimes resembles passion, strong
> emotion that stands in opposition to the corrupt world. This
> impression can arise from the solidity of the symptoms; depression
> looks like a sit-down strike. Or it can arise from depressives'
> tendency to act impulsively. Who would puncture her arms but a woman of
> passion? In truth, the puncturing is an attempt to feel anything at all.
> Depression is passion's absence.
> Simply to name emotions—you feel such guilt—is to lend them
> legitimacy. With Margaret, in employing the most basic elements of
> therapy—empathy, tentative interpretation, the search for meaning—I
> had in effect sided with the illness and against the person Margaret
> was in health. The feelings I had underscored for Margaret were
> foreign to her. She experienced them, she reported them, but there is a

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[97] Ibid., 14-29.

sense in which they were not hers.

I don't mean to exaggerate my doubts over Margaret's treatment. The episode of depression we worked on together ended more quickly, and with less destruction in its wake, than the one that preceded it. I was open to the possibility that I had done Margaret some good. I am pointing to one of many experiences that convinced me, cumulatively, on an intimate basis, that depression is best understood as disease, for good and all.[98]

The second story concerns a question he was oftenasked, in a variety of contexts and with different examples—"What if Prozac had been available in Van Gogh's time? Or Kierkegaard's?" In response, Kramer reverses the question: "So? What if it had?" He argues that "depth" and "depression" have become so closely associated in the public imagination that it is difficult for people to imagine creativity without despair, but that this represents a failure in imagination rather than an inseparable bond. As a consequence, he argues, depression can have a certain "charm," and recounts the stories of several patients for whom depression represented the allure and possibility of the tortured artist, or the mystery of a lover pursued but not quite caught. Using the example of Sisyphus, Kramer contends that if there is to be heroism found in occasions of suffering, it is to be found "because he faces endless futility without succumbing to despair."

In the second section, "What It Is," Kramer argues that recent research supports a view of depression as a physical illness. He summarizes research that observes "depression-associated abnormalities in the hippocampus and the prefrontal cortex of the brain. Those regions, along with the amygdala and some others, form a circuit that appears to govern the core symptoms of depression, the sadness,

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[98] Ibid., 27.

hopelessness, lack of energy, and difficulty with memory and concentration."[99]

Kramer draws from the work of a variety of researchers to address questions of

environmental factors and genetic predisposition—e.g., why not everyone who

survives a terrible trauma becomes depressed, and why people become depressed who

have not suffered in a significant way. Whatever the cause or causes, he sees the

result as being about the same: a problem with a "stuck switch" that leaves an

individual producing excess stress hormones that cumulatively damage the brain and

also progressively slow repair functions:

> …chronic stress leads to the production of stress hormones. Stress
> hormones damage hippocampal (and other) brain cells, isolating them
> and pushing them to the brink of destruction. Further stressors push
> the cells over the edge. As damage progresses, feedback systems fail.
> Even minor adversity then causes the overproduction of stress
> hormones. What would otherwise be limited injuries extend, in the
> presence of stress hormones, into substantial brain damage. The
> hormones also dampen repair and regeneration functions, so that
> temporary injuries become permanent.[100]

Although he acknowledges that the scientific understanding of depression-as-illness

is still incomplete and as a work in progress will likely change over time, the

cumulative research is sufficiently compelling to him to close the conceptual gap

between depressive symptoms and physical illness, at least in practical terms.

The final section, "What It Will Be," reimagines the world when depression

has been accepted exclusively as a disease, and as a disease for which treatment

should always be sought. There is but a single argument advanced, and it is an

extension of his first: as the existential intrigue and allure of the classical melancholia

are narrowed down to and replaced with an understanding of depression as a disease,

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[99] Ibid., 115.
[100] Ibid., 118.

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society will have to reevaluate its understanding of insight and of art. The

understanding of what constitutes a valuable or insightful discomfort will alter.

> If we could treat depression reliably, we would have different artists, different subjects, different stories, different needs, different tastes. The details—what sort of art and artists—are matters for science fiction. Which is what the whole of this speculation amounts to—fantasy intended finally to provide a perspective on the present. I mean mainly to ask why we would not let go of melancholy, and trust ourselves with responsive minds and resilient brains.
> If this fantasy, substituting resilience for depression, remains eerie, it may be because the terms of the discussion retain their complex connotations. We persist in asking: Seeing cruelty, suffering, and death, should a person be depressed? There are circumstances, like the Holocaust, in which depression might seem *justified* universally, for every participant or observer. Awareness of the ubiquity of horror—awareness of inhumanity as an aspect of humanity—is the modern condition, our condition.[101]

To Kramer, the proper conclusion is obvious if not easy: accept depression as no

more or less than any other illness and seek to eradicate it. Doing so, he argues,

carries but one risk that isn't even really a risk: it might well cost us artistic insight as

we have known it, but offers the potential of a better form of insight, borne of clearer

thinking.

Against Depression has a simple aim: to push depression onto firmer territory

as a physical pathology, thereby ensuring more consistent and aggressive treatment

and alleviating needless suffering. To Kramer, the problem is that depression is not

understood as either pathological or physical *enough*—as an idea, depression remains

stubbornly and tragically lost in a murky swampland between Culture and Science,

unable to be seen clearly as an illness because of the lingering associations of

melancholy and artistic insight. Situating depression squarely in a more traditional

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[101] Ibid., 287.

notion of pathology (as demonstrable physical illness) would clearly suggest an expanded role in public health efforts and access to certain products and services.

Such an approach would likely appeal to those in disability activism who do not contest the legitimacy of the assignment of pathology to the experience of depression, and conceptualize the appropriate "disability angle" as advocating for greater access to mental health care services. This approach would position consumers of mental health services and service providers as allies on the same side in the "battle" to "conquer the illness," to use the most prevalent metaphor. Although this position is not entirely unheard of in disability circles and the inner sanctum of the disability studies project, it's more consistent with the dominant, mainstream perspectives of conventional medicine and organizations driven by consumers' family members (e.g., the National Alliance on Mental Illness) rather than those driven by consumers. Such arguments are based in large part on the same theoretical assumptions that underlie Kramer's own argument, the most important of which are (1) a modernist understanding of the existence of a universally valid definition and taxonomy of depression; (2) an understanding of reliability in the process by which knowledge about depression is "discovered;" and (3) a kind of related certainty about the valuation of the experience as consistently and reliably pathological.

Perspectives more consistent with disability studies would necessarily problematize all three assumptions. Before examining these perspectives in detail, however, it is important to bear in mind that medical knowledge is inescapably a work in progress. Certainly there are many (important) things that medicine does not yet know about depression, yet in practice, doctors must necessarily make do with the

knowledge available. Thus, there is a difference between what should constitute

proof in a theoretical sense, and medical knowledge in a practical sense. At best, the

present understanding of depression-as-pathology constitutes medical knowledge in a

practical sense, and is largely defined in normative cultural terms. There is presently

no blood test, for example, that can diagnose "depression" as a discrete entity in the

same way that diabetes or cancer can be diagnosed. As such, the diagnosis is based

on what one might call contextualized behavioral or experiential criteria. Because

obviously most people experience the conditions described below at some time in

their lives, the point at which a time of distress and unhappiness is transformed into a

pathological status is necessarily constructed through the *context* of the criteria:

- The conditions of depression must occur outside the circumstances when a
  person is *normally expected* to experience these conditions (i.e., in
  bereavement)
- The conditions of depression must occur for a longer period or with greater
  severity than is *normally expected* in periods of distress or unhappiness.

In other words, the point at which the conditions of depression become "symptoms"

is the point at which they move beyond what is normally expected. The pathology of

depression—at least in practical, diagnostic terms—is constructed around an implicit

understanding of what is normal.

Criteria for Major Depressive Episode

A. Five (or more) of the following symptoms have been present during the same 2-week period and represent a change from previous functioning; at least one of the symptoms is either (1) depressed mood or (2) loss of interest or pleasure.
   Note: Do not include symptoms that are clearly due to a general medical condition, or mood-incongruent delusions or hallucinations.
   - depressed mood most of the day, nearly every day, as indicated by either subjective report (e.g., feels sad or empty) or observation made by others (e.g., appears tearful). Note: in children and adolescents, can be irritable mood.
   - markedly diminished interest or pleasure in all, or almost all, activities most of the day, nearly every day (as indicated by either subjective account or observation made by others)
   - significant weight loss when not dieting or weight gain (e.g., a change of more than 5% of body weight in a month), or decrease or increase in appetite nearly every day. Note: in children, consider failure to make expected weight gains.
   - insomnia or hypersomnia nearly every day.
   - psychomotor agitation or retardation nearly every day (observable by others, not merely subjective feelings of restlessness or being slowed down)
   - fatigue or loss of energy nearly every day
   - feelings of worthlessness or excessive or inappropriate guilt (which may be delusional) nearly every day (not merely self-reproach or guilt about being sick)
   - diminished ability to think or concentrate, or indecisiveness, nearly every day (either by subjective account or as observed by others)
   - recurrent thoughts of death (not just fear of dying) recurrent suicidal ideation without a specific plan, or a suicide attempt or a specific plan for committing suicide
B. The symptoms do not meet criteria for a Mixed Episode.
C. The symptoms cause clinically significant distress or impairment in social, occupational, or other important areas of functioning.
D. The symptoms are not due to the direct physiological effects of a substance (e.g., a drug of abuse, a medication) or a general medical condition (e.g., hypothyroidism).
E. The symptoms are not better accounted for by Bereavement, i.e., after the loss of a loved one, the symptoms persist for longer than 2 months or are characterized by marked functional impairment, morbid preoccupation with worthlessness, suicidal ideation, psychotic symptoms, or psychomotor retardation.[102]

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[102] American Psychiatric Association, *Diagnostic and Statistical Manual of Mental Disorders (DSM-IV-TR)*, 356.

The classic critique of the validity of a scientific concept of depression (or any other "mental illness") as a biological illness is Thomas Szasz' *The Myth of Mental Illness: Foundations of a Theory of Personal Conduct*, originally published in 1961.[103] Szasz, a renegade doctor with strong personal convictions about forced treatment and the proper conceptualization of madness/mental illness in general, argued that the concept of mental illness, though perhaps intended to be compassionate, is inadequate from a scientific perspective because of the lack of appropriate physiological evidence and the obvious socio-cultural investments in the formulation of the diagnostic criteria. Instead, Szasz argued that "illness" as a category must remain something rooted in the body, i.e., as a *physical* pathology.

> It is important to understand clearly that modern psychiatry—and the identification of new psychiatric diseases—began not by identifying such diseases by means of the established methods of pathology, but by creating a new criterion of what constitutes disease: to the established criterion of detectable alteration of bodily structure was now added the fresh criterion of bodily function; and as the former was detected by observing a patient's body, so the latter was detected by observing his behavior. This is how and why conversion hysteria became the prototype of this new class of diseases—appropriately named "mental" to distinguish them from those that are "organic," and appropriately called also "functional" in contrast to those that are "structural." Thus, whereas in modern medicine new diseases were discovered, in modern psychiatry new diseases were invented. Paresis was proved to be a disease, hysteria was declared to be one.[104]

Szasz argued that to talk of "mental illness" was to confuse *brain* (which could become diseased) and *mind* (which could not). Thoughts and actions thus could not be understood to be themselves pathological. Not surprisingly, Szasz became something of a pariah in mainstream mental health care and a hero to antipsychiatry activists. Psychiatrists (including Kramer) are quick to position him as a radical

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[103] Szasz, *The Myth of Mental Illness: Foundations of a Theory of Personal Conduct*.
[104] Ibid., 39.

quack, yet since the publication of *The Myth of Mental Illness* in 1961, biological

psychiatry has unquestionably become the dominant approach in the field of

psychiatry. (Notably, the critique has rankled mainstream psychiatry enough that

Kramer still felt the need to argue the point more than fifty years later.)[105]

Szasz's argument in *The Myth of Mental Illness* foreshadows much later work

done on the process of medical classification as a tool of knowledge and power.[106]

Szasz identified the construction of the category of "mental illness" as beginning in

Jean-Martin Charcot's conceptualization of "hysteria" as a neurological illness. He

contended that in its 19th century context, a diagnosis of "hysteria" (as an illness

producing symptoms out of the patient's control) probably provided a more

hospitable future for the individual in question than an accusation of malingering

(willful refusal to work) and was thus useful as a humanitarian social reform. By the

mid-20th century, he contends, such a conceptualization had outlived its humanitarian

usefulness, and had become instead a compromise of scientific integrity and a

potential infringement of civil rights by a psychiatric establishment interested in

protecting its own importance. Szasz positions the establishment of hysteria as a

variation of the Emperor's New Clothes, so that to ask "Who is mentally ill?" will be

answered by "Those who are confined in mental hospitals or who consult

psychiatrists in their private offices." [107]

Questions of autonomy and agency are at the heart of Szasz's objections to the

concept of a behaviorally-based mental illness. Szasz acknowledged that while

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[105] Kramer, *Against Depression*, 49-51.
[106] Bowker and Star, *Sorting Things Out: Classification and Its Consequences.*
[107] Szasz, *The Myth of Mental Illness: Foundations of a Theory of Personal Conduct*, xiii.

It might seem, at first glance, that to advocate, and indeed to insist, that an unhappy or troubled person is sick—and that he is sick in exactly the same sense and way in which a person suffering from cancer is sick—is humane and well-intentioned, as it aims to bestow upon such a person the dignity of suffering from a genuine illness over which he has no control. However, there is a hidden weight attached to this tactic which pulls the person back into the same sort of disrepute from which this semantic and social reclassification was intended to rescue him. Indeed, labeling individuals displaying or disabled by problems in living as "mentally ill" has only impeded and retarded the recognition of the essentially moral and political nature of the phenomena to which psychiatrists address themselves.[108]

Szasz referred, of course, to the fact that if pathology was to be understood as behavioral, then behavior or thought that was unproblematic to oneself could be conceptualized as pathological and "treated" involuntarily, thereby compromising the ideal of objectivity in medical science and making diagnosis and pathology a tool for "social control."

Just as it is possible for a person to define himself as sick without having a bodily illness, so it is also possible for a physician to define as "sick" a person who feels perfectly well and wants no medical help, and then act as if he were a therapist trying to cure his "patient's" disease. …psychiatric help sought by the client stands in the same relation to psychiatric intervention imposed on him as religious beliefs voluntarily professed stand to such beliefs imposed by force."[109]

The Myth of Mental Illness is not entirely comfortable reading for the contemporary disability studies scholar or advocate, nor Szasz a very charming spokesman for those who might seek to position anti-psychiatry advocacy in alliance with the disability rights movement. Szasz's relentlessly libertarian leanings and occasional ventures into monolithic commentaries on "the poor" and so forth make him a very strange and prickly bedfellow; nevertheless, his enthusiastic and idiosyncratic critique of a socially-driven conceptualization of pathology and its

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[108] Ibid., 24-25.
[109] Ibid., xi.

application as a political tool is entirely consistent with the kinds of arguments that scholars in disability studies would later employ in completely different theoretical frameworks.

Whereas Szasz focused on situations in which authority and power in relationship to the conception of illness was tangible and easily identifiable, such as forced psychiatric treatment, other critics have examined more indirect ways in which conceptions of illness serve to reiterate and reinforce more subtle or indirect cultural hierarchies.[110] As Kramer noted, while clearly depression is now predominantly understood as an illness, it is not completely assimilated as such. The observation that depression carries lingering associations with insight, intelligence, sensitivity, and creativity echoes Susan Sontag's 1977 essay *Illness as Metaphor*, in which she argues that certain illnesses function as major cultural metaphors and become inscribed on the bodies of those so afflicted—e.g., tuberculosis as a 19th century metaphor for sensitivity and passion.[111] As Kramer notes, depression continues to retain a cultural meaning, something that makes it different from high blood pressure or heart disease. T.M. Luhrmann also repeatedly returns to the cultural meanings of suffering and mental illnesses in her 2000 ethnographic study of medical residents in psychiatry, identifying the sorting out of these issues as key processes in the residents' enculturation as psychiatrists.[112] Yet the relationship of depression with insight, sensitivity and creativity isn't only metaphorical and abstract, it is also literal,

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[110] In cultural studies, this includes the work of Michel Foucault and others. Foucault, *Madness and Civilization: A History of Insanity in the Age of Reason*. However, despite the monumental impact of *Madness and Civilization* in the humanities and the social sciences, understandings of the production of knowledge and its implementations as primarily political in nature have not penetrated thinking in medicine to any significant degree.

[111] Sontag, *Illness as Metaphor; and, Aids and Its Metaphors*.

[112] T. M. Luhrmann, *Of Two Minds: The Growing Disorder in American Psychiatry* (New York: Knopf, 2000).

as illustrated by continuing medical fascination with the association, such as Kay

Redfield Jamison's 1993 *Touched with Fire: Manic-Depressive Illness and the*

Artistic Temperament.[113]

One of the frequent criticisms of the way that medical knowledge is produced

and deployed is the way in which non-"professional" perspectives (e.g., patient

perspectives) are eclipsed by the authoritative observations and conclusions of the

doctor, most typically in the way that case studies are produced and written up for

medical journals, but also (as will be discussed in Chapter Five) in the issuing of

diagnoses and "orders" for treatment. *Against Depression* echoes these authoritarian

forms, as the lay audience purchasing a trade nonfiction book is expecting to be

instructed by an expert. Because madness/mental illness resides at the more visibly

inequitable end of the unreliable patient/authoritative doctor continuum, Kramer can

reasonably expect to "correct" his patient's viewpoints and point out errors in their

perceptions without challenge. He does this in a politely assured way, confident that

not only is there a "right" answer, but also that he is the one in possession of it, which

he has almost by definition as a result of the diagnostic process. In fact, in the

example of Margaret, Kramer ultimately faults himself for giving *too much*

legitimacy to her stated feelings, because those feelings were actually a product of the

illness and as Kramer put it, "there is a sense in which they were not hers." The

healthy Margaret, Kramer argues, did not have the same kinds of emotions and

difficulties as the ill Margaret, for whom a "disease had robbed her of feelings that

[113]Kay R. Jamison, *Touched with Fire: Manic-Depressive Illness and the Artistic Temperament* (New York: Free Press, 1993).

were properly hers and imposed alternative ones."[114] Of course, his understanding of

Margaret's stated feelings as being part of the illness and not part of a "real

Margaret," would justify the traditional disregard for patients' perspectives,

particularly as Kramer describes how upon recovery, Margaret seemed quite distant

from some of the dark feelings she had previously experienced, such as her

ambivalence and doubts about her children.

This conflict presents an interesting question about self-interest, accuracy in

representation and the production of knowledge. Interestingly, in this example, both

Kramer and Margaret have explicit investments in defining the state of illness as

producing an unreliable narrator, which complicates the somewhat simplistic

insistence of the disability studies/disability rights perspective on the epistemological

supremacy of the first-person narrative. If Margaret is in one instance a reliable

narrator of her feelings and in another she is not, the explanation of her depression as

an illness that compromised her perception is certainly one way of reconciling the

discrepancies, though the potential for exploitation within this philosophical

framework is obvious. Such an explanation would appear to be even stronger if

Margaret herself seconded the assessment.[115] However, because the feelings that

Margaret articulated while depressed were ones with a considerable social penalty

(e.g., mothers are not supposed to doubt their love for their children), it could also be

seen as necessary for the recovered Margaret to claim an absolute separation between

the "ill" and "healthy" Margarets. Such a distancing is, in fact, the only way that the

recovered Margaret can maintain both the integrity of her words and social

[114] Kramer, *Against Depression*, 25.
[115] Kramer hints that Margaret does characterize her feelings in these terms, although of course it is Kramer's book and not Margaret's.

respectability in her role as a mother, as these would be in direct conflict without the conceptual circumnavigation of "illness." An alternate disability studies viewpoint might suggest that this position represents not Margaret's "true" feelings but rather represents her agency and navigation to the strongest possible position within the context of an inherent imbalance of power.

In this example, both Kramer and Margaret use the presumed unreliability of the state of illness as a fixed, central feature around which they construct their own stories of "the truth." Disability studies, even in its infancy, is accustomed to seeking and labeling relative positions of cultural power, but in this example to simply identify the more powerful cultural perspective or even Margaret's agency and means of resistance is insufficient to understand the dynamic of representation. What this example might suggest for disability studies is a consideration of the possible usefulness of looking instead for "boundary objects" (such as the unreliability of illness) as fixed, shared points of cultural knowledge, around which multiple stories can be woven like ribbons around a maypole.[116] The actual form and scope of Margaret's agency does not become clear until the multiple constraints in representation are illustrated, e.g., that Kramer speaks for her, and that she is bound by other social constraints, such as constructions of motherhood.

Lincoln's Melancholy

Lincoln's Melancholy, in contrast, is presented here as an alternative to the idea that depression is exclusively a problem to be fixed, and to illustrate what an

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[116] Susan Leigh Star and James R. Griesemer, "Institutional Ecology, `Translations' and Boundary Objects: Amateurs and Professionals in Berkeley's Museum of Vertebrate Zoology, 1907-39," *Social Studies of Science* 19, no. 3 (1989).

effort to depathologize the experience of depression could look like. Shenk contends that *Lincoln's Melancholy* is not just a psychobiography investigating a historical figure to determine if he or she were "really" insane, in the manner of the popular film *The Madness of King George*.[117] Instead, Shenk says the "goal has been to see what we can learn about Lincoln by looking at him through the lens of his melancholy, and to see what we can learn about melancholy by looking at it in light of Lincoln's experience."[118]

Shenk's reconceptualization of depression is contextual and postmodern, resulting from a working assumption that the experiences of depression and melancholy were "essentially" the same thing but also allowing that the two conceptualizations of the experience are different and historically specific.[119] While acknowledging that Lincoln's chronic depression caused him considerable suffering, Shenk's reading takes a more utilitarian and holistic approach to the meaning of the phenomenon. Even as the likelihood of the existence of a biological predisposition is noted, depression is portrayed more as a kind of lifelong pressure which both caused Lincoln to develop particular coping skills and which shaped his thinking in particular ways. Echoing Avery Gordon's concepts of haunting and complex personhood, Shenk presents depression as a force that acted upon Lincoln in complicated ways, the compound effects of which can't be accurately represented in a scheme which

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[117] Nicholas Hytner, in *The Madness of King George* (UK: 1994). The movie investigates the peculiar behaviors of King George III of England and ultimately "exonerates" him from charges of madness by revealing that he had a condition called porphyria, which can produce erratic behavior.
[118] Shenk, *Lincoln's Melancholy: How Depression Challenged a President and Fueled His Greatness*, 7.
[119] Far from being a newly "discovered" feature of Lincoln's life, Shenk argues that Lincoln's melancholy was widely known and remarked upon by both Lincoln's contemporaries and Lincoln himself. That this feature had largely disappeared from the public imagination Shenk attributes to the prediliction of historians publishing in the 1940s and 1950s to present Lincoln as a heroic figure consistent with ideals of manliness in the mid-20th century.

necessitates an understanding of the experience as strictly "healthy" or

"pathological."

Lincoln's Melancholy is organized more or less chronologically in terms of

Lincoln's life.   Shenk's fundamental theoretical argument is that the experience of

depression is too complicated to be encapsulated by a diagnosis of pathology.

Unfortunately, the chronological structure (and no doubt also the constraints of the

nonfiction trade press perceived to be seeking a yes/no answer to the question of

whether he was "really" depressed) causes the central argument to be articulated

somewhat less explicitly than it might be under another organizational scheme.

Shenk subdivides his argument into three parts, quoted here as they also correspond

to the major sections of the book:

> As I worked on the book, I heard three main questions about
> Lincoln's melancholy. First, was it "clinical depression"? Part One
> investigates how Lincoln's melancholy manifested itself in his early
> life and young manhood, and how it fits—and challenges—the
> diagnostic categories of modern psychiatry. Second, what kind of
> treatment did he undergo? Part Two shows what Lincoln did in
> response to his melancholy, the strategies he used to heal and help
> himself. Third, in what way did the melancholy contribute to his work
> as a public figure? Part Three addresses how Lincoln's melancholy
> became entwined with his mature character, ideas and actions.[120]

As indicated above, Part One describes Lincoln's life as a young man and

addresses immediately the predictable question of a diagnosis of depression and the

related "nature/nurture" issues. The first chapter, "'The Community Said He was

Crazy'" narrates the maturation of a sensitive, reflective child into an emotionally

intense young man who alternated between good-natured storytelling and

introspective solitude. Noting that insanity clearly ran in the family in a way

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[120] Shenk, *Lincoln's Melancholy: How Depression Challenged a President and Fueled His Greatness*,
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consistent with today's notions of biological predisposition, Shenk also recounts in turn the deaths of Lincoln's mother, then Ann Rutledge (to whom Lincoln was rumored to have been romantically attached), and finally his sister. However, he is also careful to contextualize death as appearing largely unremarkable to Lincoln's contemporaries and not necessarily an obvious cause of Lincoln's first major episode of melancholic despair in 1835. Around this time, Lincoln began to speak of suicide frequently enough that concerned friends conspired to supervise and restrain him for fear he would harm himself.[121] Shenk thus answers the question of a diagnosis of depression with a clear "yes," but uses that as a starting point for a reframing of the question.

The second chapter, "A Fearful Gift," distinguishes the current understanding of depression from the early-mid nineteenth century understanding of melancholy as a temperament or feature of character on a kind of continuum with ordinary sadness and sensitivity. This unquestionably Romantic conception of melancholy was linked, à la Sontag, to creativity, intelligence and refinement. A melancholic temperament was "characterized by not only gloominess, asceticism, and misanthropy, but also deep reflection, perseverance and great energy of action. …To be grave and sensitive—to feel acutely the agony and sweat of the human spirit—was admired, even glorified."[122] (The title, "A Fearful Gift," is suggestive of another tactic that disability studies might take in intentionally reinventing the meaning of mental illness, by portraying it as a kind of difference that can be extraordinarily useful in the proper circumstances, something along the lines of the superhero "mutants" of the X-

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[121] Ibid., 19.
[122] Ibid.

Men comics and films.) Shenk suggests that Lincoln's sensitivity and temperament often inspired sympathy and protectiveness in other people, who went out of their way to help him financially and otherwise.[123] One example offered is the familiar anecdote of the young Lincoln entering Joshua Speed's general store and inquiring about the price of fitting out a bed. Upon seeing Lincoln's dismay at the price and his reluctance to purchase on credit, Speed apparently offered to share his own rooms upstairs, a gesture which initiated a particularly important friendship between the two young men.

In a somewhat similar vein, Chapter Three, "The Most Miserable Man Living" examines what Shenk characterizes as Lincoln's second major bout with melancholic despair, when he again inspired great concern and worry for his well-being. Shenk devotes considerable energy to examining the potential contributing factors to this second breakdown, which he believes is more likely the result of stress in Lincoln's political career combined with the difficulties of a love triangle rather than simply a breakup with Mary Todd, as has been frequently supposed. Lincoln sought medical help this time, and was diagnosed with "hypochondriasis," a disease which Shenk describes as "a form of melancholia, less severe than others, though still serious enough to demand medical attention, lest the patient succumb to insanity or suicide."[124] As the disease was thought to be associated with too much black bile, typical treatments included bleeding, purgatives, mustard rubs, mercury (or arsenic or strychnine), and cold baths. Shenk asserts that this period was a turning point for Lincoln, in which he again seriously contemplated death and his purpose in life. He

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[123] Ibid., 28-29.
[124] Ibid., 58.

retired to Joshua Speed's luxurious family estate, where he spent five weeks recuperating. Shenk tells that upon leaving the estate, Lincoln encountered a group of slaves in chains, whose good cheer impressed him enough to write to Speed's sister about the incident in a letter famous as his first commentary about slavery. Shenk, however, contends that the letter needs to be placed in context with Lincoln's own misery, and became fuel for a rethinking of his life.

In Part Two, Shenk tells a story of coping and adapting to persistent difficulties, e.g., what Lincoln did to help himself in the face of chronic depression. "A Self-Made Man" sets the context for Lincoln's work in that arena, placing him in a context in which "self-made" was an entirely new concept. Previously, Shenk argues, people were effectively "made," economically and socially speaking, by the circumstances of birth, and the idea of being limited only by one's own imagination and character appealed greatly to young men like Lincoln, to whom it seemed that a whole new world was opening up. However, the new emphasis on individual qualities of character simultaneously created the possibility of being a failure, a born loser. Moreover, Shenk contends, this social mobility was understood to make people who disturbed the established order vulnerable to insanity, as they might be subjecting themselves to stresses for which they did not have the appropriate constitution. Shenk states, "The crucial mental health question in Lincoln's time was whether a person was sane or not. On the right side of that line, one had considerable latitude for expressions of distress. On the wrong side, one could be cast off from civilized society."[125] Certainly, according to Shenk's narrative, Lincoln's socio-

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[125]Ibid., 79.

economic status and periods of profound despair would have raised the question in his and others' minds.

Lincoln is presented as having known how to make good use of what ambiguity was available in the understanding of his own melancholy, and is described as coming to develop a view of his experience that ultimately blended features of multiple schools of thought. In Chapter Five, "A Misfortune, Not a Fault," Shenk describes Lincoln as rejecting a popular view, heavily influenced by Christianity, of pronounced melancholy as being sinful in nature and closely related to sloth. Shenk contends that when Lincoln left rural Illinois, he left the hellfire and damnation of the Baptist church as well, and instead cut his own path through both the Second Great Awakening and a concurrent maelstrom of ideas about secularism and reason. Shenk envisions these great social and philosophical questions of his day as intersecting with events in Lincoln's personal life. In 1842, Lincoln's friend Joshua Speed traveled to Louisville to seek a bride, and shortly thereafter became deeply distressed and depressed himself. Shenk describes Lincoln as seeking to provide support to Speed, and through his letters revealing what Shenk understands to be a personal philosophy or conclusion about the nature of depression. In a letter designed to be read by Speed in a moment of low mood, Lincoln explains his prediction of Speed's depression as a result of three special causes in addition to a general one, namely that speed is "naturally of nervous temperament." Shenk quotes the additional "special causes":

> The first special cause is your exposure to bad weather on your
> journey, which my experience clearly proves to be verry severe on
> defective nerves.
> The second is, the absence of all business and conversation of friends,
> which might divert your mind, and give it occasional rest from that

intensity of thought, which will some times wear the sweetest idea thread-bare and turn it to the bitterness of death.
The third is the rapid and near approach of that crisis on which all your thoughts and feelings concentrate.[126]

Shenk argues that this letter shows that Lincoln understood melancholy as something to which a person of nervous temperament was vulnerable when aggravating circumstances arose, such as bad weather or social conditions. Shenk contends that Lincoln's characterization of Speed as "nervous" rather than "melancholy" suggests that Lincoln kept reasonably current with scientific thinking. Moreover, he argues, the substance of Lincoln's message also reflected the kernels of a kind of self-help movement that moved beyond either traditional medicine or Christianity to seek answers in new explanations of experience which emphasized management to whatever degree possible the forces that were beyond one's personal control. Shenk also describes Lincoln as responding positively to approaches to temperance, for instance, that characterized drunkenness not as an unpardonable sin, but rather as a misfortune that demanded compassion from others, and that such approaches influenced Lincoln's thinking to produce in him a similar conclusion about melancholy. Shenk relates an incident in which Speed's mother presented Lincoln with a Bible, encouraging him to seek comfort within its covers, and suggests that although Lincoln always seemed to find his own capacity for faith somewhat lacking, that the sentiments of resignation in the face of what one cannot control, as well as a recognition that one's emotions can betray one's thoughts have had a lasting impact in Lincoln's decisionmaking processes, including his decision to marry Mary Todd.

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[126] Ibid., 85. Speed quotes a letter from Lincoln to Joshua Speed on January 30, 1842, available in Abraham Lincoln, Roy P. Basler, and IL.) Abraham Lincoln Association (Springfield, *Collected Works. The Abraham Lincoln Association, Springfield, Illinois*, vol. 1 (New Brunswick, NJ: Rutgers University Press, 1953), 165.

In Chapter Six, "The Reign of Reason," Shenk investigates what he sees as some of the effects of Lincoln's careful examination of the meaning of his melancholy. Though Lincoln had long preached a triumph of reason over the passions, as a young man his actions had been far more often directed by emotion and impulse than by intellectual calculation. Shenk identifies Lincoln's decision to marry as a turning point, placing it in its mid-19th century context as a point at which a man came to bear much greater responsibility with the obligation to provide for a wife and children. In Lincoln's case, Shenk portrays the event as also marking a change in the nature of his melancholy, in which intense periods of abject misery gave way to a dutiful acceptance of life's difficulties. As Shenk notes, "One crucial distinction between major depression and chronic depression is that, in the latter, one largely ceases to howl in protest that the world is hard or painful. Rather, one becomes accustomed to it, expecting such hardship and greeting it with, at best, a stoic determination."[127] Lincoln likewise assumed an attitude of responsibility and duty, focusing the best part of his energies on his work. Noting that chronic depressives can often become extremely devoted to work (in contrast to the lethargy frequently associated with periodic major depression), Shenk argues that Lincoln withdrew from other aspects of his life so that political work became the dominant feature, and simultaneously directed his energies to his work because it was one arena in which he was successful.

Despite Lincoln's successes in politics, he expressed little joy in his achievements and perceived the world as difficult and painful even under the best of

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[127] Shenk, *Lincoln's Melancholy: How Depression Challenged a President and Fueled His Greatness*, 99.

circumstances, which, Shenk argues, serves "to powerfully illustrate the inability of accomplishments to satisfy him."[128] In Shenk's narrative, neither political successes nor personal losses (such as that of his young second son) seemed to provoke significant demonstration of feeling in him, and emotional reserve seemed to have become a pronounced character trait. Shenk contends that Lincoln's somber moods might well have represented an effort to contain his melancholy, to withdraw into himself until the dark feelings were more manageable. Though Lincoln could still entertain and charm with his stories, his melancholy came to have a somewhat different effect on people, inspiring them to stay at a distance and leave him to his private gloom rather than to step in to share his pain and suffering.

Shenk presents Lincoln as developing and employing multiple strategies to deal with his melancholy. In Chapter Seven, "The Vents of My Moods and Gloom," Shenk argues that Lincoln's use of humor and poetry as coping strategies produced increasingly complicated effects in his life. Although Lincoln's jokes and funny stories provided him with a way to amuse and connect with other people, they did not always completely cover his melancholy, and this disjuncture may have been as obvious to other people as it seemed to be to Lincoln himself. Similarly, he contends that Lincoln's withdrawal into the pathos of the copious emotion of 19th century poetry may have provided comfort in the sense of finding like-minded souls, but it may also have prolonged and deepened Lincoln's thinking about his existential and moral difficulties. In the last stanzas of Lincoln's favorite poem, Shenk sees a resonance with Lincoln's complex experience of melancholy:

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[128] Ibid., 105.

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Yea! Hope and despondency, pleasure and pain,
Are mingled together in sun-shine and rain;
And the smile and the tear, and the song and the dirge,
Still follow each other, like surge upon surge.
'Tis the wink of an eye, 'tis the draught of a breath,
From the blossoms of health, to the paleness of death,
From the gilded saloon, to the bier and the shroud
Oh, why should the spirit of mortal be proud![129]

The pertinent feature of Lincoln's chosen therapies, according to Shenk, was that they "did not dampen, but rather highlighted, the essential tension of his life," namely, the complexity of emotion and the difficulties of taking any pleasure in a life's work when so much still remained to be done.

The complicated entanglement of Lincoln's melancholy with the rest of his life is the subject of Part Three. In Chapter Eight, "Its Precise Shape and Color," Shenk argues that the same qualities which caused Lincoln so much personal distress began to have a significant positive effect in his professional life. Shenk argues:

> It was not what we would call a recovery, and certainly not what we would call a cure. Lincoln's story confounds those who see depression as a collection of symptoms to be eliminated. But it resonates with those who see suffering as a potential catalyst of emotional growth. "What man actually needs," the psychiatrist Victor Frankl argued, "Is not a tensionless state but rather the striving and struggling for a worthwhile goal." Many believe that psychological health comes with the relief of distress. But Frankl proposed that all people—and particularly those under some emotional weight—need a purpose that will both draw on their talents and transcend their lives. For Lincoln, this sense of purpose was indeed the key that unlocked the gates of a mental prison. That doesn't mean his suffering went away. In fact, as his life became richer and more satisfying, his melancholy exerted a stronger pull. He now responded to that pull by tying it to his newly defined sense of purpose. From a place of trouble, he looked for meaning. He looked at imperfection and sought redemption.[130]

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[129] Ibid., 121. Shenk quotes William Knox et al., *Oh, Why Should the Spirit of Mortal Be Proud?* (Boston; New York: Lee and Shepard; C.T. Dillingham, 1877).

[130] Shenk, *Lincoln's Melancholy: How Depression Challenged a President and Fueled His Greatness*, 126.

Shenk contends that Lincoln's longstanding ambition to leave the world a better place than he found it came to rest on the debate over slavery. Lincoln argued that slavery was fundamentally rooted in selfishness and that philosophically, any society that claimed justice as a fundamental principle must necessarily strive to eliminate slavery because it was inherently unjust. Shenk argues that this critical appraisal of the country's position relative to the philosophical ideal mirrored Lincoln's constant reassessment of himself and struggle to attain an unreachable ideal.

As Shenk describes it, Lincoln's contemporaries were well-prepared to envision a somber, even pessimistic man as appropriately prepared for public office, because such an individual was understood to be cautious and thoughtful. Shenk does not present Lincoln's anti-slavery arguments as being anti-racist in the sense that we understand such a term now, but portrays Lincoln as recognizing slavery as unjust in a political sense, and seeing in the conflict over slavery (specifically in the Kansas-Nebraska Act) the potential for the demise of the entire country. Lincoln ran for the Senate in 1855, but withdrew midway through and asked voters to support another anti-Nebraska (Democratic) candidate when it was clear that he did not have a winning margin. Shenk sees Lincoln's withdrawal from the race as an exercise of discipline, of placing a commitment to a cause over personal success. Moreover, Lincoln took this approach with others as well, encouraging them to see particular events as merely components of a much larger struggle. In particular, Shenk contends, Lincoln urged people not to become disheartened too quickly, and to take a very long-term approach to the eradication of slavery.

Shenk explicitly removes his narrative of Lincoln from the kind of ahistorical

debate about whether he was "really" a great man, noting that while Lincoln's racism

can be disappointing to those who wish to see him as singularly heroic, his

contemporaries often reflected sentiments and rationale a very great deal more

offensive to present-day sensibilities. More to the point, however, Shenk argues that

Lincoln's life does not lend itself to the standard "crisis and recovery" narrative form

of many biographies (a theme that will be explored in detail in the following chapter

of my study). Shenk states, "Whatever greatness Lincoln achieved cannot be

explained as a triumph over personal suffering. Rather, it must be accounted for as an

outgrowth of the same system that produced the suffering. This is not a story of

transformation but one of integration. Lincoln didn't do great work because he

solved the problem of his melancholy. The problem of his melancholy was all the

more fuel for the fire of his great work."[131]

In Chapter Ten, "Comes Wisdom to Us," Shenk describes how he sees

Lincoln as coming to reap the long-term benefits of his coping strategies.

Specifically, he argues, Lincoln's lifelong effort to attain unreachable ideals of

character and society had accustomed him to operating in a conceptual space of

perpetual uncertainty and even failure, in which he learned to depend upon sources of

inspiration (such as philosophy and religion) that were not connected to the successes

and failures of the battles of the Civil War. Moreover, Lincoln's continued approach

to the Civil War and the question of slavery as something so much more important

than his own political situation also prompted him carefully to attempt to restrict the

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[131] Ibid., 156.

opportunities for the victors to seek vengeance and to operate in a spirit of magnanimity whenever possible.

Unquestionably, the most useful service that a study like *Lincoln's Melancholy* performs for disability studies is to directly question the usefulness of categorizing the experience of depression as a purely pathological experience, and to do so in an understated manner uncommon in most disability studies work. Although Shenk is certainly not the first to observe that the kind of experiences usually characterized as "depression" or "melancholy" could be approached in a more complex fashion than the medical model does, making such an argument within the parameters of contemporary popular nonfiction without venturing too far into the territory of "inspirational" is something of a departure from the beaten path. It offers a "kinder, gentler" and less confrontational model that may prove to be more effective political outreach for disability studies than the more common, strident tone.

Most obviously, Shenk challenges the naturalized universality of the contemporary idea of depression by maintaining the historical specificity of "melancholy" in the 19th century U.S. By framing the question of the meaning of Lincoln's experience in historical terms of "melancholy," rather than in the contemporary terms of "depression," Shenk immediately guides readers towards an alternate reading of the meaning of the experience, i.e., as something associated with insight, sensitivity, and spirituality.[132] In so doing, Shenk is not only presenting his subject matter in the appropriate historical context, but is also capitalizing on any lingering tendency on the part of the reader to imagine depression as a kind of

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[132] This tactic of taking the long view, of making the meaning of melancholy in the 19th century U.S. just one meaning among a broader historical range of meanings, might also serve disability studies well.

suffering with a greater importance than that of ordinary physical illness (exactly what Peter Kramer complained about).

Shenk's portrayal of Lincoln's experience of melancholy emphasizes the utility and practicality of Lincoln's strategies of adaptation—the usefulness of his emotional vulnerability in creating connections with people, his resigned pessimism that taught him to confront his difficulties head-on, and his embracing of the emotional component of poetry and humor as a means for thinking through problems with existential implications. In other words, Shenk focuses on those accomodations that Lincoln made to his depression resulting in what today might be termed the "positive outcome" of substantial personal success. By emphasizing the relationship between Lincoln's adaptations and his successes (both personally and for the country as a whole) and using the medical model's own implicit criteria of productivity, Shenk essentially disarms the social/cultural/medical process of turning undesirable behavioral traits into pathology—and along the way, quietly exposes that process as political rather than scientific. From this vantage point in history, it would be impossible to say that Lincoln wasn't a fully functioning member of society, given that he was able to get elected as President. It's difficult to argue that he had "inappropriate guilt" for the ownership of slaves. And if he were working late at night instead of sleeping, in retrospect, that activity is more likely to be attributed to a good work ethic and sense of responsibility than to a disturbance in sleep patterns. At some point, common sense begins to question the validity or utility of a conceptualization of "mental illness" that could be applied to someone like Lincoln. After all, how "sick" could he be if he managed a career like that?

Shenk insists that Lincoln's success was a direct result of his strategies of adaptation, and clearly implies that this success effected a much greater good than he would have likely achieved if he were "normal." In this way, Shenk challenges the presumption that "normal" is the most desirable state, and echoes academic disability studies' explication of the conflation of the normal with the ideal through the historical relationship between statistics and eugenics. Lennard Davis' 1995 work on statistics in *Enforcing Normalcy: Disability, Deafness and the Body*, for example, describes the way in which the idea that a population could be "normed" was superimposed on and merged with well-established classical notions of the ideal, in which human beings could only imperfectly embody small fragments of the divine ideal.[133] This transformation replaced the abstract ideal with the "upper" end of the bell curve, which in visual, graphic terms can be conveniently pivoted mid-curve to show a progession from the low to the high in a way that parallels the valuation of certain traits. Shenk exploits the conflation and exposes the paradox: Lincoln's overachievement is certainly not "normal" in a purely statistical sense, but is so desirable in a social sense that the presumptive ideal in the assertion of normal is necessarily questioned.

In practice, Shenk's call to the reader to re-think depression is gentle, non-confrontational, and subtle, sufficiently so that a reader who isn't actively looking for a radical reconceptualization of the meaning of illness may not even notice that he's seen one. This approach may be of considerable use to disability studies in the current context of dominance of biological psychiatry. Because disability studies has

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[133] Davis, "Constructing Normalcy: The Bell Curve, the Novel, and the Invention of the Disabled Body in the Nineteenth Century."

grown out of the disability rights movement, it has primarily grown in the direction of

analyzing what makes disability a site of oppression, and often still frames its work in

the voices of those outraged at the injustice of that oppression. Although this analysis

is intellectually necessary and serves as a kind of social glue within the disability

community, it also has a number of difficulties. This kind of explicit, head-on

conflict creates an awkward position for those whose disabilities are the result of

illness, and who seek medical care and improved health at the same time that they

want to resist the social and cultural forces that bear down on disability. Thus, in

practical terms, Shenk's more low-key approach of speaking in the dominant

language (metaphorically, by demonstrating "positive outcomes" and the paradox of

the conflation of normal and ideal) constitutes a new kind of disability rights

discourse that can potentially have much wider application.

It is important to understand the discursive importance of Shenk's harnessing

the power of haunting in his narrative, and how this contrasts with the traditional

narratives of disability. The traditional and usually autobiographical narrative forms

of the lived experience of (physical) disability, although they describe stories of

resistance against an oppressive medical model of disability, continue to be haunted

by the first impression, so to speak, of being disabled and thus victimized by an

oppressive culture. Authors of the physical disability narratives may position the

origin of their disability in cultural terms rather than as their impairment, but in both

cases the narratives focus on the authors' own positions in the struggle. Their

discursive success is dependent upon their ability to persuade the reader to identify

more closely with them than with the oppressive system, and the narratives are haunted by this process of victimization.

But in Shenk's storytelling, haunting functions differently. Because Lincoln is first and foremost understood as a hero, even a tale attempting to establish that he was depressed is haunted by the ghost of the Great President. In other words, the narrative of Lincoln's "deficiency" is consistently haunted by the presence of his professional success. In fact, the presence of this ghost is so strong that it is effectively prevents Lincoln's depression from becoming pathological, in cultural terms at least. Of course, Lincoln is an unusual subject in this regard, and most of us do not have such profound success as to be functionally beyond reproach. However, the comparative success of this anomalous subject suggestive of a need to think about how standard narratives of illness and recovery or political resistance to an oppressive theoretical model may not be the most effective way of repositioning disability culturally, even if this is the way in which depression or disability is experienced. In other words, a disability studies project that wants to achieve social and cultural change may want to think about whether an emphasis on the voice of lived experience is the most useful theoretical approach to take, and whether other ways of representing and conceptualizing disability might be more effective.

The issue of discourse isn't just about developing more sophisticated public relations. It also signals an opportunity to remodel disability theory to include—or rather to correct the exclusion of—people whose disabilities involve illness. By reshaping the engagement with power from the implementation of the system, so to speak, to the theory behind the system, it is possible to de-emphasize the collision

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with the implementation of health care. A disability studies project that is more subtly engaged with fundamental difficulties of the medical model (e.g., in the case of depression, that the behavioral criteria for pathologizing it are the materialization of capitalist social norms) focuses less on the day-to-day struggle and conflict with health care providers. It stops making people with illness-related disabilities less politically authentic than those with impairments that don't cause suffering.

Recognizing of the difficulty of this conflict also creates conceptual space for Avery Gordon's notion of complex personhood described earlier in this chapter, which has a number of other implications. As I will discuss in the next chapter, because so many illness-and-recovery narratives of madness/mental illness have been published and now constitute at least in practice a standard for such things, *Lincoln's Melancholy* makes several contributions towards a more complex conception of the representation of the experience of depression than either a case study or the standard illness-and-recovery model permit.

By explicitly using depression as a "lens," (i.e., as a theoretical framework that also functions somewhat as an organizing devices), Shenk addresses the difficulties of attempting to fit a portrait of a complete, complex person into the standard idea of biography as linear chronology.   The inevitable inconsistencies and contradictions of mind and experience can appear as sloppy errors in continuity if held to either a traditional biographical narrative model or a traditional idea of scholarly evidence. For example, at times, Lincoln's melancholy is expressed as vulnerability that motivates others to help him, yet at other times it acts to divide him emotionally from other people, who leave him alone during his blue periods. In his

physical life, of course, both were probably simultaneously true enough to be recognized as such, or fluctuated at a level of detail that the historian can neither practically represent nor likely even access. The linear narrative generates a need to choose, to pin it down, to contour the portrait of the character at any given moment of time to fit into a larger and coherent story of an event or series of events. Unfortunately, the necessity of creating a linear narrative that can accommodate a sequential chain of events generally does not accommodate a story that loops back on itself or branches off in multiple directions as one's thoughts and moods typically do.

The comparison of these two interpretations of the meaning of depression establishes that they do share one common understanding, though its significance is in dispute. They both assert, in their own ways, that the experience of depression has not been entirely assimilated into medical discourse (though medical discourse has clearly become the dominant discourse) and that depression still retains traces of the character of melancholy, i.e., it is still able to be understood as some kind of ennobling suffering, or a refined kind of affliction to which deeply sensitive people are vulnerable.

What is at stake can be mostly broadly understood as a *de facto* collective cultural judgment of whether the experience of depression is a kind of pathology. In this particular context, in one way that question boils down to whether we understand and judge the experience of depression as uniformly bad, to put it as simply as possible, or whether that experience can be judged to be complex, with components that can be both good and bad. That, obviously, is one of those questions for which there will never be an absolute answer, and what sort of response you get depends on

who you ask. But that is, ultimately, what the disagreement of whether depression is "really" an illness is about.

That disagreement, however, is also about the degree to which medical authority is accepted as valid, and to which other ways of thinking are successful in resisting the dominance of medical authority. This component might be understood as a struggle between modernist views of an absolute, scientific medicine that "discovers" cures for illnesses in an arena where judgment is not in question, and postmodern approaches that position medicine as an inherently political arena. What is at stake here is the viability of a disability rights project that seeks to depathologize non-normative bodies and experiences.

However, in the intellectual arena, this is also a struggle about the ownership of knowledge and what can be broadly understood as legitimate evidence and scholarship. This is also a modernist/postmodernist kind of struggle, but it also includes a disciplinary component in terms of who may lay claim to certain kinds of intellectual terrain. It's a question of accountability in using the authority of a field to make certain kinds of claims (e.g., that depression is a disease) and the responsibilities of other intellectuals to hold such claimants and their arguments accountable to broader, multi-disciplinary standards for intellectual rigor. The question of what counts as evidence is crucial, as it defines both what we know and how we know it, and determines what is judged legitimate enough to be understood as "real."

Chapter 4: The Standard Story of the Unique Individual Experience

Although the gradual institutionalization of disability studies as a field has resulted in its beginning to be integrated in the larger body of work of "the scholarship of difference," disability studies thus far has been fueled largely by the same highly specific forces of political unrest as the disability rights movement, and disability studies scholars are still almost always people with disabilities. The oft-quoted rallying cry of "nothing about us, without us" epitomizes the disability rights movement's emphasis on personal experience as an extremely valued form of knowledge. As such, an emphasis on perspective, personal experience, and representation characterize writing associated with both the disability rights movement and with academic disability studies. The scholarly and theoretical literature informing my inquiries having been analyzed in Chapter Two, I turn now to examine what some might call the *real* literature of disability.

The literature of the disability rights movement (and much of the fledgling disability studies project) emphasizes perspective, personal experience and representation for several reasons. First, the construction of perspective and personal experience as a form of knowledge positions people with disabilities as *the* experts on the subject, with unique and valuable forms of insight and experience. Second, memoir as a literary form is, at least in theory, accessible to anybody who has the means to write, though publication is another issue. Third, memoirs of illness or disability (what Nancy Mairs refers to as "the literature of personal disaster") fit neatly within the publication explosion of "confessional" literature recounting abuse

or trauma of various kinds.[134] The rise in popularity of personal accounts dealing

with experiences of disability or illness (one's own or that of a family member) has

often been observed, but as I will discuss in more detail later on, little critical work

has been done on what sort of impact these texts have, or might have, on disability

studies/disability rights activities or on the position of disability in public culture

more generally.

      In this chapter, I will argue that autobiography and memoir of disability and

illness may be roughly sorted into two major philosophical-political camps. These

memoirs tend to share characteristics depending on whether the individual has

experienced a "physical" or "mental" disability or illness. Specifically, I will argue

that the "physical disability" narratives align with a political consciousness and

conceptualization of disability as a socially-produced kind of difference, and the

"mental illness" narratives align with the dominant medical model of biological

psychiatry. Both sets of binary classifications—"physical" vs. "mental" and

"medical" vs. "minority"—are rough and simplistic, but the point is to establish a

provisional working structure through which certain characteristics, similarities, and

differences become more easily visible. My use of this rough taxonomy is intended

to illuminate an important distinction absent from conventional systems of organizing

or investigating autobiography and memoir, namely the identification with or refusal

of the process of good/bad judgment associated with pathology. That alignment can

be used to predict and to contextualize, to a large extent, what kind of tale will be

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[134] Nancy Mairs, *Voice Lessons: On Becoming a (Woman) Writer* (Boston: Beacon Press, 1994), 124.

told.[135]   My taxonomy theorizes that conceiving of a particular experience of embodied difference as "disability" (rather than as "illness" or "defect") is strongly associated with the capacity for imagining progressive social action.   The narratives that engage a politicized idea of disability consistently share certain characteristics, and the reverse is true as well. My experiment in this chapter is to examine ten narratives of disability and illness, and consider them in the context of my provisional taxonomy.

My inquiry is directed more to the *production* of memoir and what it means for disability studies than to its consumption; consumption has been studied to the point that the "liberatory potential" of amplifying previously unheard voices and demonstrating political agency on the part of oppressed groups has become a truism of cultural studies. However, consumption also can affect production, because contemporary authors of memoirs and autobiographies don't live in a vacuum. This means that the ideas about how personal stories are consumed and what effects they have upon readers have *themselves* become part of the cultural ideology about such stories (at several different levels) and, I contend, affect how such memoirs are created, because many of these stories seem to be created with the express intent of helping or reaching out to the reader.

I will focus more closely on the intellectual aspects of the production of memoir rather than the economic aspects, though of course they are related.   A writer can look at her text and see a political argument, and an editor can look at the same

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[135] This absence is illustrated clearly in the categorization of Library of Congress subject headings, which have historically classified memoirs of disability or illness *by* the disability or illness, a categorization scheme which shows the difficulty of conceiving of disability or illness in any terms other than the usual medical model.

text and see a potential bestseller for completely different (and perhaps even contradictory) reasons—hence, the intellectual and economic aspects of production and publication are another instance of King's idea of lacquered layerings. To further complicate matters, there is a related academic cycle of the consumption of disability memoir and the production of academic disability studies *on* memoir. The production/consumption cycle in academic disability studies is of greater strategic concern to me than consumption of such memoir by the general public or even the disability rights community as a whole.[136]

It's important to note a particular assumption on which this chapter is based. Specifically, I'm assuming that the writing of life stories—especially those published in formats likely to have wide accessibility—can have a powerful impact on how people formulate their ideas about what the experience of a particular illness or disability will look like. I base this assumption on what I would describe as overwhelming anecdotal observation that people who receive a diagnosis of one sort or another will often rush to find out more about it through whatever means they have readily available to them, which might be the Web, books, television, or friends and family.[137] As far as I can tell, one very frequent source of information is biography or autobiography, which is not surprising, inasmuch as biography or autobiography is easier to read than medical texts. Autobiographies and memoirs may also address other kinds of questions that might well be more important—what it's like to actually

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[136] As disability studies moves from being a fledgling academic enterprise to being more integrated in mainstream cultural studies, it has the potential to affect people exponentially (e.g., first scholars, then the students who take their classes, etc.).

[137] There are, of course, a vast array of narratives on the Web, representing an extraordinary diversity of perspectives. Primarily for reasons of scale, these were not included in this study. Published narratives were also chosen because they have been "vetted," so to speak, by the publication houses, which to some extent serve as third-party verification of the cultural intelligibility of the narratives, something more difficult to obtain with websites.

live with this illness or that disorder.   People with disabilities or illness are not

necessarily surrounded by family and friends who also share that particular

experience of difference, nor necessarily likely to have an extended social network

built around the category in quite the same way as, say, some kinds of LGBTQ

communities.

This assumption is supported by Anne Hunsaker Hawkins' observation that

such stories "are often written with the expectation that the author's experience might

serve as a mirror, or model, or the prospective reader. Thus authors with heart

disease will direct their narratives to potential readers with heart disease; women

writing about breast cancer will write for other women with the same problem. To

some extent, the assumption about the 'generalizability' of illness is a part of our

modern nomothetic mythology about disease, which assumes a uniformity of

experience within a diagnostic category."[138] And which also, I would add, reinforces

the idea of the diagnosis as the most pertinent way of categorizing experience.

Existing academic scholarship on illness and narrative (including, but not

limited to, autobiography and memoir) has tended to center primarily on what I would

describe as content (as opposed to structure or function), and certainly has not

considered such narratives as salable goods that are manufactured for consumption.

In general, much of the work on illness and narrative focuses on medical discourse,

with the implicit intent of identifying sites or practices in which medical discourse

dehumanizes ill people or otherwise denigrates or rewrites their "stories," and such

work usually seeks explicitly to improve and facilitate doctor-patient

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[138] Anne Hunsaker Hawkins, *Reconstructing Illness: Studies in Pathography*, 2nd ed. (West Lafayette, IN: Purdue University Press, 1999), 5.

communication.[139] Of the works attending more specifically to narrative and

discourse in autobiography and memoir, most focus primarily on what individual

authors have used such memoirs to "do" in terms of reconciling themselves to their

bodily experiences, and how the authors use (or refuse) the discourse of medicine.

Such studies include most notably Anne Hunsaker Hawkins' *Reconstructing Illness:*

Studies in Pathography (1993), Thomas Couser's *Recovering Bodies: Illness,*

Disability and Life-Writing (1997), Cheryl Mattingly and Linda C. Garro's edited

volume *Narrative and the Cultural Construction of Illness and Healing* (2000), and

Dwight Fee's edited volume, *Pathology and the Postmodern: Mental Illness and*

Discourse and Experience (2000). [140] Couser's *Recovering Bodies* is of particular

importance relative to this study as it is from his comparatively "data-driven" and

very detailed observations of many of the mechanics of narrative (e.g., whether the

narrative downplayed an illness/disability experience by contextualizing it within a

whole life, or emphasized the experience by beginning the story at the onset of

illness) that I came to realize that there was actually a distinct difference in how

narratives of physical disability and narratives of mental illness were constructed.

Yet such scholarship, while often tremendously insightful and clearly oriented

towards improving the quality of life for patients, does not question to any great

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[139] An enormous amount of work in medical anthropology is applicable here. Some of the better-known examples of the most relevant scholarship include Arthur W. Frank, *The Wounded Storyteller: Body, Illness, and Ethics* (Chicago: University of Chicago Press, 1995), Arthur Kleinman, *The Illness Narratives: Suffering, Healing, and the Human Condition* (New York: Basic Books, 1988), Arthur Kleinman, *Writing at the Margin: Discourse between Anthropology and Medicine* (Berkeley: University of California Press, 1995)..

[140] G. Thomas Couser, *Recovering Bodies: Illness, Disability, and Life-Writing, Wisconsin Studies in American Autobiography* (Madison: University of Wisconsin Press, 1997), Dwight Fee, ed., *Pathology and the Postmodern: Mental Illness as Discourse and Experience* (London; Thousand Oaks, CA: SAGE Publications, 2000), Hawkins, *Reconstructing Illness: Studies in Pathography*, Cheryl Mattingly and Linda C. Garro, *Narrative and the Cultural Construction of Illness and Healing* (Berkeley: University of California Press, 2000).

degree the ideological categories of "health" and "illness," or interrogate the validity of the idea of pathology in the same way that scholarship more explicitly associated with a disability rights/disability studies consciousness usually does. The difference is not merely one of having a radical political objective versus a more liberal approach to reform; it is also a fundamental intellectual issue of the degree to which the assumptions and naturalization of the medical categories of health/illness, or normal/pathological are questioned.

Thus, this study addresses the gap between a vague understanding of certain texts as having "liberatory potential" and the strategic deployment of ideas in the service of either scholarly theory or practical action. It assumes that meaningful political change—i.e., materially recognizable respect for the autonomy and embodiment of disabled or ill people—can't occur within an intellectual system that presupposes such individuals as deficient, and seeks to identify the points at which understandings of embodiment diverge into recognizable narrative patterns.

Criteria for Selection

Texts were selected for examination in this chapter primarily on the basis of their visibility and perceived importance in shaping perceptions of what an autobiography or memoir of experience with disability or illness is "supposed" to look like. Those selected are comparatively popular texts in straightforwardly measurable ways (i.e., published by major trade presses, still in print at the time of writing, and available through major booksellers such as Borders or Amazon.com), and as such, have some claim to reaching a broad audience. They are also popular texts in less easily quantifiable, but perhaps more influential ways: they are among

the most frequently cited texts of their kind in the relevant scholarly literature; they are often popular "teaching books," (the kind of texts teachers use to first introduce students to new perspectives); and they are the sorts of books that people are likely to share with their friends and families, because they communicate powerful feelings in "plain English" without substantial technical language or esoteric concepts.

A second consideration is of demographic diversity. There are very few commercially published memoirs of illness and disability by people who are not white and middle-class, and clearly there is a discrepancy between the publication record and the epidemiology of disability and illness. My primary purpose here is to document how disability and illness are currently presented in memoir, and in turn to illustrate how ideas of health and illness are entwined with the construction of narrative. That logic would require that the most representative texts be used, to most accurately reflect the representations that actually *do* exist, and not those that *should*. Indeed, 80% of the texts used fit this description. However, two illness memoirs published by black writers have also been included here, however unrepresentative they may be, because they function as the exceptions that prove the rule—they illustrate exactly how memoirs of illness and disability are frequently misunderstood to be universal experiences of disability rather than disability understood in the particularity of race, gender, class, etc. (The larger implications of disproportionate representation will be discussed at length later in the chapter.) I have also attempted to represent a range of sexualities, which has created some asymmetry in the texts chosen, but again, that asymmetry is also revealing.

The ten texts chosen for examination are as follows:

Mental Illness[141]

- Meri Nana-Ama Danquah, *Willow Weep for Me: A Black Woman's Journey through Depression, A Memoir*
- Lauren Slater, *Prozac Diary*
- William Styron, *Darkness Visible: A Memoir of Madness*
- Elizabeth Wurtzel, *Prozac Nation: Young and Depressed in America*
- Faith Reidenbach, "Backward by Threes," in *Restricted Access: Lesbians on Disability*, edited by Victoria A. Brownworth and Susan Raffo,

Physical Disability[142]
- Kenny Fries, *Body, Remember: A Memoir*
- Simi Linton, *My Body Politic: A Memoir*
- Audre Lorde, *The Cancer Journals*
- Nancy Mairs, *Waist High In the World: A Life Among the Nondisabled*
- Irving Kenneth Zola, *Missing Pieces: A Chronicle of Living with a Disability*

I have deliberately omitted memoirs that are explicitly "inspirational" because they are of a fundamentally different nature than the non-religious texts. The focus in these texts, as Anne Hunsaker Hawkins notes, tends to be on the explanation of the *meaning* of suffering more than anything else, or, I would add, serve an explicit purpose promoting or affirming religious belief. While this approach is certainly relevant to understanding the ways in which people attribute meaning to the experiences of disability or illness, including these narratives would necessarily complicate and divert this project away from my primary interest, which is the relationship between narrative and the construction of pathology.

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[141] Meri Nana-Ama Danquah, *Willow Weep for Me: A Black Woman's Journey through Depression, a Memoir* (New York: Norton, 1998), Lauren Slater, *Prozac Diary* (New York: Random House, 1998), William Styron, *Darkness Visible: A Memoir of Madness*, 1st ed. (New York: Random House, 1990), Elizabeth Wurtzel, *Prozac Nation: Young and Depressed in America* (Boston: Houghton Mifflin, 1994). Victoria A. Brownworth and Susan Raffo, eds., *Restricted Access: Lesbians on Disability* (Seattle: Seal Press, 1999).Faith Reidenbach, "Backward by Threes,"

[142] Kenny Fries, *Body, Remember: A Memoir* (Madison: University of Wisconsin Press, 2003), Simi Linton, *My Body Politic: A Memoir* (Ann Arbor: University of Michigan Press, 2006), Audre Lorde, *The Cancer Journals*, Special ed. (San Francisco: Aunt Lute Books, 1997), Nancy Mairs, *Waist-High in the World: A Life among the Nondisabled* (Boston: Beacon Press, 1996), Irving Kenneth Zola, *Missing Pieces: A Chronicle of Living with a Disability* (Philadelphia: Temple University Press, 1982).

Commonalities and Divergences

The most important characteristic of this literature is its reformulation of authority, and its relocation of where discourse about bodily experience belongs. Obviously, all memoir positions the author as the expert to some degree, but in literature associated with the disability rights movement, the positioning of author-as-expert has particular significance as a rejection of medical authority. To the extent that disabled bodies are often understood to have a "medical condition," they are placed physically and discursively under the authority of medicine. The repositioning of the disabled person as the source of the most pertinent and comprehensive expertise (at least on the subject of that particular life) is a re-appropriation of authority and at least in that capacity, challenges the traditional authority of medicine to speak on behalf of "patients."

However, the narratives diverge in how they choose to use this re-acquired authority. The narratives of madness/mental illness tend to use the authority of voice largely to reinforce dominant conceptualizations of what constitutes health and illness; their goal is usually either to reduce the stigma of madness/mental illness by showing that the author is a regular person, just like everybody else, or to urge others so afflicted to seek help in the hopes of bettering their quality of life.[143] They may show some criticism of individual doctors, or perhaps a critique of a mental health care system insufficient to societal needs. Very rarely, however, do they seriously

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[143] This kind of "public service" approach also echoes through the scholarly literature on the subject. For instance, in the opening sentences of a recent volume on depression and narrative, editor Hilary Clark writes "…there can never be enough visibility for this illness or condition whose stigma causes the sufferer to dissemble and 'pass,' foregoing needed treatment, or to withdraw from others in shame—a condition misrepresented by myths and stereotypes that inevitably color, and cover, our understanding." Hilary Anne Clark, *Depression and Narrative: Telling the Dark* (Albany: SUNY Press, 2008), 1.

question the legitimacy of the medical establishment to issue a diagnosis or treatment that pertains to them. The central question that ultimately differentiates these two groups of texts is whether the experience is understood as being fundamentally *individual* in character (i.e., illness) or fundamentally *social/cultural* (i.e., disability), and this determines whether the experience is understood as pathological or not.

Memoirs of Mental Illness

The memoirs dealing with mental illness (as these authors characterize the experience) tend to conform to trends in contemporary psychiatry, meaning that the experience is understood unequivocally as *illness* (as opposed to a test of religious faith, a form of social oppression, etc.), and specifically as illness that can be physically located in the brain, in the functioning of neurotransmitters, etc.[144] Perhaps the most striking difference between the memoirs of mental illness and those of physical disability is that the memoirs of mental illness frequently cite the DSM definition of whatever illness they are experiencing, and some of the earlier narratives even included contact information for mental health resources at the end.[145] This practice of citing the DSM is in some ways a routine borrowing of authority that positions the author as a well-informed individual who, by citing the dominant diagnostic tool of the trade, speaks with the implicit weight of the medical

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[144] It is noteworthy that the texts selected here discuss unipolar depression, bipolar disorder (manic depression), and anxiety. There are, of course, memoirs that discuss experiences ranging from schizophrenia to dissociative identity disorder (a.k.a. multiple personality disorder) and everything in between. However, there are fewer of these and they are much more sparsely distributed, as are narratives of depression or manic depression that portray the diagnosis as a mask and tool for political oppression (e.g., Kate Millett, *The Loony-Bin Trip* (New York: Simon and Schuster, 1990).). While an argument could be made that the diagnosis qualifies such a book for inclusion here, this study is concerned with looking at the idea of pathology and its relationship to bodily experience and the inclusion of such narratives here would be inappropriate.

[145] Of the works studied here, Styron, Slater, and Danquah all cite the DSM.

establishment behind him or her. However, this practice of citation is interesting in the context of these narratives, as it also serves to establish the author as a reasonable person, in the most literal sense of the term as "having reason" or being sane, thereby avoiding a potential weakness in credibility.

Mental illness narratives also tend to employ one or more strategies to separate the illness from the self. Thomas Couser observes:

> Although it may seem counterintuitive, narratives of somatic dysfunction tend to become life writing to the degree that the writer identifies the self with the body. Thus pure illness narrative tends to disengage the body from the self in the way that medical discourse often tends to do. Full life-writing is facilitated, authorized, or even required when one assumes that what happens to one's body happens to one's life…[146]

Couser's assertion, however, presents a curious narrative problem for the writer of a mental illness narrative. If they assert that mental illness is a real physical illness, and that illness is located in the brain (which is as close to a physical location of the "self" as one is likely to get), then there is an inherent crisis of credibility and personhood. Chronology is thus often used to create the necessary distance between illness and self. The narratives of mental illness often begin (excepting anecdotal introductory material) with the onset of the illness, rather than at childhood or early adulthood, or following a more holistic framing of the life. They tend to follow a narrative trajectory that describes an "ordinary life" interrupted by an illness, which gets progressively worse until the proper cure arrives. Normalcy is then more or less restored, often leaving the writer somewhat battle-weary but wiser for the experience. In many narratives, there is an implicit distancing of the period of illness from the

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[146] Couser, *Recovering Bodies: Illness, Disability, and Life-Writing*, 14.

writer's current self. The distancing serves to avoid questions of the author's credibility as witness (e.g., "*Then* I was sick, *now* I am well.")

William Styron's *Darkness Visible: A Memoir of Madness* (1990), while not the first account of depression ever written, was at the forefront of a wave of such memoirs in the 1990s, and in some ways set a standard for those that came after. Styron's popularity and recognition as a novelist no doubt accounts, in part, for the memoir's hitting the bestseller list.

Styron opens the narrative in Paris, 1985, at the moment he realizes that "the struggle with the disorder in my mind—a struggle which had engaged me for several months—might have a fatal outcome".[147] His description of the struggle potentially having a "fatal outcome" immediately and firmly places his experience in the context of physiological illness, avoiding any possibility of his depression being interpreted in romantic terms as a "merely" a Camus-like angst. The narrative trajectory takes the reader through progressive difficulties, unsuccessful psychopharmacological treatments of various kinds, equally unhelpful psychotherapy, and ultimately a period of profound suicidality that culminated in hospitalization. As Styron moves through time with these unsuccessful treatments, he simultaneously unravels back to what he feels is the origin of his depression in the previous summer, when he abruptly quit drinking and started taking extremely large doses of the tranquilizer Halcion. (He later firmly identifies Halcion as a contributing factor to his depression in a way that strongly suggests that the heavy dosage was tantamount to medical malpractice.)

One of the distinguishing features of Styron's narrative is an insistence that depression is a disease. Styron refers to depression as an "illness" and "disease"

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[147] Styron, *Darkness Visible: A Memoir of Madness*, 3.

repeatedly, so while there is no question that he is *describing* the kind of anguish and existential angst that prompted Albert Camus, his literary hero, to remark that the only serious philosophical problem was whether to commit suicide, he also clearly understands that anguish to be a *byproduct* of disease, not an entity with meaning in its own right. Styron, who describes himself as interested in medicine and more knowledgeable than most, explains the relationship between madness and depression:

> Our perhaps understandable modern need to dull the sawtooth edges of so many of the afflictions we are heir to has led us to banish the harsh old-fashioned words: madhouse, asylum, insanity, melancholia, lunatic, madness. But never let it be doubted that depression, in its extreme form, is madness. The madness results from an aberrant biochemical process. It has been established with reasonable certainty (after strong resistance from many psychiatrists, and not all that long ago) that such madness is chemically induced amid the neurotransmitters of the brain, probably as the result of systemic stress, which for unknown reasons causes a depletion of the chemicals norepinephrine and serotonin, and the increase of a hormone, cortisol. With all of this upheaval in the brain tissues, the alternate drenching and deprivation, it is no wonder that the mind begins to feel aggrieved, stricken, and the muddied thought processes register the distress of an organ in convulsion.[148]

Ordinarily, the depression-as-illness stance implies that feelings of anguish aren't quite real because they are merely the effect of "chemicals," but Styron's grace and skill as a writer is such that he is able to combine two different conceptual arenas— "anguish" and "neurotransmitters"—in a way that they don't seem incompatible.

The effort to reconcile personal experience with a medical (and therefore "real") explanation is typical of depression narratives, as is the suggestion of justification or absolution that the explanation carries. In one particularly intriguing scene, Styron describes his rude behavior in abruptly declining an invitation to a

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[148] Ibid., 47.

lunch in his honor from the French committee that is awarding him a literary prize, and begs forgiveness, explaining that he is sick with "*un problème psychiatrique*." Styron's explicit attribution of responsibility for his behavior to the illness, and his concurrent expectation that illness will be understood to be an acceptable excuse for the rudeness is provocative: it suggests that he understands himself to be literally "not himself," and that it is the illness, not he, who has control over his actions.[149] Despite the compassion that his evocative description of his suffering evokes in the reader, it is difficult not to also see Styron's new identification of depression as illness as a somewhat self-serving philosophy inasmuch as it excuses him from responsibility for his own behavior. Styron's recognition of depression as an illness is described as a fairly new phenomenon. After portraying himself as a comparatively knowledgeable person with regard to medical issues, "it came as an astonishment to me that I was close to a total ignoramus about depression, which can be as serious a medical affair as diabetes or cancer. Most likely, as an incipient depressive, I had always subconsciously rejected or ignored the *proper* knowledge; it cut too close to the psychic bone, and I shoved it aside as an unwelcome addition to my store of information."[150] [Emphasis mine.] The "proper" knowledge presents depression as a much different phenomenon than did his previous "improper" knowledge. However, although the convenience of the excuse may be suspect, Styron's fear of suicide is tangible and resonates throughout the account. Recounting the suicides of friends and colleagues, Styron clearly considers a cause-and-effect relationship to be obvious, and

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[149] Ibid., 14.
[150] Ibid., 9.

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the fear of suicide as a distinctly possible outcome underlies his argument, whatever other purposes it might serve.

One of the very curious features of this narrative is Styron's choice to frame it as a memoir of depression, rather than one of medical malpractice. Styron explains at some length that he had been prescribed the tranquilizer Halcion, and at doses three times the ordinary strength. He describes Halcion as a "causative factor in producing suicidal obsession and other aberrations of thought in susceptible individuals" and observes that at the hospital, when he was prescribed a different drug to help him sleep and discontinued Halcion, his suicidal notions soon disappeared. Perhaps a memoir of depression could better capture the existential angst that he clearly felt; or perhaps a memoir of being poisoned by prescription drugs would implicitly dismiss that the existential angst was quite real to him. Then, too, the "victims" of illness have hope for recovery not only from the illness but from the concurrent association of weakness, whereas to be the victim of medical malpractice, when one is ostensibly reasonably informed in medical matters, is a somewhat less flattering portrait.

Whereas Styron tends to answer the question of the legitimacy of depression obliquely, in *Prozac Nation: Young and Depressed in America* (1994), Elizabeth Wurtzel explicitly focuses on arguing that depression as "real" and different from merely being unhappy. The characterization of depression as an illness, per se, is of considerably less significance than making it clear that the experience is utterly overwhelming, pervasive, and undeniable. More than anything, Wurtzel seeks to make depression intelligible as a real *problem*, as she clearly believes she is perceived by those around her as malingering.

The trajectory of Wurtzel's narrative coincides with the onset of her illness at age 11. Her parents divorced when she was two, and much of her childhood was spent in confusion and fear, in ways that she attributes to her circumstance as a child of divorced parents. Wurtzel describes in detail her overdoses at summer camp, the occasions in which she cut herself with razors, her feelings of being a social outcast, and the misery that she presents as the defining characteristic of her personality even as she earns a scholarship to Harvard. It follows the standard depression memoir narrative path of opening with the onset of illness, following it down into the depths of crisis, and then being resolved through therapy or drugs or both, in this case Wurtzel's relationship with psychiatrist Diana Sterling, who prescribes Prozac.

Wurtzel's memoir was regularly pilloried in reviews for being endlessly self-pitying and whiny.[151] Nevertheless, first as a New *York Times* bestseller and later turned into a major studio movie starring Christina Ricci, *Prozac Nation* enjoyed considerable visibility.[152] In some respects, one can see the narrative as tapping into some very traditional story lines, i.e., the nearly-tragic coming of age story, the story of the tortured and alienated artist, etc. Though Wurtzel describes in detail the unfortunate circumstances of her life, she also regularly punctuates that narrative with observations that her mother went to great lengths to ensure that she was comfortably (though not luxuriously) provided for, educated carefully, and deeply loved. Recounting an exchange with her therapist, she writes:

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[151] Michiko Kakutani, "The Examined Life Is Not Worth Living Either," review of Prozac Nation: Young and Depressed in America, *The New York Times*, September 20 1994, Karen Schoemer, "To Be Young, Gifted, and Blue," review of Prozac Nation: Young and Depressed in America, *Newsweek*, August 29 1994.

[152] Erik Skjoldbjærg, "Prozac Nation," (United States and Norway: Miramax Films, 2003).

> "This is going to sound dumb," I began, far too aware that everything I said was so trite, "but, the thing is, I really don't feel like I have a right to be so miserable. I know we can look back and say my father neglected me, my mother smothered me, and I was perpetually in an environment that was incoherent to me, but—" But what? What other excuses do you need? I wasn't feeling gross enough to mention Bergen-Belsen, cancer, cystic fibrosis, and all the other *real* reasons to be sorrowful. "But a lot of people have hard childhoods," I continued, "much harder than mine, and they grow up and get on with it."[153]

In this passage, Wurtzel both disrupts the usual Tortured Young Artist narrative and reinscribes it: ultimately, her point is that although she hasn't suffered through anything so horrible as the Holocaust—or cancer or cystic fibrosis, which should possibly be of greater note in a dissertation on disability studies—she nevertheless has suffered as a result of depression and her suffering ought to be understood as legitimate as a result.

Wurtzel clearly seems to understand that a well-mannered "good girl" is expected to diminish her own experiences as meaningless and trite and does so, yet it is also quite clear that she is expecting the reader to contradict her and protest, "But you *do* have a real reason to be sorrowful! You're *depressed*!" Wurtzel's differentiation between depression and "all the other *real* reasons to be sorrowful" is interesting, particularly in the context of this chapter. Though her tone is very self-consciously sardonic, she nevertheless makes a serious distinction between her depression and the presumably more tangible bodily experiences of cancer and cystic fibrosis. Ironically, this suggests that depression actually is *not* fully materialized as illness for Wurtzel; she does not identify herself as ill in the same way that she would if she had cancer, even though she contends elsewhere that depression has the potential to be a fatal illness, and one which nearly killed her.

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[153] Wurtzel, *Prozac Nation: Young and Depressed in America*, 192.

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Yet as explicitly as Wurtzel identifies her suffering as a result of depression-as-illness, she also claims alienated youth as a kind of style and even a point of pride. Recalling high school, she writes:

> By then, I was the perfect weirdo by any standard. This was the year of the cheerleader-style miniskirts that Norma Kamali and Betsey Johnson had foisted upon the unfortunately fashion-conscious, and all the girls at my high school fell into that category. It seemed everybody in school was on the cheerleading squad except me, I alone was stuck somewhere in Stevie Nicks-land, showing up every day in these long, diaphanous things that nearly reached the ankles of my leather riding boots, matched with romantic, loosely tied tops that showed off my collarbone. I was all belts and bows and ties and fabric, always weighted down by so much *stuff*, and this was in the beginning of the Reagan-era optimism of the early eighties, the time of lightheartedness and good tidings and bright colors. When all the girls adorned themselves with plastic earrings and accessories in turquoise and yellow and chartreuse and hot pink, there I was in everything cold and dark, silver and lapis hanging from my ears like an old throwback to the sixties or the seventies, or maybe to an unhappy time and place that everyone who surrounded me didn't remember or had never even been to in the first place.[154]

Here, Wurtzel presents her dark mood as manifested in her attire, but despite her description of herself as the "weirdo," she also hints at her prescience in refusing to follow the herd, and implies that her darkness is a "cool," iconoclastic kind of alienation. This is by no means the dominant characterization of depression in her memoir, but that she can't seem to resist including it—despite the contradiction to her central thesis that she was plagued by an overwhelming, tangible misery that was completely beyond her control—suggests that even if depression is understood as illness, it is an illness with significant cultural meaning.

Of the many autobiographical accounts of depression published in the last few years, Lauren Slater's *Prozac Diary* is quite possibly the most complex and

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[154] Ibid., 96.

thoughtful. Slater was one of the first to go on Prozac, and the publication of *Prozac Diary* marks approximately her ten-year anniversary on the drug. Diagnosed with borderline personality disorder at age nineteen, Slater had at various points been anorexic, attempted suicide, and was a veteran "cutter" (intentionally cutting the skin on her arms with razor blades). At the time she started Prozac, Slater had been hospitalized five times for depression, anxiety, and eventually obsessive-compulsive disorder, the problem for which she was referred to the person she calls the "Prozac Doctor."

Slater describes her first visit to the Prozac Doctor almost in terms of religious ritual, a theme which recurs and is slowly transformed through the course of the diary. After the Prozac suddenly takes effect—a revelation, a stunning transformation of her entire life—the pill itself becomes a mixture of the *object* of worship and the *means* of worship. On Prozac, Slater is suddenly released from her tight, constant, and intense world of counting calories and checking stove dials. The new freedom is exhilarating, and Slater throws herself into exploring what is now an almost entirely unrecognizable world.

"Unrecognizable" is perhaps the key word—as Slater recounts her experimentation with new food, new books, and new friends, she also places these new experiences on a virtually blank page. She writes:

> ... Doctors assure the public that psychotropic drugs don't get a patient high; rather, supposedly, they return the patient to a normal state of functioning. But what happens if such a patient, say myself, for instance, has rarely if ever experienced a normal state of functioning? What happens if such a patient has spent much of her life in mental hospitals, both pursuing and pursued by one illness after another? What happens if "regular life" to such a person has always meant cutting one's arms, or gagging? If this is the case, then the "normal

state" that Prozac ushers in is an experience in the surreal, Dali's dripping clock, a disorientation so deep and sweet you spin...[155]

Without her identity of illness, she doesn't know who she is. Prozac may have brought a cure, but the cure has brought an identity crisis of major proportions. Slater continues:

> After all, when you are sick, there are plenty of places (insurance willing) where you can go to get healed, but when you are healed are there any places you can go to learn not to be sick? The very idea of having to learn the landscape of health sounds vaguely ridiculous, so ensconced are so many of us in the notion that health is as organic as grass, in the right conditions growing green and freely.[156]

As Slater became somewhat more accustomed to her expanded life on Prozac, she began to consider her relationship to and dependence on the drug, describing it at various stages as: a lover; similar to peyote as a cultural means of accessing God; (later) as a former lover; and (later still) as a good friend, the presence of whom can help a difficult situation but who can't eradicate a problem completely.

At her ten-year mark, Slater is profoundly ambivalent towards Prozac. Though grateful that she's no longer checking stove dials, she is uncomfortable with what is essentially a drug dependence, describing herself at one point as an orchid with a wide bloom, but one which is growing more or less out of the Eli Lilly company. "It's one thing to be dependent on a drug," she writes, "but the issues get more thorny still if the substance imparts unfair advantage [reference to Peter Kramer's claims that Prozac makes people 'better than well']. Thus I wonder, am I now entering the wrestling ring of life on psychic steroids?"[157]

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[155]Slater, *Prozac Diary*, 24.
[156]Ibid., 35-36.
[157]Ibid., 188.

Slater foreshadows—or perhaps begins a bridge towards—disability studies, through her gnawing discomfort with her depression being cast as intrinsically and completely pathological. For example, though Slater clearly claims an illness identity, she also clearly values the creativity that she associates (not without precedent) with her depression. She does acknowledge some element of pathology in terms of her behavior (rather than in terms of her emotional state.) Yet despite diagnostic criteria focusing on behavior, depression is generally thought of as being primarily an *emotional* or mental disorder that is manifested in behavior. This is an important distinction because it suggests that social construction (in the form of one's position as doctor or patient, for example) creates variations and subtleties in the perception of the nature of pathology, creating multiple readings even for a single event which both doctor and patient would label pathological. Slater, a psychologist as well as a writer, certainly aligns her experiences with the category of illness, but perhaps her concurrent authority as another kind of mental health professional permits some philosophical musings about illness, self, brain, and mind.

One of the very few autobiographical accounts of mental illness by a person of color, *Willow Weep for Me* focuses very specifically on the intersection of Ghanaian Meri Nana-Ama Danquah's experience of depression with her experience of life as a black woman. Danquah tends to follow the standard narrative trajectory, though with some variation.[158] She begins the main story line with the onset of her first major depression when she was twenty-two, having moved to Los Angeles from

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[158] Danquah's memoir seems to be as fueled by the necessity to write about her life as a black woman as it is to write about her experience with depression. Though not at all surprising inasmuch as the naturalization of depression as a white illness is part of her concern, her emphasis does raise the question of whether there are as many narrative conventions for the representation of identity as a black woman as there are for the representation of a depressed person.

Washington, D.C. At first, she was enthusiastic about her life in L.A., and started a twice-monthly poetry series called "Positive Vibrations through Spoken Word," through which she met a 38-year-old Ghanaian accountant. They began dating and Danquah soon found herself pregnant. Unfortunately, she also gradually found herself unable to cope with the daily tasks of self-care, and her prolonged absences led temp agencies to drop her from their lists. The relationship with the accountant dissolved soon after the baby was born, and Danquah found herself in serious straits, eventually moving into a run-down building that she managed in exchange for free rent, and working a phone sex line to help pay the bills. When she became truly overwhelmed, she moved back to Washington, D.C., where her parents still lived, and into her mother's apartment, which is where her memoir really gets underway.

Although Danquah's narrative is akin to other depression narratives in most of its major features, it "reads" somewhat differently. Though Danquah moves more or less chronologically through the main line of the story, she keeps dipping back into memory, making the chronology difficult to map. She has a sense of humor which is muted but always present; it is a perhaps some sort of quiet hopefulness rather than the cultivated, dry sarcasm of some of her white counterparts. Danquah's narrative also feels less removed and, in a way, more personal than some other narratives, even though she is much less revealing about some of the intimate details. This reserve seems to make the details that she does reveal—e.g., that she sets four separate alarm clocks to ring up to an hour and a half before she actually rises—feel very genuine, personal, less of a spectacle.

One of the other distinctive features of Danquah's narrative is the way in which she represents lay people (e.g., not doctors) as major catalysts to action. For example, as Danquah is falling apart in Los Angeles, her friend Eugene tells her that he thinks she's depressed. When she challenges him on his knowledge on the subject, he reveals that his mother, a prominent figure in D.C. black middle class society, has a seasonal depressive disorder. Danquah is astonished; she is further astonished when she later meets the woman and finds her to be "normal"—and not at all what her idea of a depressed person should look like. Likewise, when Danquah meets Jade, a friend of a friend who also ended up in Washington, D.C., she comes to understand that Jade is also depressed, recognizing the "masks" involved in covering up the depression. This shared experience helps to forge a very strong bond between them.

These relationships seem to serve to ease Danquah towards acceptance of the diagnosis of depression, which she has resisted because it seems impossible for her, a black woman, to be depressed. She writes,

> Stereotypes and clichés about mental illness are as pervasive as those about race. I have noticed that the mental illness that affects white men is often characterized, if not glamorized, as a sign of genius, a burden of cerebral superiority, artistic eccentricity—as if their depression is somehow heroic. White women who suffer from mental illness are depicted as idle, spoiled, or just plain hysterical. Black men are demonized and pathologized. Black women with psychological problems are certainly not seen as geniuses; we are generally not labeled "hysterical" or "eccentric" or even "pathological." When a black woman suffers from a mental disorder, the overwhelming opinion is that she is weak. And weakness in black women is intolerable.[159]

This is an intriguing passage for several reasons. First, Danquah's assertion that mental illness is a different sort of cultural event for different people differentiates her

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[159] Danquah, *Willow Weep for Me: A Black Woman's Journey through Depression, a Memoir*, 20.

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somewhat from most of the other authors of mental illness narratives who tend to

stick rather closely to the biological "it's an illness, like diabetes" line of argument,

and which make little mention of such kinds of variables in their descriptions of their

cultural contexts. (This is perhaps not surprising, as these published narratives are

often written by those who do not seem to see economic or white privilege as being

relevant factors.) Second, she does not seriously differentiate between "mental

illness" and "psychological problems," in terms of kind, but only in terms of scale,

which also differentiates her somewhat from the majority of authors who tend to

understand the phenomenon in terms of physiological illness. For instance, Danquah

writes, "…when depression reaches clinical proportions, it truly *is* an illness, not a

character flaw or an insignificant bout with the blues that an individual can 'snap out

of' at will." [160] This, of course, suggests that depression that has not yet reached

clinical proportions *could* be a character flaw or insignificant bout with the blues.

(Interestingly, Danquah notes that depression in black men is "pathologized" but says

no more about it, a curious contradiction in a book that claims that depression is an

illness, e.g., pathological, in the technical sense.)

On the surface, Danquah's framing of depression as an illness when in clinical

proportions can be read as the standard protest that depression "really" is an illness,

and should be taken seriously; however, by the time of publication in 1998, this

argument had been made repeatedly in mainstream depression memoir and was losing

some of its novelty. Instead, I think it can also be read with a slightly different slant,

perhaps one that better reflects Danquah's Ghanian cultural heritage. On the whole,

Danquah seems much less likely to compartmentalize and distinguish between

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[160] Ibid., 18.

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"herself" and "her illness" in the way that, say, Wurtzel or Styron do. Danquah's

white counterparts seem to understand depression-as-illness at least to some extent in

the context of the mind-body split, so that while body (which in this case includes the

physical brain) may be ailing, mind still remains somehow aloof and protected from

accusation of illness. Danquah, who came to the U.S. as a child and who remains

partially connected to Ghanaian culture, does not seem to need to perform this kind of

contortion, or at least not to the same degree; the book chronicles her slow acceptance

of her depression as real, but once she does, she understands it as an integral part of

her life. Likewise, an explication of her childhood (and descriptions of traumatic

events or potential causes of psychological distress) is noticeably absent. Danquah

only briefly mentions the fact of her emigration or her parents' divorce. She notes,

"When I first started therapy, I found myself unable to talk about my parents or admit

that I felt a tremendous amount of rage toward them. I imagine that it was because in

African as well as African-American cultures, talking about one's parents is frowned

upon; only an ingrate would do such a thing."[161] Unlike her white counterparts who

usually either explicate the psychology of their youth in detail, or protest that they

had happy childhoods (to lend support to the biological illness explanation), Danquah

says very little—again the exception that proves the rule.

Finally, *Restricted Access: Lesbians on Disability,* edited by Victoria

Brownworth and Susan Raffo, provides an additional "diverse" perspective to the

narratives examined here. However, I will treat this anthology both as a whole object

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[161] Ibid., 35.

(foreshadowing extended discussion of the "physical disability narratives") and also focusing more particularly on four short essays about mental illness.[162]

As a complete object, it represents one of the better efforts to date at compiling a demographically diverse pool of memoirs. Published by a feminist press with academic associations, it is often cited in disability studies/activism when an effort is being made to include lesbian perspectives on disability, probably because the editors so explicitly address the categories of identity that shape much of contemporary cultural studies. In the introduction, for instance, Brownworth remarks that at the onset of her disability she went looking for writing by working-class disabled lesbians, found a conspicuous absence of such texts, and that this absence became much of the impetus for the establishment of this collection. Brownworth's efforts to publicize explicitly lesbian perspectives on disability encapsulates the social and intellectual advantages of representing a variety of points of view, as well as the difficulties of using social categories of difference as demarcations to stand in for intellectual differences. (This latter point will be discussed at length later in the chapter.) Brownworth notes the difficulty that she and co-editor Raffo had in obtaining manuscripts by non-white contributors, a point which echoes my own difficulty in obtaining a demographically diverse pool of published narratives to work with. Even if still unsatisfactory to Brownworth, the pool of contributors is at least as diverse in terms of race, sexuality, and class as anything else on the subject in a mainstream publication, and that effort towards a balanced demographic representation is intellectually and methodologically appropriate, if nothing else.

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[162] Brownworth and Raffo, eds., *Restricted Access: Lesbians on Disability*.

Twenty-seven of the thirty-one contributions in *Restricted Access* are primarily about physical disability, by which I mean that the authors address the experience of living with a physical disability. As with much feminist writing anchored in 1970s and 1980s feminist thought, however, there is a desire to represent the experience of the whole person, so there are ways in which the traditional Western mind/body distinctions are intentionally blurred. Also predictably, in most ways these contributions have a very disability-activist perspective, with a rejection of the pathology of disability, and call for greater opportunities for people with disabilities in the name of social justice.

However, the four contributions explicitly addressing the experience of madness/mental illness are interesting and unusual in how they have been fitted into the rest of the collection. These narratives, in general, follow the usual illness-recovery trajectory of the mental illness category, and do not reject pathologization, instead using their acceptance of the label of "mentally ill" as a call for greater availability for services, much like the popular public service announcement-style framing of breast cancer, which uses every survivor as a reason to expand the research agenda and to make diagnostic services more accessible. The editors note:

> "As a consequence of this complicated and often brutal history, [referring to the pathologization of lesbianism itself] lesbians have frequently refused to seek help for mental illness—and have found wellsprings of support for that refusal within the lesbian community. Fear of the medicalizations of the past—which continue in some communities—has led to other problems for lesbians with mental illness; there remains far more support within our community for rejecting therapeutic care, particularly medications, than for utilizing those often quite necessary therapies."[163]

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[163] Ibid., xix.

Like most other mental illness narratives, contributor Faith Reidenbach begins her narrative at the onset of her first experience with mania, in 1979, during her sophomore year at a women's college in Massachusetts. She describes her erratic behavior, how things seemed to her in contrast to how they seemed to her friends, and chronicles the events leading up to her friends taking her to the school infirmary to see a psychiatrist—and most notably, the pointed efforts of her friend Angela to make sure that Reidenbach *not* enter the psychiatric care system. From there, she describes her struggles with diagnosis and treatment, including a typical series of doctors and therapists with varying assessments and treatment plans, also with the typical emotional roller-coaster of the impact of her experiences on friendships and romantic relationships. At the time of writing, Reidenbach had come to accept the diagnosis of manic depression (bipolar disorder) and emphatically supports medical treatment, e.g., in her case, lithium. She frames her experience as a "hidden disability" and is grateful that she received treatment, though noting that some experiences were more helpful than others.[164]

Reidenbach's narrative, like others in *Restricted Access*, is different from the usual published mental illness narrative in one important way; the cultural context(s) through which psychiatric treatment is perceived. Reidenbach's friend Angela explicitly perceived psychiatric treatment as a kind of cultural policing of gender and behavior, a process from which her friend should be rescued—a perspective that should be understood in the context of 1970's feminism and lesbian-feminism, and also in the context of the behavioral approaches to psychology that were in greater fashion at that time. Reidenbach also notes her parents' concern that her lesbianism

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[164] Ibid.Faith Reidenbach, "Backward by Threes," p. 45.

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and manic depression were related, and recounts experiences with feminist therapists that perceived psychiatric illness as the oppressive tool of a male medical establishment. In other words, Reidenbach's immediate cultural context—that of 1970's and 1980's feminist communities—was an environment with a view of psychiatric treatment and diagnosis distinctly different than that seen in mainstream publications today. The official diagnosis of lesbianism as an illness has been vanquished from psychiatry, and indeed seems oddly anachronistic. But it is the realization that the psychiatric treatment that Reidenbach received in the late 1970s and early 1980s had such a strong *behavioral* component that seems most shocking today, and serves to illustrate how comprehensively biological approaches to psychiatry have become the contemporary standard. The way that Reidenbach's narrative presents the mental illness experience itself is really quite typical: it is the contrast between what "resistance" in service to people with disabilities could mean in Reidenbach's different historical contexts that is intriguing. [165]

Memoirs of Physical Disability

Like the memoirs of mental illness, the memoirs of physical disability also conform to several narrative conventions, the most important of which is a refusal of the medical model of disability as equivalent to deficiency or pathology. In some ways, this is a delicate matter; it is difficult to seriously frame progressive or terminal illness as merely a matter of a spectrum of human variation, as some people with

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[165] Unfortunately, my attempt at a chronological arrangement of the narratives is complicated a bit by the fact that the narratives of mental illness recall experiences that occurred quite a number of years ago, so the most recent book in this study includes recollections of experiences predating the first book in the study. However, I feel the asymmetry is more than compensated for by the clear illustration of how much of a shift has occurred in what we conceptualized "psychiatry" to be.

other kinds of disabilities often do. But even where pathology for the disability itself is granted (e.g., for illness such as multiple sclerosis or cancer), these narratives emphasize that there are other ways of thinking about and living with these things that refocus attention to what is possible, beautiful, or enjoyable, rather than seeing all aspects of the experience as detractions from a "normal" life.

Memoirs of physical disability usually serve as the chronicle of a journey to acceptance—usually less about acceptance of the physical disability or illness itself than acceptance of the need to consider disability a political category or issue. Without exception, all of the memoirs studied here include some revelation that some sort of social/political action is needed, whether that action is indirect, such as raising awareness about disability by writing about one's personal experience with it, or more direct, such as street protests or lobbying for stronger occupational, consumer, and environmental protections, to help reduce the ingestion of carcinogens by an unsuspecting public.

Closely related to the embracing of disability as a political category is the emphasis on developing a personal community of people who share some understanding of what the experience of living with disability is like. This is not so much the "support group" sort of help with tips for transferring from wheelchair to toilet, but rather the sort of community in which it is not necessary to accommodate the discomfort of nondisabled people.   To some extent, this overlaps with the recognition of the need for actions toward social justice, but there is also a way in which it is an assertion that the ability to socialize without always being uncomfortable in one's own skin is something akin to a fundamental human right.

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Occasionally described as the book that gave birth to disability studies, Irving Kenneth Zola's *Missing Pieces: A Chronicle of Living with a Disability* (Temple University Press, 1982) frames the author's experiences visiting Het Dorp, a Dutch residential facility for people with disabilities. Zola was physically disabled as a result of polio and a later car accident, and used back and leg braces in combination with a cane to move around, but he did not claim an identity as a disabled individual prior to his visit. His visit to Het Dorp was originally a professional one, in his capacity as a medical sociologist at Brandeis University. In an act that comes to be the catalyst to epiphany (and that would generally be critiqued today for its presumptuousness), Zola chose to use a wheelchair during his week-long 1976 stay so that he might "live like a resident." In fact, it is Zola's experiences at Het Dorp that lead him to identify much more actively as a person with a disability in the political sense of the term. The epiphany Zola describes is actually quite bizarre to the contemporary reader who is more apt to wonder how he managed *not* to see himself as disabled prior to his visit.

Zola describes the 165-acre Het Dorp as a relative utopia, at least compared to other facilities for people with disabilities. At Het Dorp, residents have private apartments designed specifically to be wheelchair accessible with electrical outlets placed higher, windows and countertops lower, and spacious bathrooms also suitably arranged. The residences are organized into tree-lined streets with a central kitchen, library, and church/community center. "Dogelas"—essentially a pool of personal assistants—provide services at the request of residents, but do not anticipate needs or provide medical care. (Medical services are available on site if needed, however.)

Zola's dual perspective as both a medical sociologist and as a person with a disability, in combination with his adoption of the wheelchair for the week, come together to elicit a revelation that despite, or perhaps precisely because of, his own disability, he has internalized a series of prejudices and assumptions about people with disabilities. The change of scenery resulting from his use of the chair sensitizes him to how many ordinary activities have new layers of practical difficulties that must be managed, but more importantly how some of the practical difficulties have substantial social effects on the residents. He observes that there are very few units available for married couples, despite considerable demand, and from a surprisingly honest and straightforward conversation about sex (with a male resident who is unable to masturbate by himself) and gains an understanding that even this comparatively respectful facility falls far short of recognizing the full humanity of its residents. For Zola personally, these observations and others combine to elicit an epiphany that he has a greater solidarity and identification with the residents than he thought he did.

Simi Linton's *My Body Politic: A Memoir*, is a hybrid of memoir and academic essay that also describes her journey to becoming politically identified as disabled. Published by the University of Michigan Press—notable among academic presses for its disability studies series—and written by one of the eminent disability studies scholars and activists, it is an exceptional book in many respects. Linton's memoir did not make her a celebrity within disability studies or amongst paraplegics; she was already known for her academic scholarship and this text, though written in a

conversational style and based on the terms of her personal life, is no less "argued" or theoretically informed than her scholarly work.

Linton's memoir begins with the 1971 car accident that killed her husband and best friend and left her paralyzed from the waist down. This temporal structure is reflective of the sudden onset of Linton's career as a person with a disability, but is explicitly much less concerned with the onset of the paralysis per se than the process of her becoming disabled in the political, epistemological senses of the term. Linton observes, "The new shape and formation of my body were set on that April day; the meaning this new body would have for me took years to know."[166]

Linton's memoir seems to flow in fits and starts; she gives comparatively little attention to formal experiences that academics usually tend to set greater weight on (such as her graduate work) and a great deal more attention, proportionally speaking, to moments that are perhaps best described as deeply symbolic, such as an occasion in college when she encountered a man using a wheelchair who was engaging in a playful yogurt-throwing dance/foodfight with three women on a Berkeley street. Likewise, Linton often reminisces, which also disrupts the trajectory and gives the impression of a strung-together series of discrete moments. Briefly summarized, Linton covers her recovery from the accident, her rehab center experiences, her first solo apartment without her husband, and her decision to go to California to study. She returned from California to study psychology at Columbia University, and later went on to obtain a Ph.D. in counseling psychology from NYU. She taught for more than a decade, and left academia a few years ago to pursue a career as a consultant and activist, promoting disability in the arts.

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[166] Linton, *My Body Politic: A Memoir*, 3.

Linton's history emphasizes her relationships with other people with disabilities, and the way that knowing them has changed her thinking. The climax of the memoir seems to be either the chapter in which she describes the people whom she's met through the Society for Disability Studies (SDS), or the chapter in which she describes her second husband, and their lives with their various friends, many of whom are also disabled. While it is certainly understandable that Linton's journey to political identification as disabled would be strongly, even primarily, shaped by the people with whom she surrounds herself, as well as the people with whom she finds many things in common, her relationships become overtly politicized in some ways but less so in others. For example, when Linton describes her friends from SDS, she describes beautiful and talented people without whose support (and rapport) she could not manage, and the importance she places on them emphasizes the degree to which something can seem either possible or impossible depending on the kind of knowledgeable encouragement and collaborative support is available.

However, Linton is also describing the intelligentsia of academic disability studies, many of whom inform much of the scholarly direction of the field and/or do various kinds of work with autobiographical narrative or other forms of representing personal experience. Linton's representations of the people she knows from SDS or similar situations certainly can and should be read as providing respectful (and generous) portraits of people with disabilities and a legitimate counter-narrative to the discourse of disability-as-deficiency, but the modest size of the community also makes the interrelationships complicated. Linton, for example, sits on the editorial board for the "Corporealities: Discourses on Disability" series for the University of

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Michigan Press, and her chapter on her friends from SDS includes portraits of other members of the editorial board and the series editors. *My Body Politic* is not a part of that series, but the fact of its publication through the University of Michigan Press (a press of choice in disability studies) and not a trade press publisher is notable nevertheless, because some of those figures—Linton included—are simultaneously subject matter, author [Linton only, in this case], and influential in the publication of disability-related texts from this university press. I make this point not to suggest impropriety, but to illustrate that a fairly small number of people have, through multiple roles, an exponentially large impact on the circumstances of production of this narrative, in both the literal sense of its production as a discrete book and also in a more abstract way of producing alternative (i.e., alternative to disability-as-pathology) discourse on disability.[167] Though mediated by a different and much more respectful set of expectations about the appropriate kind of discourse on disability, the self-referentiality inevitably means that Linton's memoir operates under narrative and discursive constraints just as surely as her fellow authors at trade presses.

Kenny Fries's *Body, Remember* is a very "written" memoir, perhaps the most obviously framed as a journey to political acceptance. It is crafted carefully to develop and unfold several intertwining stories at once, reflecting Fries's tangled process of coming to terms with himself as a disabled, gay, Jewish man. Fries's narrative argues for a conception of disability as a political identity by paralleling it with his Jewishness and gayness.

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[167]These overlapping relationships are easily attributable to the small size of this emerging field and the necessity of having editorial boards composed of prominent figures in the field.

Fries's description of his early life is fairly centered on issues of power and its manifestations: physical pain from surgeries; the emotional pain of realizing the social meaning of his body's difference; and abuse from his father and older brother. While memoirs written by people with a disability-rights consciousness often portray the medical establishment in a predominantly negative light, Fries describes his experiences in more complicated terms. Although he describes the considerable fear he felt prior to his childhood surgeries (which in at least one circumstance he suggests manifested itself as a sudden fever the night before the surgery) and the pain thereafter, his relationship is ambivalent. It might be described as being genuinely and warmly grateful that it wasn't worse. For example, Fries appears to have relatively warm feelings towards his pediatrician, Dr. Milgram, who performed several surgical interventions to allow Fries to walk in his own way on his own legs, rather than recommending amputation to "manage" the missing and unusually-formed bones in his feet and legs. Though these interventions were painful and Fries implies that they may possibly have contributed significantly to back pain in later years, Milgram remained Fries's trusted doctor until the end of his career.

A trip to Israel in early adulthood is an important component in solidifying Fries's identification as a disabled, gay, Jewish (and American) man. The men he meets there are both like him and not like him, and these juxtapositions help to crystallize for him who he is, by allowing him to see who he is not. In a clever literary parallel of the theory of the social construction of disability, what Fries's legs "mean" in Israel plays a much smaller role in this section than in others in the book;

"disability" as a category of identity is greatly overshadowed by Jewishness, Americanness, and gayness.

The third section of the memoir focuses on the way in which these identities come together, and come together in crisis. In this section, Fries describes a complicated period of crisis in his life, where the discontinuities have multiplied to a point in which Fries feels himself becoming fractured. Physically, he begins to experience significant back pain and an exaggeration of his limp, which he attributes to a gradual change in his stride, yet for a long time he doesn't seek medical care. Emotionally, he begins to experience severe depression. Two major romantic relationships are marred by distrust, infidelity, and domestic violence; stress is also contributed by the discovery that his first partner is HIV positive, and that the second is an alcoholic. Fries eventually checks himself into a psychiatric ward when he becomes suicidal. In the course of psychotherapy, Fries begins to recall more vividly experiences of childhood abuse by his father and brother, and realizes that the separation of his life into discrete categories (and experiences) is contributing to his sense of disjuncture and unrealness.

Predictably, Fries's psychotherapy and the addressing of these issues results in healing and a bridging of these facets of life kept separated. Fries confronts both his brother (who turns out also to be gay) and father about the abuse and reaches reconciliation with his family. In some technical respects, the reconciliation serves as the denouement, inasmuch as there was an obvious crisis to be resolved (depression as a result of the repression and fragmentation of parts of his life). However, Fries's reconciliation is complex, and the resolution of some crises lead to

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new difficulties rather than resolution. A scene in which Fries visits the Holocaust museum and observes remembrances of the Jews and homosexuals, noticing the absence of acknowledgement of the people with disabilities who also perished. Fries imagines a monument for people with disabilities, similar to the Homomonument, and this imagining sets the tone for the closing of the memoir. Although at the end Fries has come to a place of maturity where fragments of his life are no longer hidden or concealed, disability remains the uncertain component. In many ways, Fries's resolution with disability is that it is something that has no resolution; any answers as to what it means will always be provisional.

Nancy Mairs echoes Fries's acceptance of the provisional. She frames her *Waist-High in the World: A Life Among the Nondisabled* as being grounded in her own experience, as that is the one thing she has that no other writer can offer, and thus, because MS is interwoven through her life, MS is interwoven through her writing. Mairs claims that a "desire for accuracy" prompts her to describe herself as a cripple rather than as a person with a disability, because as she says, "In truth, though I am severely crippled, I am hardly disabled at all, since, thanks to technology and my relatively advantaged circumstances, I'm not prevented from engaging in the meaningful activities and relationships the human spirit craves."[168] Mairs uses this "desire for accuracy" to startle her reader and vandalize expectations about what life with a disability is supposed to be. Perhaps better described as a shock tactic, she frequently describes in a very matter-of-fact way details that most people would choose to conceal (e.g., incontinence) to put her illness' worst face forward. Of

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[168] Mairs, *Waist-High in the World: A Life among the Nondisabled*, 13.

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course, this approach presents a life comprised of small annoyances and pleasures, and nothing near as dreadful as most people would imagine her life as a whole to be.

Mairs divides the book roughly into two sections, the first dealing with the "Home Truths" of her life in her body, and the second dealing with "The Wider World" and her place in it. This arrangement is essentially the journey to activism story told elsewhere; as Mairs adapts to the gradual deterioration of her body, she also gradually assumes a progressively greater identification in her life in her body, and thus a progressively greater identification with the position of other disabled people. Mairs avoids the idea of pathology, not so much as a conscious refusal, but rather by making the idea seem irrelevant as she focuses instead on the practical materialities of what her body can and cannot do. She takes a similar approach to her depression; although she resists drugs at first, she comes to the conclusion that they make her feel better and therefore are useful to her.

Mairs engages the politics of disability throughout, but her engagement with the most personal aspects are among the most interesting. Mairs recounts a day in which there is a "breakdown in the Nancy-care apparatus," meaning that schedules got mixed up and there was nobody there to help her get dressed and started in her day. Mairs then recounts the specific challenges of getting washed and dressed, in which it becomes very clear that even a slight mistake could have dire consequences; if her wheelchair is parked too far away and she falls getting from bed to chair, there will be nobody there to help her for several hours. She couldn't even telephone for help. Eventually, she succeeds in getting dressed and fed, but it's a complicated success:

> And now I am in front of the computer, limp but victorious: clean, clothed, and fed. I can hardly wait for George to get home so I can gloat. He'll be horrified, I know, but also hopeful at this sign that I'm not yet wholly incapacitated. We both recognize that such efforts aren't a wise use of my limited resources and that the more often I try to repeat them, no matter how cautiously, the more likely some serious mishap would become. I owe much of today's triumph to pure luck.[169]

Of particular note is her recognition that her ability to perform certain tasks are not necessary good for her—e.g., they represent a risk, and a more beneficial long-term approach considers her overall safety more prominently. Mairs engages the ideas of "dependence" and "independence" in far more sophisticated ways than do most writers, and does not approach them as direct metaphors for her political status. Rather, Mairs offers a completely different sort of model for approaching the valuation of abilities; her journey is not only about coming to accept activism as a necessary part of her activities, but also about accepting her MS as a set of complicated circumstances that offer both limitations and new opportunities.

Audre Lorde's *The Cancer Journals* is one of the more challenging narratives described here because it bears little formal relation to what has become the usual disability rights-based memoir, yet it is undeniably true to the spirit of the enterprise. First published in 1980, *The Cancer Journals* predate Zola's *Missing Pieces* by two years, and should be understood in context: *The Cancer Journals* were published with a feminist audience in mind. Lorde's writing and thinking was organized around her feminist sisters, especially her black feminist sisters, and in any event, the idea of a disability rights audience did not yet really exist.

The Cancer Journals is comprised of a series of essays interspersed with excerpts from Lorde's journal, and thus does not proceed along the usual

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[169] Mairs, *Waist-High in the World: A Life among the Nondisabled*, 68.

chronological path. Section I, "The Transformation of Silence into Language and Action," is a manifesto on the need to speak as an antidote to fear, silence, and isolation. Section II, "Breast Cancer as a Black Lesbian Feminist Experience," recounts Lorde's discovery of the tumor, her surgery, and recovery. Section III, "Breast Cancer: Power vs. Prosthesis" examines the ways in which cultural pressures to wear a prosthesis deny the life-threatening and life-changing implications of cancer.

Rather than the "journey to activism" story that many of the disability rights memoirs tell, Lorde is already immersed in the context of social justice activism at the beginning of the book. Instead, Lorde struggles to fight the cancer with conventional Western medicine and equally, struggles to resist assimilation into what she sees as a silencing of the experience of breast cancer. It is worth noting that *The Cancer Journals* were published by a small lesbian feminist press and not a major corporate press; Lorde published with both in her lifetime, but in 1980, perhaps the story of a one-breasted black lesbian warrior poet not trying to conceal her surgery would have been a bit too much for a mainstream corporate press.

Again, it is an African American woman writer who serves as the exception that proves the rule, in this case the (dominant, and white) rules about writing disability memoir. Lorde uses *The Cancer Journals* to address her audience in a more holistic way than is typically seen in later memoirs, which seem much more targeted to disability as a discrete identity. Perhaps the most striking difference is that Lorde does not internalize the identity of "cancer patient" too deeply, embracing it merely as a descriptor of her particular circumstances rather than as a way of

thinking about herself. Instead, she identifies as a black lesbian dealing with multiple forms of injustice and oppression, among which she counts environmental pollution, hormone- and chemical-laden foods, and the generally unhealthy conditions in urban areas in which many non-white people live. The famous scene in which Lorde is chastised by a nurse for failing to wear a prosthestic breast form to conceal the fact of her mastectomy (because it's "better for morale" for the other women in the waiting room) is unquestionably a vivid illustration of the silencing and erasure of disability-related issues, a concern shared with many disability rights activists. Even where other writers acknowledge other facets of identity (e.g., Kenny Fries's homosexuality), disability is treated as a very specific kind of oppression to be overcome, and thus, a very specific kind of identity.

In contrast, Lorde approaches her cancer (and all the accompanying attitudes that demand its erasure) more as a symptom of a larger disease, the systems of power that relegate certain people (people of color, women, lesbians, and those who have breast cancer) to having to deal with greater proportions of injustice. From a historical perspective, comparing her memoir with those written more recently is akin to comparing apples and oranges, and there is much to be said about understanding her narrative in context. But I'm not at all sure that such narratives are necessarily *read* in a historical context, at least by those who might read such things outside of scholarly pursuits, and Lorde's acclaim means that she is read much more widely today than Irving Zola, for instance, perhaps because the anger with which she approaches the injustices of her cancer and its treatment.[170] Lorde approached her

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[170] "Injustice" requires a bit of contextualization here, as Lorde is not talking about individual justice in the sense that it is unfair when bad things happen to good people. Lorde is angry about the difficulties

cancer as she approached the rest of the world; cancer was but one of many problems

in the world that needed addressing, and in many ways her tone in addressing her

cancer is quite like a lot of 1970s lesbian feminist work. My point here is that *The

Cancer Journals* functions quite nicely as an ahistorical artifact; what is on the page

fits in well with what contemporary disability studies argues, and of course any

current social justice movement would cheerfully claim Lorde as a member to the

extent possible.[171] Therefore, Lorde is posthumously and retroactively claimed by the

disability rights movement, and by disability studies. I am not necessarily critical of

this posthumous inclusion, as it seems consistent with who she was and how she

thought. But it does seem to capitalize on an awareness of the political work that

memoir can do, with something of an intent to make *The Cancer Journals* into one

more foot soldier in a larger army. The fact of that usage underscores my point in this

chapter that these narratives take on something of a life of their own; they necessarily

become read in context with other stories that are classified as "like" or "unlike" in

ways that are at least as much about contemporary agendas and power as about the

documents or writers themselves.

Standardizing the Story

        One of the most interesting questions about these groups of narratives as a

whole is the issue of diversity, in both the demographic and the intellectual sense of

the term. As noted earlier, the overwhelming majority of narratives of mental illness

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of living a healthy life in an urban environment and clearly considers pollution of various kinds as a possible cause of her cancer. Likewise, she is angry about her options in treatment, both of which she sees as evils perpetrated by a racist, sexist, capitalist society, and to that extent Lorde essentially approaches all cancer or related illness as having some component of injustice.

[171] Gary L. Albrecht, *Encyclopedia of Disability*, 5 vols. (Thousand Oaks, CA: Sage Publications, 2006), 468. The inclusion of Lorde in the *Encyclopedia* speaks to the standard acceptance of her status as a figure in disability studies.

and physical disability—when framed primarily as such—are written by (apparently) middle-class whites.

The predominance of middle-class writers is fairly easily explained. As the publication record obviously does not correlate to epidemiology, it's important to understand these texts as reflecting a very limited portion of the population, e.g., those for whom the writing and publishing of books is a response that can be contemplated in the circumstances of the adversity of disability (whether the adversity is an illness itself, or the many forms of social/cultural discrimination and disadvantage that tax the time and energy of disabled people who are otherwise unhampered by their disabilities).

The issue of race is more complicated. Of the narratives in significant popular circulation (e.g., meaning published by mainstream publishing houses, not those published through vanity presses), there are very few illness narratives by people of color, and no memoirs by people of color about other kinds of physical disability (to the best of my knowledge), at least not in this type of published book form. I would speculate that the fact that there are so few is probably reflective of a wide range of factors: publication patterns in general, differences in preferred media, and differences in preference for the kinds of stories that people want to tell (i.e., the kind of illness narrative described in this chapter might reflect a level of individual self-absorption that is unflattering in some cultural contexts.)[172]

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[172] In his doctoral dissertation, Tyrone Stewart examines the politics of emotionality in black men, most especially in terms of clinical depression, and provides a number of arguments for developing a more complex understanding of the experience of depression. Stewart challenges the pathology of the diagnosis of depression by arguing that a holistic understanding of the emotional experiences of black men should be more inclusive of other factors (e.g., the particularity of race). Likewise, he makes a compelling case that black male depression can be seen in a much wider range of forms of self expression than the depression memoir, many of which tend to reject outright classification as

However, the functioning of what one might call "popular conceptual taxonomies" also complicates the issue, and can hinder and obscure the relationship of illness or disability to other conceptual categories. For example, even when illness plays a significant role in the context of an autobiography, it can disappear from the way a book is classified by Library of Congress subject heading in libraries, or by commercial booksellers. Thomas Couser also notes that nonliterary celebrities' accounts of illness are usually shelved in the biography section (e.g., Arthur Ashe's *Days of Grace*).[173] The hierarchy of popular conceptual taxonomies also means that "race" can trump "disability" or "illness," so that even contemporary biographies of such figures as Harriet Tubman or Wilma Rudolph do not generally appear under "disability" or "illness."

I believe this kind of taxonomy to be enormously significant, though quantification is beyond the scope of this study. For example, I originally found Meri Nana-Ama Danquah's memoir of depression—classified by the LOC headings first as "Danquah, Meri Nana-Ama—Mental Health," then as "Depressed persons— United States—Biography" and finally as "Afro-American women—Biography") shelved in the African-American section in Borders Books and Music (as well as a random selection of other bookstores, as I usually now check out of curiosity.) Interestingly, however, one online equivalent—the "Customers Who Bought This

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depression. But Stewart does not seriously challenge the idea of the experience of depression itself as anything other than "bad." Tyrone Anthony Stewart, "What Is a Black Man without His Paranoia? Clinical Depression and the Politics of African Americans' Anxieties toward Emotional Vulnerability" (University of Maryland, 2009). It is also my understanding that a forthcoming book from Sheri L. Parks will address some issues related to emotionality in black women. Sheri L. Parks, *Fierce Angels: The Strong Black Woman in American Life and Culture* (New York: One World/Ballantine, 2010)
[173] Arthur Ashe and Arnold Rampersad, *Days of Grace: A Memoir* (New York: Alfred A. Knopf, 1993).

Item Also Bought" section on Amazon.com—associates this book overwhelmingly

with other memoirs about mental illness.

All of that said, I am not suggesting that what is needed is just for more

people of color who have experienced illness or disability to write about it and

publish. I am addressing the absence of narratives of illness or disability by people of

color because I believe inquiry into the causes of the disproportionate representation

is important to an ethically and an intellectually rigorous methodology.   I am not the

first to notice this publication pattern; both Thomas Couser and Victoria Brownworth

have also observed this difficulty and challenge. Brownworth muses:

> "Wide-ranging as I feel the essays in *Restricted Access* are, and
> diverse as the complement of writers appears to be, it is important to
> point out that even working together from our very different
> communities…we would have liked to have had an even broader
> representation, particularly from women of color. In the past, I have
> chastised other editors in reviews for lack of representation of people
> of color; I believe it is incumbent upon white editors to make
> anthologies as inclusive as possible. In my other anthologies, I have
> striven for racial balance and managed to achieve it. This anthology,
> for reasons neither Susan nor I understand, and despite our best efforts,
> was far more difficult. Though Susan posted our call for submissions
> on every conceivable Internet site, the responses were, throughout the
> process, predominantly from white women. I do not make this point to
> excuse having fewer women of color—especially black women—than
> either Susan or I would have preferred in this anthology, but to signal
> what I believe is a concern for both the disabled community and the
> lesbian community. Access to the Internet by women of color seems
> far more restricted than it is for white women even when they are of
> limited income… Nearly every woman writing in *Restricted Access*,
> regardless of her particular disability, geographical location or class
> status, speaks of a certain level of isolation. Not surprisingly to me,
> women of color and women who are not middle class felt this more
> acutely. If the writers in *Restricted Access* represent a cross-section,
> as we hope they do, of disabled lesbians in America, then women of
> color and poor and working class women are even more isolated from
> lesbian community than their white, middle-class sisters. Perhaps an

anthology of writing by disabled women of color compiled by disabled women of color would help bridge that gap."[174]

Brownworth, however, is too simplistic in her implicit assumption that a broad demographic representation will actually ensure intellectual diversity. In theory, her efforts to collect contributions from a demographically diverse base should result in a more representative view of the experiences of illness and disability—but it doesn't seem to work that way.

I don't mean to say that Brownworth should be focusing on matching the demographic distribution of her narratives to epidemiology, though of course that might prove interesting. One of the contentions of this chapter is that the fact that memoirs of disability and of madness/mental illness can be grouped so easily into two kinds of camps and share so many characteristics means that *there are remarkably few kinds of stories that are granted legitimacy*, or at least legitimacy in the sense of being understood to be published in a mainstream press. Because there are two such very distinct narrative sub-genres suggests that, culturally speaking, there are *disability-specific* ways to articulate the experience of being physically disabled or mentally ill. Further, it is no coincidence that these sub-genres correspond to a difference in the framing of the experience as fundamentally an individual phenomenon of pathology (mental illness) or a socio-cultural phenomenon of oppression (physical disability).

However, it is curious that the mental illness narratives give no hint at all that the concept of mental illness has been severely criticized as means to judge and control individuals who do not conform. Foucauldian-type arguments that judgment

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[174] Brownworth and Raffo, eds., *Restricted Access: Lesbians on Disability*.

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against an individual for behaving in ways unacceptable to society can and is materialized as mental illness have been around for nearly half a century and have had profound effects on academic thought and grassroots movements of the 1960s and 1970s.[175] In fact, grassroots versions of Foucauldian-type analyses of how the disabled physical body is also disciplined and punished have been a cornerstone of the (physical) disability rights movement, and can be seen echoing (albeit sometimes distantly) throughout the physical disability narratives examined here.

Thus, it strikes me as fairly significant that the idea of mental illness as a tool of social control would have disappeared altogether from these memoirs (except when directly rejected, as by Faith Reidenbach). The continuing association of "pathologization" with "oppression" by the disability rights movement/disability studies enterprise means that the concept has not faded from the public arena, but it has clearly changed, at least as pertains to mental illness. The most obvious explanation is the shift in psychiatry towards biological ("chemical") explanations for experiences such as depression, with drugs for addressing the same. This shift, which has been accompanied by a concurrent lessening of the stigma of experiences of at least certain kinds of mental illness (e.g., depression and anxiety) has made it possible to redraw the boundaries where mental illness, physical disability, stigma, and oppression are concerned.

These memoirs of mental illness and physical disability routinely get grouped together through a variety of the "popular conceptual taxonomies" I mentioned

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[175] By the term "Foucauldian-type arguments" I also refer to the work of Thomas Szasz, Ronald Laing, and Erving Goffman, who made similar arguments about mental illness functioning as a form of social regulation, but whose arguments were more pertinent to the on-the-ground activities of the anti-psychiatry movement of the 1960s and 1970s. Similar lines of thought make extensive appearances in feminist theory as well.

earlier—Nancy Mairs' description of them as "the literature of personal disaster," my own grouping of them as a subject of analysis in a dissertation, their suitability as subject matter for inspiring stories of "courageously overcoming a challenge" on the six o'clock news. However, it seems that memoirs of mental illness and physical disability actually do very different kinds of cultural work.

While the authors of the mental illness narratives reinscribe the idea of pathology onto the experience, they simultaneously distance themselves from the experience. The writing of the experience—from the safe position of relative health—almost functions as a kind of "passing" inasmuch as it is simultaneously a validation of the practice of judging (e.g., by endorsing the interpretation of the experience of mental illness as a pathology) and an attempt to camouflage themselves so as not be counted among those on the negative side of the judging. The more the experience can be conceived of as not really about *them*—i.e., by making it a matter of brain chemistry and not of the Self—the more it can be managed and distanced. To appropriate Judith Butler's theory on the cultural "intelligibility" of gender, one could argue that because biological psychiatry (unlike psychoanalysis) offers a way to still be read as being on the right side of the pathological divide, they have an investment in keeping that boundary intact.

The authors of the physical disability narratives, on the other hand, focus on deconstructing the boundary between "health" and "illness," (inclusive, in this sense, of disability not related to disease) and seek instead to establish the idea of a spectrum of human variation. The narratives focus on a rejection of pathology—not always of the fact of illness or impairment in a literal way, but of the associated expectations

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that the person with the disability will assume a marginalized social role and quietly

retreat from most kinds of public life. Like the illness narratives, there is an

implication that the story has been written to help the prospective reader, but the

overall sense is that the help provided will be less about learning to cope with

limitations than of encouraging a journey towards activism and a demand for full

social inclusion. Here, the expectation in the telling of the story is that the author will

be recognized as a full person through the telling of the story, and that this kind of full

personhood, along with a degradation of the idea of "normal" through the "spectrum

of human variation," will achieve a far more radical restructuring of cultural power.

Chapter 5: Gender Identity Disorder and the Enforcement of Medical Authority

This chapter examines the political "work" done by pathologization of transgenderedness through the creation of Gender Identity Disorder (GID) as a mental illness—not so much as an example of heteronormative gender regulation, as is usually the primary concern of scholars working on transgender-related subjects, but rather as a way of looking at the process of pathologizing other experiences classified as mental illnesses by the mainstream medical establishment. One of the assumptions made in this project is that the *idea* of mental illness is sufficiently "naturalized" in mainstream American culture that the central mechanisms for the production and reproduction of medical authority are virtually invisible when approached straight on, and must be examined from an oblique angle to make the machinations visible.

Gender Identity Disorder provides an ideal subject for such examination because it lies at the margins of the category "mental illness." It is clearly delineated as a psychiatric disorder in all formal respects, yet it is also fundamentally different from the kinds of phenomena historically identified as mental illness (i.e., words such as "psychosis," "lunacy" and "insanity," are not easily linked to "gender identity"). It is also a useful subject because it has come into existence as a medicalized disorder—as opposed to an idiosyncracy or a perversion—in fairly recent history. Gender-related distress caused by living in the "wrong body" only really began to be a popularly meaningful idea in 1952, when Christine Jorgensen made her very public transition, and Gender Identity Disorder was not officially included as a diagnosis/pathology in the DSM until 1980.

In this chapter, I will examine two documents that formally govern the diagnosis and treatment of Gender Identity Disorder: (1) the relevant sections of the *Diagnostic and Statistical Manual of Mental Disorders,* Fourth Edition (Text Revision), properly abbreviated as the DSM-IV-TR, but more casually known just as the DSM, and (2) the Harry Benjamin International Gender Dysphoria Association's Standards of Care for Gender Identity Disorders (6th version), published in 2001.[176] Since that time, the organization has changed its unwieldy name, and is now the World Professional Association for Transgender Health (WPATH). I will focus primarily on the Standards of Care, which effectively build on the DSM criteria and serve as clinical guidelines governing practice and implementation, and which are also in some ways more intriguing because of their (relative) subtlety. The DSM criteria for Gender Identity Disorder effectively position "healthy" gender behavior in such traditional terms that it is easy to see *what* is being pathologized, and why; however, the question of *how* the DSM criteria actually function to pathologize non-normative bodies/persons is more difficult to see because the DSM is such a central part of an incredibly large and complex system for regulating ideas of health and illness. Because the Standards of Care function in a much smaller domain, it's easier to see how they work. I will examine these documents both as texts and as objects with agency, a somewhat artificial distinction intended to get at the fact that sometimes what a text says is not the same as what it does. As texts, I am interested in representation and rhetoric; as objects, I am interested in how representation and rhetoric are used to do certain kinds of work.

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[176] The International Classification of Diseases-10 also has an entry for Gender Identity Disorder, but in the United States, the DSM is the standard manual in professional practice.

My concerns in this chapter are with the kinds of stories that are told in relation to Gender Identity Disorder, what those stories are taken to mean, and how those stories are reproduced. As with other chapters, I focus on how the personal story engages with the construction of pathology, but in this particular context I am concerned with two kinds of stories not normally encompassed in the realm of autobiography: the "patient's story," meaning what a patient/client tells a doctor about what he or she is feeling, and the "doctor's story," meaning what a doctor tells the patient/client and the world about his or her own engagement with the specific pathology.[177] These stories are then situated in the context of conceptualizing gender-related distress as Gender Identity Disorder. While this approach might not work in other situations, the contested pathologization and treatment of Gender Identity Disorder has produced both patient/client and scholarly commentary on the requirements of the "patient's story," and likewise, the particular features of the Standards of Care offer substantial material for the "doctor's story."

What these stories are taken to mean is complicated, particularly the "patient's story." Because it is given under somewhat compromised circumstances, I will argue, it becomes suspect—perhaps of necessity, and perhaps rightly so, but with complicated consequences. If there is only one kind of story about an "illness" that will serve to secure for its teller the desired "treatment," then of course people will tell that story, at least in the examining room. The required story, in this case, is of an entire lifetime feeling as though one were the "other" gender in the binary gender

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[177] I include "client" in preference to "patient" in part from a disability rights sensibility, but also because it helps to paint the engagement in less familiar terms, encouraging a fresh look at the relations between the parties.

system, of wanting all the trappings of traditional gender presentation and behavior, and of having "appropriate" (heteronormative) objects of sexual desire.[178]

But some tellers are deliberately lying when they tell this story, as they readily admit in other contexts. This lying is provoked by a primitive ideology of binary gender unable to accept any shades of gray, and, to my mind at least, is substantively different from the many mean and nasty kinds of lies that human beings create. I cast no judgment on lies of this nature, but it is important to identify that they are lies nonetheless, and to understand the context in which they occur, because it challenges the understanding of the personal story, and shapes how certain kinds of personal narratives become the only "right" story to tell about whatever feature of difference is at hand.

When lying is known to occur in this context, and yet some people continue to tell that same story outside of the examining room, the story becomes suspect and its tellers become vulnerable to accusations of being sellouts or dupes, identifying themselves in contextually normative ways to gain social approval at the expense of their less normative peers. That suspicion, however, conflicts with the "nothing about us, without us" philosophy informing the disability rights/disability studies project,

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[178] It is important to remember that there are a variety of perspectives on the validity of the binary gender system. First, there is the population of people that have historically been understood as "transsexual," e.g., which do not contest the binary gender system as a system but who locate themselves as being in the "wrong body." This is a perspective on gender identity disorder that is roughly similar to the narratives of madness/mental illness described in the previous chapter, and is exemplified in such works as Holly [Aaron] Devor, *FTM: Female-to-Male Transsexuals in Society*, (Bloomington, IN: Indiana University Press, 1997) or Jamison Green, *Becoming a Visible Man*, (Nashville: Vanderbilt University Press, 2004), Second, there is also an important critique of the legitimacy of the binary gender system itself, which is also a kind of critique of the pathologization of bodies that are non-normative in terms of gendered presentation. There is a very large and important body of academic literature in this area, but for purposes of this study, the principle is perhaps most clearly exemplified in Halberstam's study of the separation of "masculinity" from the male body. Judith Halberstam, *Female Masculinity*, (Durham and London: Duke University Press, 1998).

and challenges the reliance on the personal story or personal experience a valuable—

perhaps *the* most valuable—form of knowledge.

The Standards of Care and Medical Authority

The first story told through the Standards of Care is one about the medical

establishment, including both psychiatry and the related semi-medical fields of

clinical psychology, social work, and therapy by any other name—fields that

incorporate psychiatric classifications and diagnoses, even if diverging in some ways

on the best approaches to treatment.   This story is about the medicalization of

transgenderedness; about the pathologizing of the phenomenon overall but

specifically focused on the contemporary rhetoric that positions "professionals" as *de

facto* gatekeepers.

One of the most striking features of The Harry Benjamin International Gender

Dysphoria Association's (HBIGDA) Standards of Care for Gender Identity Disorders

(6th version) is that the document is extremely concerned with outlining the standards

of care in terms of *persons*, rather than *procedures*; i.e., the Standards place a

considerable emphasis on defining the roles of both providers and receivers of care.

The statement of purpose asserts (emphasis mine):

> **The Purpose of the Standards of Care**. The major purpose of the
> Standards of Care (SOC) *is to articulate this international
> organization's professional consensus* about the psychiatric,
> psychological, medical, and surgical management of Gender Identity
> Disorders. Professionals may use this document to understand the
> parameters within which they may offer assistance to those with these
> conditions. Persons with Gender Identity Disorders, their families, and
> social institutions may use the SOC to understand the current thinking
> of professionals. All readers should be aware of the limitations of
> knowledge in this area and of the hope that some of the clinical

uncertainties will be resolved in the future through scientific investigation. [179]

The statement of purpose provides an initial framing of an issue of contention that runs throughout the Standards; namely, the delineation of "the professional" and his or her rights in relation to "the patient." The fact that there was a perceived need for such a delineation, however, indicates some instability of the diagnosis, treatment, and the general cultural/professional legitimacy of Gender Identity Disorder *as a disorder*. From a Butlerian perspective, the statement actually suggests the opposite of what it says: there would only be a need for a declaration of consensus (which, by its very nature, suggests that this viewpoint is obvious and widely shared), if in fact the reverse were true and no such professional consensus existed. To be precise, the organization states that it articulates "*this* [WPATH'S] international organization's professional consensus," [emphasis mine] but evokes its "international" membership to suggest that its consensus should be interpreted as the consensus of a much broader group of professionals.

Gender Identity Disorder, the subject of all this contention, was created and introduced into the DSM in 1980. The DSM-IV diagnostic criteria for Gender Identity Disorder (as presently written) include a specific code for children, and another for adolescents and adults. The primary criteria include "a strong and persistent cross-gender identification" and "persistent discomfort with his or her sex or sense of appropriateness in the gender role of that sex," which must not be concurrent with a physical intersex condition and which must cause "clinically

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[179] World Professional Organization for Transgender Health Inc., *Harry Benjamin International Gender Identity Dysphoria Association's Standards of Care for Gender Identity Disorders, Sixth Version* (World Professional Organization for Transgender Health, 2001 [cited August 1 2009]); available from http://wpath.org/Documents2/socv6.pdf.

significant distress or impairment in social, occupational, or other important areas of functioning."[180]

The initial positioning of Gender Identity Disorder as a mental disorder is presently understood—by academic historians, at least—as an effort by progressive individuals within the medical profession to reach a tolerable practical solution to a thorny philosophical problem. Joanne Meyerowitz's 2002 *How Sex Changed: A History of Transsexuality in the United States* remains the definitive history on what might be called the era of transsexuality, meaning the period when the twinned ideas of sex and gender as a binary, representative system were challenged by those who wished to change their bodies to match their preferred gender role. In chronological terms, this stretches roughly from Christine Jorgensen's transition in 1952 through the 1970s.[181] Because much of the popular understanding of these categories closely followed the authority of the medical establishment and its understanding of these categories, her study examines in some detail the careers of doctors such as Magnus Hirschfield and Harry Benjamin, considers the ways in which medical perspectives were neither uniform nor uncontested, and includes substantial evidence that transgendered people sought to participate actively in the shaping of access to medical services. (Her efforts at balance notwithstanding, I find it telling that one

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[180] American Psychiatric Association, *Diagnostic and Statistical Manual of Mental Disorders (DSM-Iv-Tr).*

[181] Joanne J. Meyerowitz, *How Sex Changed: A History of Transsexuality in the United States* (Cambridge, MA: Harvard University Press, 2002). A note on terminology: The explosion of the ideas of "queer" and "transgender" and all the variations of meaning associated with those terms have made "transexuality" a difficult word to use now even in historic specificity. It seems inherently dated, a reference to a kind of change that existed in a more simplistic political economy of sex and gender than now exists, and feels as though it is a concession to the more conservative, medical configuration of the phenomenon. For that reason, I will use "transgendered" to refer to individuals diagnosed with Gender Identity Disorder and seeking hormones or surgery, even though the term "transgender" is often now understood to encompass a variety of gender identities and expressions that do not involve engaging with Gender Identity Disorder or the medical establishment.

reviewer defined the study as "trac[ing] the changes in attitudes among medical

professionals and the establishment of a separate diagnostic category"—a good

example of how (medical) professional definition of a phenomenon is implicitly

understood as, if not the only legitimate definition, at least the default one.[182])

Overall, Meyerowitz represents the events leading to the establishment of the

diagnostic category of Gender Identity Disorder essentially as a series of

compromises between multiple conflicting interests. Meyerowitz generally portrays

the doctors who performed surgeries, prescribed hormones, and asserted the

legitimacy of the need for such services as doing so in a good faith effort to serve the

needs of their clients, even though criticisms of the pathologization of transgenderism

were made by transgendered individuals at the time. Consequently, she portrays the

creation of Gender Identity Disorder as an achievement of sorts, at least in context,

because by establishing a formal theoretical basis for the diagnosis and treatment of a

disorder, it legitimized the use of hormones and surgery and made the treatment of

clients with Gender Identity Disorder something that a doctor could do without fear

of charges of malpractice or "local mayhem," (statutes preventing the mutilation of

healthy males, originally envisioned relative to concern about attempts to avoid

military service).

Without disputing Meyerowitz's assessment of the intentions behind the

establishment of Gender Identity Disorder, I seek to illustrate that the establishment

of Gender Identity Disorder nevertheless reflects an expansion of medical authority in

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[182] Vern Bullough, "Review of Meyerowitz, '*How Sex Changed: A History of Transsexualism in the United States*'," *Bulletin of the History of Medicine* 77, no. 4 (2003): 984.

ways inconsistent with most other kinds of elective services and procedures.[183] Riki

Anne Wilchins' fantasy on a rhinoplasty consultation makes the point succinctly:

> "How do you know you want rhinoplasty, a nose job?" he inquires, fixing me with a penetrating stare.
> "Because," I reply, suddenly unable to raise my eyes above his brown wingtips, "I've always felt like a small-nosed woman trapped in a large-nosed body."
> "And how long have you felt this way?" He leans forward, sounding as if he knows the answer and needs only to hear the words.
> "Oh, since I was five or six, doctor, practically all my life."
> "Then you have rhino-identity disorder," the shoetops state flatly. My body sags in relief. "But first," he goes on, "we want you to get letters from two psychiatrists and live as a small-nosed woman for three years… just to be sure."[184]

Wilchins' point is that such treatment would be inconceivable were the "disorder" in

question not concerned with disrupting conventional notions of sex and gender. [185]

However, the concern here is with the expansion of medical authority through

the establishment of treatment eligibility guidelines that transform an individual's

pursuit of a somatic procedure into a psychiatric disorder. The Standards of Care

require one letter for hormone therapy or breast surgery (either to enlarge or reduce),

and two letters for genital surgery, with further stipulations: "If the first letter is from

a person with a master's degree, the second letter should be from a psychiatrist or a

Ph.D. clinical psychologist, who can be expected to adequately evaluate co-morbid

psychiatric conditions. If the first letter is from the patient's psychotherapist, the

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[183] Some would argue with my use of the term "elective," on the grounds that the "necessity" for such surgery is highly subjective. That point is well taken, but my purpose here is just to distinguish between planned surgeries and emergency procedures where the client/patient is routinely not consulted.

[184] Riki Anne Wilchins, *Read My Lips: Sexual Subversion and the End of Gender* (Ann Arbor: Firebrand Books, 1997), 63.

[185] This is not strictly true, as the diagnosis of Body Dysmorphic Disorder is now also used to prevent "excessive" cosmetic procedures of other types. Sander L. Gilman, *Making the Body Beautiful: A Cultural History of Aesthetic Surgery* (Princeton, NJ: Princeton University Press, 1999), Victoria Pitts-Taylor, *Surgery Junkies: Wellness and Pathology in Cosmetic Culture* (New Brunswick, NJ: Rutgers University Press, 2007). Both of these studies discuss at length controversies surrounding cosmetic procedures of various kinds,

second letter should be from a person who has only played an evaluative role for the patient. Each letter, however, is expected to cover the same topics. At least one of the letters should be an extensive report."[186]

These eligibility guidelines represent quite an extensive expansion of the psychiatric enterprise, so to speak, so as to be functionally necessary to obtain hormones or surgery. Though the Standards of Care explicitly state that psychotherapy is not an absolute requirement for triadic treatment, in context, there is an implication that for most people, psychotherapy will be required.

> **Psychotherapy is Not an Absolute Requirement for Triadic Therapy.** Not every adult gender patient requires psychotherapy in order to proceed with hormone therapy, the real-life experience, hormones, or surgery. Individual programs vary to the extent that they perceive a need for psychotherapy. When the mental health professional's initial assessment leads to a recommendation for psychotherapy, the clinician should specify the goals of treatment, and estimate its frequency and duration. There is no required minimum number of psychotherapy sessions prior to hormone therapy, the real-life experience, or surgery, for three reasons: 1) patients differ widely in their abilities to attain similar goals in a specified time; 2) a minimum number of sessions tends to be construed as a hurdle, which discourages the genuine opportunity for personal growth; 3) the mental health professional can be an important support to the patient throughout all phases of gender transition. Individual programs may set eligibility criteria to some minimum number of sessions or months of psychotherapy.[187]

Likewise, the last sentence functionally undermines the rest of the paragraph as it indicates that it is permissible for individual programs (e.g., individual clinics) to set more restrictive guidelines that do entail psychotherapy as an absolute requirement.

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[186] World Professional Organization for Transgender Health Inc., *Harry Benjamin International Gender Identity Dysphoria Association's Standards of Care for Gender Identity Disorders, Sixth Version*. Letters are typically presented to the internist or endocrinologist prescribing hormones, or to a surgeon, as a kind of protection against accusations of malpractice.
[187] Ibid.

Curiously, the result is to require something that is normally considered

"treatment"—therapy or counseling—to *confirm a diagnosis* of psychopathology.

The same section of the Standards of Care goes on to describe the desired sort

of relationship between the therapist and the client, and to identify the goals of

therapy as "to help the person to live more comfortably within a gender identity and

to deal effectively with non-gender issues."[188] In general, this section of the

Standards describe an approach that positions gender in the context of a "whole

person," that deals not only with specific issues of gender identity but also how they

fit with the person's work, family, and other kinds of relationships. While a

comprehensive approach would seem to be a logical one, and probably very useful to

those who truly seek assistance and not merely formal validation, the Standards of

Care bury within the rhetoric of support an act of force (perhaps even violence): the

transgendered individual must display trust in the therapist:

> The therapist should make clear that it is the patient's right to choose
> among many options. The patient can experiment over time with
> alternative approaches. Ideally, psychotherapy is a collaborative effort.
> The therapist must be certain that the patient understands the concepts
> of eligibility and readiness, because the therapist and patient must
> cooperate in defining the patient's problems, and in assessing progress
> in dealing with them. Collaboration can prevent a stalemate between a
> therapist who seems needlessly withholding of a recommendation, and
> a patient *who seems too profoundly distrusting to freely share
> thoughts, feelings, events, and relationships*.[189] [emphasis mine]

"Trust" and "distrust" effectively become metaphors for "submission" and

"noncompliance." It's difficult to understand the grounds on which the WPATH

Standards of Care Committee would think that anybody would *want* to submit to

having his or her "thoughts, feelings, events and relationships" probed and reviewed

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[188] Ibid.
[189] Ibid.

by a therapist if that person did not have any doubt about his or her desire to obtain hormones or therapy. The underlying presumption is that medical and semi-medical professionals have an inalienable right to determine the circumstances when their services are needed, and in effect to issue a judgment of pathology ("distrusting") if there is any resistance. "Distrusting" seems, from a Marxist perspective, to be a perfectly appropriate response to the suggestion that a person should purchase services for a need defined by an authority that stands to profit form the sale of the services—and this response works in a more abstract sense of cultural regulation as well.

It is, however, the assumption of the superiority of professional knowledge that is most important here. The question of what constitutes a "professional" looms large in this examination and a few words about assumptions and values are appropriate. It is unfashionable to offer criticisms of the helping professions and difficult to critique one's colleagues, but I contend that such actions are also necessary if the idea of professionalism or professional respect is to retain any real meaning. I don't doubt that therapists can offer transgendered and transsexual people real and substantial help in sorting through complicated thoughts and feelings, but I take issue with the notion that holding a master's degree in social work in and of itself constitutes appropriate qualifications to make decisions about what is best for another person and his/her body. In other words, I am concerned with the way that these guidelines deploy power to serve the interests of the "professionals"—not necessarily as individuals, but certainly as a class. Such an explicit use of power "on behalf of" the presumed best interests of others is highly questionable from a social justice

perspective, as such arguments have been used to justify unfair and even inhumane treatment of other human beings on countless occasions, but it is equally offensive on an intellectual basis.

Perhaps the most obvious question to ask about a document that so clearly separates the qualified professional from the unqualified layperson is who created it, in the sense of the creators' qualifications. As a general rule, professional credibility is established through transparency; it should be easy to see who is making decisions in a professional organization and who those individuals are (particularly in terms of their professional qualifications, affiliations, etc.), and this kind of transparency is generally considered to be an issue of ethics. In medicine and psychology—the dominant fields relevant to Gender Identity Disorder—organizations such as the American Medical Association and the American Psychological Association include recommendations related to transparency among their ethics guidelines.[190]

WPATH does not make the professional identities of the Standards of Care Committee members as clear as it might. It's not at all uncommon for organizations comprised primarily of "professionals" to include (hypothetically) representative members of the constituencies that the field or organization purports to serve, and normally these alternative qualifications are described in biographical sketches or even by title (e.g., Consumer Representative). The Standards of Care Committee website lists the committee members and their highest degree earned, but it does not

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[190] For example, the American Medical Association includes guidelines on peer review, and the American Psychological Society includes guidelines on the representations of credentials in public statements. American Medical Association, *Code of Medical Ethics: Opinion 9.10 - Peer Review* ([Issued prior to April 1977; Updated June 1994.] [cited August 29 2009]); available from http://www.ama-assn.org/ama/pub/physician-resources/medical-ethics/code-medical-ethics/opinion910.shtml. American Psychological Association, *Ethical Principles of Psychologists and Code of Conduct* (2002 [cited August 29 2009]); available from http://www.apa.org/ethics/code2002.pdf.

specify the field. More problematically, WPATH does not provide any biographical

information for those whose participation on the committee is best explained by

qualifications other than a terminal degree, and this creates a certain awkwardness.

Of the eighteen members of the Standards of Care Committee in 2001, four are

publicly identifiable as transgendered (though not on the WPATH website): Holly

(now Aaron) Devor, Ph.D.; Sheila Kirk; M.D.; Anne Lawrence, M.D.; and Jude

Patton, PA-C. Of course, it's possible that other members of the Standards of Care

Committee may also be transgendered and choose to keep that information private.

But by not clearly distinguishing community participants from professional

participants, WPATH invites speculation (at least from external audiences) that the

transgendered participants serve on the committee in part because of their non-

professional credentials (particularly as there appear to be two transmen and two

transwomen, which could well be coincidental but hints at controlled inclusion). This

functions to detract from their professional credibility even where it should not be in

question, and can be seen as a particularly subtle and egregious form of tokenism. On

the flip side, by not explicitly identifying community participants as being invited to

participate on the grounds of having a different sort of expertise, WPATH

compromises the idea of qualifications; however wonderful a therapist Patton might

be, surely certification as a physician's assistant is not an appropriate *professional

credential* for this kind of committee.[191] The identification of discipline would seem

not only useful but essential from a professional ethics perspective, especially as a

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[191] In an interview, Jude Patton confirmed the intent of the committee was to have a "consumer advocate," but noted that there was concern about having an advocate unlikely to support practices that positioned doctors as gatekeepers. Deborah Rudacille, *The Riddle of Gender: Science, Activism, and Transgender Rights* (New York: Pantheon Books, 2005), 177-78.

good portion of the Standards seek to explicitly define the appropriate credentials for

caregivers.

In the context of the Standards of Care, the definition of qualifications and

appropriate credentials is well beyond an issue of good management or even ethics; it

is a concern that calls into question the legitimacy of the Standards, by its own stated

purpose. The articulation of "this international organization's professional

consensus" invokes the rhetoric of professional authority and expert knowledge,

presumably to ensure patient wellbeing, and establishes requirements concerning

provider credentials. For example, the criteria for the "Adult Specialist" are:

> The education of the mental health professional who specializes in
> adult gender identity disorders rests upon basic general clinical
> competence in diagnosis and treatment of mental or emotional
> disorders. Clinical training may occur within any formally
> credentialing discipline -- for example, psychology, psychiatry, social
> work, counseling, or nursing. The following are the recommended
> minimal credentials for special competence with the gender identity
> disorders:
> 1. A master's degree or its equivalent in a clinical behavioral science
>   field. This or a more advanced degree should be granted by an
>   institution accredited by a recognized national or regional
>   accrediting board. The mental health professional should have
>   documented credentials from a proper training facility and a
>   licensing board.
> 2. Specialized training and competence in the assessment of the
>   DSM-IV/ICD-10 Sexual Disorders (not simply gender identity
>   disorders).
> 3. Documented supervised training and competence in
>   psychotherapy.
> 4. Continuing education in the treatment of gender identity disorders,
>   which may include attendance at professional meetings,
>   workshops, or seminars or participating in research related to
>   gender identity issues.[192]

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[192] World Professional Organization for Transgender Health Inc., *Harry Benjamin International Gender Identity Dysphoria Association's Standards of Care for Gender Identity Disorders, Sixth Version*.

Yet the committee, which is in effect making decisions about the entire population of individuals seeking hormones or surgery, does not itself meet the kind of credentialing requirements that it defines as the "minimal credentials" to make decisions on behalf of single transgendered person seeking hormones or surgery. This is a disturbing contradiction. One wonders, if half the committee members aren't qualified to make such decisions by the committee's own definition, on what basis are they qualified to establish the standards, particularly as the document is positioned as a collective professional position? Figure 1 presents the information I was able to obtain on each committee member by searching databases covering the professional literature (e.g. PubMed, LGBT-related databases, etc.), databases covering newspaper coverage and biographic materials such as Who's Who (Lexis-Nexis Academic), and Google. In the cases in which researchers were associated with universities or hospitals, I took their qualifications at face value with the knowledge that such institutions typically require verification of credentials at the time of hiring. It is far more difficult to obtain information on the credentials on living people working in private practice, especially when they do not have a particularly flourishing career publishing in scholarly or peer-reviewed journals.

Of the 18 members of the committee, fewer than half can be publicly identified as holding the credentials required in the first criterion alone, which requires a "master's degree or its equivalent in a clinical behavioral science field." Meyer, Bockting, Cohen-Kettenis, Coleman, Di Ceglie, Kuiper, Webb, and Wheeler all hold Ph.D.s in psychology or a related field, specialize in psychiatry, or hold an M.S.W., thereby meeting the qualification (assuming that they obtained the degrees

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from accredited institutions). Patton's educational credentials could not be ascertained. One might make a plausible argument that Schaeffer, who describes herself as a psychologist, might also have obtained comparable counseling training if her Ed.D. were in an area such as counseling and school psychology, but education, as a field, is not normally considered to be a "clinical behavioral science." Webb qualifies with her M.S.W., though her Doctor of Human Sexuality was earned at the Institute of Advanced Study of Human Sexuality in San Francisco, an institution which holds neither national nor regional accreditation.

The rest of the committee is comprised of doctors who have specialized in an area of medicine, such as plastic surgery, that does not meet the criterion of a "clinical behavioral science" field. Of particular note is Anne Lawrence, who appears to have resigned her hospital position in 1997 after allegations about an inappropriate examination of an unconscious client, and now practices psychotherapy (holding a valid Physician and Surgeon license in the State of Washington).[193] Trained as an anesthesiologist, Lawrence appears to have been practicing psychotherapy without the minimum credentials required by the committee, and to have been doing so for several years at the time of the 2001 publication. She apparently obtained a Ph.D. from the Institute of Advanced Study of Human Sexuality, but again, this institution is not accredited, the normal way of validating an institution's ability to provide

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[193] Documentation on the investigation was collected and disseminated by the author of a transgender resources website. Andrea James, *TS Roadmap [Appendix to "the Anne Who Would Be Queen"]* [website, cited September 5 2009]; available from http://www.tsroadmap.com/info/lawrence/anne-lawrence-incident.html.. Lawrence's own website indicates that she holds a M.A., a M.D., and a Ph.D. Anne A. Lawrence, *Transsexual Women's Resources (About the Author)* [cited August 22 2009]; available from http://www.annelawrence.com/twr/index.html. However, neither her website nor a substantial sampling of her recent publications indicate the institution or discipline of her Ph.D. An editorial in *Transgender Tapestry* states that Lawrence received a Ph.D. in 2001 from the Institute of Advanced Study of Human Sexuality in San Francisco. International Foundation for Gender Education, "[Opinion] Concerns About Dr. Anne Lawrence," *Transgender Tapestry* 105 (2004).

quality education. All private practitioners the United States were determined to hold

the appropriate state licenses to practice legally.

Figure 1. Qualifications of WPATH Standards of Care Committee Members

Name	Degree[194]	Discipline/Specialization/ Field of Practice	Affiliation/Notes
Walter Meyer III	M.D.	Pediatric Psychiatry, Pediatric Endocrinology	Kempner Professor of Child Psychiatry, Department of Psychiatry and Behavioral Sciences, University of Texas Medical Branch, Galveston
Walter O. Bockting	Ph.D.	Psychology	Associate Professor, Center for Sexual Health, University of Minnesota Medical School
Peggy Cohen-Kettenis	Ph.D.	Psychology	Professor, Department of Medical Psychology, VU University Medical Center, Amsterdam
Eli Coleman	Ph.D.	Counseling and Student Personnel Psychology	Professor and Director, Program in Human Sexuality, University of Minnesota Medical School
Domenico DiCeglie	M.D.	Psychiatry, child and adolescent gender disorder	[Practicing psychiatrist], Tavistock and Portman Clinic, London
Holly (now Aaron) Devor	Ph.D.	Sociology	Professor, Department of Sociology, University of Victoria, British Columbia
Louis Gooren	M.D., Ph.D.*	Internal Medicine; Endocrinology	Retired. Professor Emeritus, Vrije Universiteit of Amsterdam.
J. Joris Hage	M.D., Ph.D.*	Plastic surgery	Department of Plastic and Reconstructive Surgery, Netherlands Cancer Institute, Antoni van Leeuwenhoek Hospital

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[194] Where I could determine an affiliation with a hospital or university, I have considered this sufficient evidence of the acquisition of the degree. Information that I could not verify but which I don't have any particular reason to doubt is in brackets.

Name	Degree[194]	Discipline/Specialization/ Field of Practice	Affiliation/Notes
Sheila Kirk	[M.D.]	[Surgery, gynecology]	Apparently retired from private practice. Opened Transgender Surgical & Medical Center with two other physicians with university hospital appointments; some professional publications. Center is now closed.
Bram Kuiper	Ph.D.	Clinical psychology	Since 2000, Director of the Helen Dowling Institute, specializing in psycho-oncology. Previously a psychologist at the VU hospital in Amsterdam.
Donald Laub, Sr.	M.D.	Plastic Surgery	Adjunct Clinical Professor at Stanford University, private career in plastic surgery.
Anne Lawrence	M.D., [Ph.D.]	Anesthesiology/unknown	Worked as an anesthesiologist until 1997, following an investigation into a complaint about an inappropriate vaginal exam on an unconscious patient. Holds a current Physician and Surgeon license in Washington State. Currently provides psychotherapy, counseling about gender concerns and consultations/evaluations.
Yvon Menard	[M.D.]	Plastic and reconstructive surgery	Private practice specializing in gender reassignment surgery, Montreal.
Stan Monstrey	M.D.	Plastic and reconstructive surgery	Tenured academic staff in the Department of Surgery, University of Ghent.

Name	Degree[194]	Discipline/Specialization/ Field of Practice	Affiliation/Notes
Jude Patton	PA-C (Physician Assistant, Certified)		Practicing therapist. Holds Physician Assistant, Mental Health Counselor and Marriage and Family Therapist licenses from Washington State. No information available on academic degrees held.
Leah Schaefer	Ed.D.	[school counseling? Describes herself as a psychologist]	Practicing therapist. Holds a New York State license as a Marriage and Family Therapist.
Alice Webb	M.S. W., D.H.S. (Doctor of Human Sexuality)	Social work, human sexuality	Apparently retired from private practice. D.H.S. is from the Institute of Advanced Study of Human Sexuality, San Francisco, California (not accredited).
Connie Christine Wheeler	[Ph.D.]	[Psychology]	Licensed as a Marriage and Family Therapist through September 2009 by the New York State Education Department Office of the Professions. Some professional publications.

While not every organization publishes biographical information on its key participants or makes its membership roster available to the public, WPATH's membership is curiously restrictive for an interdisciplinary area, and functions more to maintain boundaries between professional and non-professional than to distinguish practical intellectual boundaries in an interdisciplinary field. WPATH limits full membership to "professionals working in disciplines such as medicine, psychology, law, social work, counseling, psychotherapy, family studies, sociology, anthropology, speech and voice therapy, sexology and other related fields."[195]

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[195] World Professional Organization for Transgender Health Inc., *Membership Benefits (Web Page)* ([cited September 4 2009]); available from http://www.wpath.org/membership_benefits.cfm.

Supporting memberships (without voting privileges) are available to those who don't

work in the fields cited above, which provokes an interesting question. This is a very

curious range of fields: certainly one sees the *relevance* of all of these fields to the

phenomenon and experience of transgenderedness, taken broadly. But by that token,

insight into and professional interest in the overall phenomenon of transgenderedness

could also be provided by a much larger range of "professionals," perhaps most

pointedly those who work in LGBT or transgender studies, public health, law

enforcement, etc. Conversely, one might argue that law, family studies, sociology,

anthropology, speech and voice therapy, and sexology are not professional fields

appropriate to transgender *health* concerns, inasmuch as practitioners of these fields

are not licensed to treat the mental disorder outlined in the DSM. Emeritus and

student memberships are also available (although student membership "requires

sponsorship and recommendation by a full member along with proof of **current full-

time status as a graduate student in a program directly related to transgender

health**." [emphasis original][196] Again, it appears that there is a deliberate attempt to

exclude students in LGBT or gender studies programs.

The incoherence of WPATH's definition of full association membership

reveals several sorts of instabilities. To state the obvious, the experience of

transgenderedness—or the experience of providing gender "reassignment" services to

transgendered people—is larger and more complex than its positioning as a

psychiatric disorder can encompass. That broadening of the field, however, has the

potential to open doors that blur professional boundaries and threaten to destabilize

the rationale for professional authority. It's one thing to expand "professional" to

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[196] Ibid.

include a sociologist who studies female-to-male "transsexuals," e.g., those who are primarily concerned with *changing* their own genders (and not challenging WPATH's mission or values), rather than *deconstructing* "gender" as a concept. It's quite another to expand the category of "professional" to include an academic with a Ph.D. in philosophy, who argues against the neat differentiation of sexuality from gender, or to give voting rights to the accomplished artist, theorist, engineer and academic often cited as the "founder" of transgender studies, because her expertise does not include a "patient/health care provider" approach to the subject.[197]

The circling of wagons around the concept of "professional" echoes back to the histories of psychiatry that frame psychiatrists as constantly battling insecurity in the profession. The emphasis on distinguishing "professional" persons from "lay" persons gets to the fundamental issue of gatekeeping. An entity as new as "transsexualism," in the sense that such a thing did not exist as an American cultural phenomenon until the 1950s, means that it does not have the kinds of historical associations with medicine that other "illnesses" do, and with pressure from some segments of the transgendered population to depathologize the phenomenon, the reasoning as to why "professionals" should be the ones making decisions about who has access to hormones and surgery is by no means uncontested.

Gender Identity Disorder and the Social Regulation of Gender

Gender Identity Disorder and the Standards of Care also tell a story about what gender—or, in this case, what the two normative genders—should look like, through the means of diagnosis through the DSM-IV (or ICD).

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[197] I refer to Aaron Devor, Judith Butler, and Sandy Stone respectively.

The "Diagnostic Features" (a more free-form textual description of the

Diagnostic Criteria) of Gender Identity Disorder in the DSM-IV are quite shockingly

traditional to many contemporary eyes, and perhaps give a better feel for what is

meant by the Diagnostic Criteria:

> In boys, the cross-gender identification is manifested by a marked preoccupation with traditionally feminine activities. They may have a preference for dressing in girls' or women's clothes or may improvise such items from available materials when genuine articles are unavailable. Towels, aprons, and scarves are often used to represent long hair or skirts. There is a strong attraction for the stereotypical games and pastimes of girls. They particularly enjoy playing house, drawing pictures of beautiful girls and princesses, and watching television or videos of their favorite female characters. Stereotypical female-type dolls, such as Barbie, are often their favorite toys, and girls are their preferred playmates. When playing "house," these boys role-play female figures, most commonly "mother roles," and often are quite preoccupied with female fantasy figures. They avoid rough-and-tumble play and competitive sports and have little interest in cars and trucks or other nonaggressive but stereotypical boys' toys. They may express a wish to be a girl and assert that they will grow up to be a woman. They may insist on sitting to urinate and pretend not to have a penis by pushing it in between their legs. More rarely, boys with Gender Identity Disorder may state that they find their penis or testes disgusting, that they want to remove them, or that they have, or wish to have, a vagina.

> Girls with Gender Identity Disorder display intense negative reactions to parental expectations or attempts to have them wear dresses or other feminine attire. Some may refuse to attend school or social events where such clothes may be required. They prefer boys' clothing and short hair, are often misidentified by strangers as boys, and may ask to be called by a boy's name. Their fantasy heroes are most often powerful male figures, such as Batman or Superman. These girls prefer boys as playmates, with whom they share interests in contact sports, rough and tumble play, and traditional boyhood games. They show little interest in dolls or any form of feminine dress-up or role-play activity. A girl with this disorder may occasionally refuse to urinate in a sitting position. She may claim that she has or will grow a penis and may not want to grow breasts or to menstruate. She may assert that she will grow up to be a man. Such girls typically reveal

marked cross-gender identification in role-playing, dreams, and fantasies.[198]

The use of phrases such as "stereotypical female-type dolls" and the like (without any irony whatsoever) puts the entire Gender Identity Disorder diagnostic procedure into a realm of absurdity almost without parallel. The DSM-IV concept of gender seems completely unblemished by second-wave feminism, or in fact nearly any kind of cultural change since the early 1960s, and the extraordinary *abstraction* of gender seems to be much more revealing of the gender-related insecurities of the authors/editors of the DSM-IV than of any transgendered individual. The reference to Batman and Superman, for instance, seems more a nostalgic recollection to the author/editors' own childhoods than any kind of realistic picture of contemporary children and their engagement with, say, Harry Potter, Wii, or contemporary toys. My arguments about the specific kinds of stories that Gender Identity Disorder requires from transgendered individuals seeking hormones or surgery are drawn primarily from Dean Spade's essay, "Mutilating Gender." Others have made similar points, but Spade's essay more explicitly and effectively addresses lying than most others, an issue which, as will be examined in more detail later in the chapter, is of considerable concern.[199]

Spade's essay examines the relationship between transgendered individuals seeking surgery and "the medical establishments with which they must contend in order to fulfill their goals."[200] His primary contention is that transgendered

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[198] American Psychiatric Association, *Diagnostic and Statistical Manual of Mental Disorders (DSM-IV-TR)*. 576-577
[199] Dean Spade, "Mutilating Gender," in *The Transgender Studies Reader*, ed. Susan Stryker and Stephen Whittle (New York: Routledge, 2006).
[200] Ibid., 316.

individuals' efforts to obtain surgery are policed primarily because the specific

surgical interventions sought are in conflict with the regulation and policing of gender

expression—or, in other words, surgical interventions sought by transgendered people

are policed when similar surgeries by non-transgendered people are not (or at least

not in the same ways across the board.)

Several excerpts from Spade's personal story of trying to obtain free or low-

cost counseling in pursuit of a double mastectomy tell of his learning what "story" he

is supposed to tell in order to obtain surgery, and of the difficulties in reconciling the

prescribed story with his own "real" story.

> "When did you first know you were different?" the counselor at
> the L.A. Free Clinic asked. "Well," I said, "I knew I was poor and on
> welfare, and that was different from lots of kids at school, and I had a
> single mom, which was really uncommon there, and we weren't
> Christian, which is terribly noticeable in the South. Then later I knew
> I was a foster child, and in high school, I knew I was a feminist and
> that caused me all kinds of trouble, so I guess I always knew I was
> different." His facial expression tells me this isn't what he wanted to
> hear, but why should I engage this idea that my gender performance
> has been my most important difference in my life? It hasn't, and I
> can't separate it from the class, race, and parentage variables through
> which it was mediated. Does this mean I'm not real enough for
> surgery?
> I've worked hard not to engage the gay childhood narrative—I
> never talk about tomboyish behavior as an antecedent to my lesbian
> identity, I don't tell stories about cross-dressing or crushes on girls,
> and I intentionally fuck with the assumption of it by telling people how
> I used to be straight and have sex with boys like any sweet trashy rural
> girl and some of it was fun. I see these narratives as strategic, and I've
> always rejected the strategy that adopts some theory of innate sexuality
> and forecloses the possibility that anyone, gender-troubled childhood
> or not, could transgress sexual and gender norms at any time. [201]

Of particular note is Spade's articulation of his efforts to avoid "the gay childhood

narrative," which I see as less the "gay" childhood narrative than as the kind of

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[201] Ibid., 319-20.

essentialized abstraction of childhood gender described in the DSM-IV. But it does

clearly position the content of the narrative at odds with any sort of transgression of

traditional sexual and gender norms, and effectively positions transgendered

individuals seeking surgical modification as having to present their genders in hyper-

traditional ways. Spade continues,

> The counselor at the L.A. Free Clinic decided I wasn't transsexual
> during the first (and only) session. When I told him what I wanted,
> and how I was starting counseling because I was trying to get some
> letters that I could give to a surgeon so that they would alter my chest,
> he said, "You should just go get breast reduction." Of course, he
> didn't know that most cosmetic surgeons won't reduce breasts below a
> C-cup (I wouldn't even qualify for reduction), and that breast
> reduction is a different procedure than the construction of a male-
> looking chest… To this counselor, my failure to confirm to the
> transsexuality he was expecting required my immediate expulsion
> from that world of meaning at any cost. My desire couldn't be for
> SRS because I wasn't a transsexual, so it must be for cosmetic surgery,
> something normal people get.[202]

It is perhaps unsurprising that psychiatrists and therapists in these narratives

are often portrayed as idiots, trafficking in such simplistic models of health-as-

normativity that one wonders what good they might ever do anyone. Anne Bolin,

however, offers the observation that an explanation for such a profound disconnect

might be better located in the structuring of the diagnostic criteria itself: she observes

that "In the process of interacting with the caretakers, transsexuals are merely

engaging in something they have learned as a consequence of transsexualism. They

are fabricating personal identities in order to present caretakers a picture consistent

with caretakers' own research and the literature on transsexualism. The therapeutic

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[202] Ibid., 324-25.

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encounter is ideal for such false oral documentation and "biographical editing."[203]

The fact that the medical establishment has always required a single kind of story has

meant that transgendered people have always figured out what that story needed to

sound like to convince the doctors, and produced it as required.[204] Spade also

describes great awareness amongst transgendered and transsexual people of the need

to provide this monolithic story.

> After attending only three discussion group meetings with other trans people, I am struck by the naivete with which I approached the search for counseling to get my surgery-authorizing letters. No one at these groups seems to see therapy as the place where they voice their doubts about their transitions, where they wrestle with the political implications of their changes, where they speak about fears of losing membership in various communities or in their families. No one trusts the doctors as the place to work things out. When I mention the places I've gone for help, places that are supposed to support queer and trans people, everyone nods knowingly, having heard countless stories like mine about these very places before. Some have suggestions of therapists who are better, but none cost less than $50/hr. Mostly, though, people suggest different ways to get around the requirements. I get names of surgeons who do not always ask for the letters. Someone suggests that since I won't be on hormones, I can go in and pretend I'm a woman with a history of breast cancer in my family and that I want a double mastectomy to prevent it. I have these great, sad, conversations with these people who know all about what it means to lie and cheat their way through the medical roadblocks to get the opportunity to occupy their bodies in the way they want. I understand, now, that the place that it is safe to talk about this is in here, with other people who understand the slipperiness of gender and the politics of transition, and who believe me without question when I say what I think I am and how that needs to look.[205]

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[203] Anne Bolin, *In Search of Eve: Transsexual Rites of Passage* (South Hadley, MA: Bergin & Garvey, 1988), 64.

[204] Ibid, Meyerowitz, *How Sex Changed: A History of Transsexuality in the United States*, 161.

[205] Spade, "Mutilating Gender," 326-27.

Gender Identity Disorder and the Personal Story

The third story with which this chapter is concerned is about the "patient's story" as autobiography, and the context in which that story is produced and consumed. This consideration argues that the presentation of a personal history to a doctor is an autobiography of sorts—a somewhat curious form, to be sure, but an autobiography nonetheless.

This form of autobiography has several unique features. First, the story is implicitly contextualized as a somatic story—even when it is a story with substantial psychological, spiritual, or political components, the telling of it in the context of the doctor's office of necessity makes it a story about the body. Second, this kind of story is told provisionally; the doctor retains the authorial privilege in this storytelling activity and may either confirm or reverse any conclusion the client-patient offers. The client-patient may craft a story very carefully with the intent of obtaining a particular diagnosis, but the privilege of drawing conclusions and assigning a diagnosis (and therefore, in some circumstances at least, an identity) is the doctor's. As noted, the criteria for diagnosis with Gender Identity Disorder are comparatively narrow and conventional, which means that people seeking that diagnosis tell a fairly constricted sort of story. But if there is only one kind of story that is understood as valid to obtain surgery and hormones, then the truth of the personal story is immediately tainted, at least in some ways. In other words, people lie, and the fact of lying creates multiple kinds of social difficulties. It creates a community context ripe for the policing of authenticity, it creates a certain difficulty in for scholarship heavily invested in making oppressed voices heard (my primary concern here), and generally

creates an uncomfortable fact that has to be gotten around. Overall, the entire process

of the construction of identity in mainstream, secular culture—and specifically

including "therapeutic discourses"—has very little in the way of ability to deal with

intentional falsification.[206]

The fact of lying, and the need to align stories with normative ideas of gender,

creates a context for a transgender "community" that virtually ensures a degree of

infighting and the policing of authentic identity.   I turn here to David Valentine's

Imagining Transgender: An Ethnography of a Category, which examines the idea of

"transgender" as a site of contestation between contemporary academic/professional

understandings of "gender" and "sexuality" as being fundamentally different aspects

of identity and older conceptions of "gayness" or homosexuality as including

components of both. Valentine's project is to examine what kinds of political work

can be done through the idea of "transgender" as separating gender variance from

sexuality; to examine what conceptual possibilities this notion opens up and what

conceptual possibilities it forecloses.

> "Since the early 1990s… the category transgender has come to be
> understood as a collective category of identity which incorporates a
> diverse body of male- and female-bodied gender-variant people who
> had previously been understood as distinct kinds of persons, including
> self-identified transsexuals and transvestites, but also many others…
> In its collectivity, the capacity of transgender to incorporate all gender
> variance has become a powerful tool of activism and personal
> identification. And even more remarkably, in the period since the
> early 1990s it has already become institutionalized in a vast range of
> contexts, from grassroots activism, social service provision, and

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[206] To clarify: I say this without moral judgment. But I do find this to be an interesting intellectual
problem with considerable implications for any kind of scholarship related to identity. As noted in
Chapter Two, the literature on trauma and memory touches on this kind of question, yet remains on the
margins of discourse in scholarship pertaining to identity. My point is only that the fact of lying seems
to make people generally uncomfortable and it tends to be avoided, rather than embraced, in
scholarship.

individual identification, to journalistic accounts and the way that this book itself is categorized. Most importantly, transgender identification is understood across these domains to be explicitly and fundamentally different in origin and being from homosexual identification, a distinction referred to in the social sciences as ontological. This distinction, in turn, has been made possible through another that developed in social theory and activism over the past thirty years: that between sexed body, social gender, and sexuality. In this ordering of human experience, gender identity is not causally related to sexual desire, and both are conceptualized as independent of sexed bodies. In short, "transgender" has changed the terms by which U.S. Americans understand and differentiate between gendered and sexual variance."[207]

Valentine's project contrasts the contemporary academic notion of "transgender" as ontologically distinct from sexuality with an ethnographic exploration of the declared identities of ["transgendered"] people who instead describe themselves with a range of different terms and conceptions including "gay," etc. Valentine, however, observes that in the context of his study, these views of sexual and gender identities were generally viewed by social service providers not as alternative views but rather as *false* ones, as though his informants used such definitively outmoded ideas of identification because they lacked education. In the view of the social service providers, gender and sexuality are fundamentally different kinds of facets of identity and those who would persist in "conflating" them are merely confused or lack awareness of the unquestionable truth of this separation. To the service providers, Valentine's informants were all clearly "transgendered," but did not know the proper name for themselves. The emphasis of Valentine's project thus evolves from being an ordinary ethnography of a community to an investigation into how the idea of

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[207] David Valentine, *Imagining Transgender: An Ethnography of a Category* (Durham: Duke University Press, 2007), 4.

"transgender" as an umbrella description of a wide range of gender variance works to *constitute* a community, **and that this political work is done in service of activism.**

It seems, however, that the process of intentionally working in support of activism is a double-edged sword. Encouraging activism—or at the very least self-liberation—is the implicit goal of much transgender studies and disability studies work. But the more intentional such work becomes, the more it seems that the goal determines what sorts of stories can be told, and again, stories become subject to excessive social pressures. Within (some) transgendered "communities," for instance, authenticity seems to be policed on basis of the normativity of the story told outside the doctor's office. It is presently fashionable, at least in some circles, to identify as transgender in ways that are as deliberately disruptive of all gender norms as possible, e.g., "femme transman." The idea is that the normative binary gender structure is far too restrictive to encompass individual identity. While some of this kind of identification can indeed be read as a kind of fashion among young people in the same ways that various counter-cultural ideas have been for years, it also functions as a way of policing identity and authenticity, and of the boundaries of community. That sort of ideology makes the more traditional transsexual narrative ("I've always felt I was really a woman"), when told outside the doctor's office, look like a form of false consciousness, of having succumbed and finally come to believe the dominant narrative through having to tell the normative lies so many times. Whether this sort of policing serves a useful purpose depends on one's point of view, but it certainly indicates that these kinds of stories are subject to validation in ways that are less formal than either the doctor's office or even the publishing house. To

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apply my early argument in a different context, if there is sufficient incentive to tell a particular kind of story to achieve a desired result in the doctor's office, then it also stands to reason that if there is sufficient incentive to tell a particular kind of story in a social context, then it is likely that people will tell those stories as well, which recasts the personal story as primarily an exercise in social positioning and identification rather than as an individual story about an experience.

This kind of suspicion seems especially problematic for any kind of scholarly project based in progressive values because it raises a question that is particularly difficult to answer wisely: when is the normative story a "reliable" personal account and when is it an example of false consciousness? Surely there must in fact be such a thing as false consciousness, as how else can scholars account for the fact that pressures of various stripes encourage certain kinds of stories to be told? And then there is the question of individual autonomy—whatever arguments may be made about how certain kinds of arguments do political work for certain groups, isn't there a point at which individuals should retain some authority in the telling of their own lives?

I have deliberately postponed discussion in the chapter an issue that I expect will be somewhat contentious, namely the complicated circumstances surrounding Gender Identity Disorder as a "mental disorder." Transgendered individuals do not ordinarily consider themselves "sick," or "mentally ill" even if they have intentionally sought a diagnosis of Gender Identity Disorder in order to obtain hormones or surgery; "disability" is occasionally discussed as a possible strategy to obtain services but it isn't a meaningful form of personal identification in the same way that it is for

others who experience other kinds of illnesses or disabilities. Susan Stryker explains, "In spite of its being an official psychopathology, "treatments" for Gender Identity Disorder are not covered by health insurance in the United States because they are considered "elective," "cosmetic," or even "experimental." This is a truly inexcusable double bind—if being transgendered is not considered psychopathological, it should be delisted as a mental disorder; if it is to be considered psychopathological, its treatment should be covered as a legitimate healthcare need."[208]

Transgender identification and activism is usually more closely (albeit uncomfortably) tied to lesbian/gay or queer activism, under the generic "LGBT" acronym. This examination implicitly considers what identification with disability might mean for transgendered people. Hopefully it is obvious that I am making a point about the legitimacy of the process of assigning pathology to these experiences and the inherent problem of assuming that personal or social identification should occur along the lines of a diagnosis. My suggestion is not that transgendered people should think of themselves as mentally ill and therefore disabled, rather that the medical regulation of certain kinds of thoughts and behaviors are similar enough that both the disability studies/disability rights project and the LGBT rights project might consider what alliances are possible.

Again, David Valentine makes an insightful point:

"… I examine claims about "inclusion" to think about the historical and contemporary meanings that have enabled transgender-identified and gay and lesbian activists to simultaneously come to an agreement on a recognition of shared histories while insisting on their differences. The analysis of inclusion I undertake here is focused on the processes

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[208] Susan Stryker, *Transgender History* (Berkeley, CA: Seal Press, 2008), 14-15.

whereby certain categories are produced as having certain kinds of boundaries in the first place, so that some people may see themselves as being included or excluded from them. Thus, "inclusion" for me is not simply a positive political act but an object of analysis itself, for it already assumes a coherence to the working categories of these politics." [209]

Valentine's point about certain categories being produced with certain kinds of boundaries is important here, as it is what keeps "transgendered" separate from "disability," or more properly, some as-yet-unformed category comprised of "all those shaped by normative ideas about bodily experience and thus subject to 'professional' regulation." The conventions of identification (as transgendered, as disabled, etc.) in the personal story have become more effective means of policing what the personal story should say in service of activism than a reliable description of experience.

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[209] Valentine, *Imagining Transgender: An Ethnography of a Category*, 175.

Chapter 6: Conclusion

Whose Story Is It Anyway? seeks to broaden the current academic disability studies conversation and address the absence of a significant discussion on madness/mental illness. While its central focus has been to examine how the cultural authority of medicine works to "flatten" discourse on the experience of madness/mental illness into standardized narratives of illness, it has had two equal goals: to assess and evaluate strategies for the political enterprise of the disability rights project, and to contribute to the intellectual exchange and practices that constitute disability studies.

Two major insights stand out. First, this research argues for a redirection of disability studies scholarship away from a focus on identity and toward more tangible objects of analysis, most especially the "policies" and practices that define and enforce the categories of "normal" and "pathological." It is useful to think of the diagnostic criteria in the DSM and the WPATH Standards of Care as policies and practices in this context, as they provide a virtually unique example of the ways in which an authoritative body can make judgments about the value of difference and then impose those judgments on a disempowered group (disempowered in this specific context, at least).   Unlike many kinds of difference, where the most powerful means of reproducing power differentials are diffuse and not coming from a single authority, disability has a large number of very specific kinds of entities that make policy-like decisions with considerable practical impact; e.g., the Social Security Administration determines eligibility and the rates of benefits for those who can't work as a result of disability, employee health insurance policies determine what sorts

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of treatments or support will be covered (which can determine what sort of health care an individual can obtain); businesses and employers make policy-like decisions about accessibility and accommodations, and the Food and Drug Administration has policies and regulations about the development, testing, manufacture and distribution of various drugs. All of these "policies" represent concrete points of decisionmaking about the valuation of physical and mental difference, and each has an attendant set of practices for implementation that can impose further control on people's lives.[210] Second, this research stands as an argument for the need for the humanities to engage other disciplines, most especially the "hard" sciences and the constellation of disciplines involved with health care, in a far more vigorous way than they have often done in recent years—again, for reasons related both to intellectual integrity and the quality of scholarship and to efficacy in promoting a progressive political agenda.

My research takes a pragmatic approach to both activism and scholarship and argues that for humanities scholarship in general, and for disability studies in particular, the time has come when explorations into identity yield less new insight, pound for pound, than explorations in other kinds of scholarly directions, most especially in the kinds of policies and practices outlined above. In no way does this challenge the need to include a diversity of perspectives in scholarship or to neglect issues of identity when they can continue to offer useful insight; rather, it speaks to the principle of diminishing returns.[211] Continuing to subdivide the categories of identity into more particular pieces (e.g., Victoria Brownmiller's insistence on a

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[210] To a large extent, this situation is the result of the ongoing association of disability with illness.
[211] My argument to move away from a focus on identity is an effort to expand the field and increase a diversity of perspectives: one of my greatest frustrations with the disability studies project is that it often feels too inwardly focused. Self-reflexivity is enormously important and useful to an extent, but too much can breed insularity.

racially diverse group of working-class disabled lesbians) will no doubt yield *some* kind of new insights, but this dissertation research argues that there may be a point after which insisting on collecting a fully representative demographic sample may not actually provide very many really new ideas, and in fact can work to the opposite.[212] In the context of this study, the latter statement dovetails with the recognition that "personal" stories of a presumably unique individual experience can come to be standardized, and that a wide sampling of stories can in fact end up being essentially many copies of the same story.

On the identity side of the equation, that conclusion suggests that more refined tools are needed for assessing what kinds of personal stories are likely to yield substantial new insight and what stories are less likely to do so, or perhaps better ways in trying to account for the process of standardization. For instance, the work in this study, especially the portions in Chapters Four and Five that describe the standardization of personal narratives, indicate that timing and/or novelty may be important in obtaining personal narratives that are less mediated by dominant narratives on the subject. Likewise, it also suggests that scholars looking at an emerging body of published literature on the experience of, say, obsessive-compulsive disorder, should anticipate that these narratives may be informed by each other and should plan to consider this as a variable in his or her analysis. As noted in Chapter Four, the question of exactly *how* such narrative forms come to be standardized would be a fascinating project. To what extent is this standardization

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[212] This point refers primarily to the development of new intellectual approaches to thinking about power and difference, which has been my primary concern throughout this study. However, there may be a useful distinction to be made between scholarly contributions to theory and scholarly contributions to evidence.

the result of commercial publication and the intentional manipulation of such accounts (by either author or editor) into products for sale? To what extent does the particular medium of the trade-published book affect the process? At the time that this project was conceptualized, blogging was not as well-established a communications medium as it is now, and blogging also adds new questions. If, say, a new kind of "transient mental illness" (such as the "fugue states" that provoked urban working-class European men to suddenly go traveling for months at a time before "waking") were to emerge and accounts of this phenomena were to appear first in the blogosphere, would such narratives become standardized in the same way?

This research also serves as a reminder that there are circumstances in which scholars can and should act as critics within their cause, and here I offer two examples. First, I offer the example of absence. I contend that scholars bear a particular responsibility to make it possible to ask as many kinds of questions as possible, and to remember that it is possible for certain kinds of ideas to be foreclosed (including, for all practical purposes, in this study) when a scholarly agenda is driven by any particular kind of ideology, including popular activism. A tyranny of the majority of the scholar-activists involved in a social justice project is still a tyranny of the majority, and can effectively foreclose ideas that are just too radical or controversial to be acknowledged. For instance, the disability rights movement and groups like Not Dead Yet have long crusaded against legalizing euthanasia, which they feel has and will be used in the service of the outright murder of people with disabilities, as well to bully people with disabilities to "choose" death, which from their perspective amounts to nearly the same thing. A philosophical difficulty arises,

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however, when a person determines that he or she *wants* to die. The primary response from the disability rights/disability studies project has been to use that sort of circumstance as an example and opportunity to argue against the disempowerment and the lack of satisfying living circumstances that some people with disabilities are forced to endure. Another response, however, argues that people with disabilities should receive the same psychiatric care as non-disabled people, and that a desire to die should be considered as evidence of depression and treated accordingly. Such an argument can and will work to re-pathologize the experience of depression (or at least a possible component of it), as it is clearly intended to do. My point is that there is such a strong social taboo against suicide that the idea that a person might want to die without being depressed is simply unthinkable in this context. Whether this seems like a *good* idea is not the point; my concern is that this is an impossible conversation to have in the context of this particular activism-driven research agenda, and the absence of the possibility of discussion potentially forecloses new avenues of thought.

Second, there are more straightforward and practical reasons that scholars should approach memoirs of madness/mental illness with some skepticism and care. While all memoirs are necessarily representations, rather than reflections of experience, these may need to be approached as particularly difficulty and slippery. It is not that illness renders these personal stories unreliable, but instead that they are vehicles through which the dominant cultural narratives of depression-as-illness legitimize themselves using modernist narratives of scientific process. Authors (or at least those who want to publish a "successful" book) have little choice; the only way to be culturally reconstituted as fully human and a credible witness is to embrace the

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medical model, testify to the pathology of the experience, and then distance themselves from it through some variation of "recovery." Telling a different kind of story would be the proverbial tale told by an idiot, full of sound and fury, but signifying nothing.

This observation is corroborated from another angle by an incident that occurred in the preparation of this study. In reading my drafts, and hearing my expressions of frustration at finding it difficult to talk about the experience of depression in its larger sense (i.e., what would have been called melancholy in another time and place) without referencing the contemporary clinical ideas of depression-as-illness, my dissertation advisor, John Caughey, mentioned that he was reminded of some of his own work on imaginary social worlds, published twenty-five years earlier, and suggested that I might want to take a look.[213] In particular, he suggested that I look at a chapter examining social relations in hallucinations and delusions. Although I had read the work years earlier, my re-reading of the chapter was a complete surprise. An anthropologist, Caughey took an ethnographic approach to madness/mental illness, examining patients' perspectives as well as the doctors', and his work included commentary on a case study of a woman who had visions and saw ghosts. In traditional diagnostic terms, he argued, Mrs. M. had all the classic symptoms of a paranoid schizophrenic, and would have certainly been diagnosed as such by any psychiatrist on the ward he was studying, and committed.[214]

However, this didn't happen. Mrs. M's mother took her to a card reader and spirit medium in hope of finding some answers about her daughter's visions. The

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[213] John L. Caughey, *Imaginary Social Worlds: A Cultural Approach* (Lincoln: University of Nebraska Press, 1984).
[214] Ibid.

medium offered a different kind of explanation for her strange experiences, that Mrs. M. was not crazy but was making contact with the spirit world. Mrs. M. undertook spiritual study, became a trance medium herself, and eventually received considerable local recognition for her talents in this arena. "If she is 'schizophrenic,'" he wrote, "she is a highly successful, happy, socially well-adjusted schizophrenic."[215] Caughey's central point was that the context of the social world determines what imaginary social relationships will be valued, and that particular comment was somewhat playful. Nevertheless, I was astonished that he would dare say that—and in a tenure book, no less—because twenty-five years later, the context is so dramatically different. Now, the modernist universalism of biological psychiatry seems so entrenched that to offer the story of a happy trance medium as a challenge to the pathologization or the diagnostic category of paranoid schizophrenia, even with some level of jest, seems inconceivable. Today, to challenge the dominant medical model of biological psychiatry and its insistence on certain experiences as being understood exclusively as pathological would seem to require a completely irreproachable example—literally, somebody with the status of hero, such as Abraham Lincoln.

My point in recounting this story is to illustrate that a real shift has taken place in the extent to which the medical model of biological psychiatry is dominant, and conversely, the extent to which there are viable models for resistance. Caughey was able to talk about other kinds of social worlds as *other possibilities*; his comparison elevated the social world of trance mediums to a level of legitimacy that it could "talk back" to psychiatry, so to speak. Although Caughey uses psychiatry's own criteria to

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[215] Ibid.

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re-establish Mrs. M. as a credible witness, describing her as "highly successful,"

"happy," and "socially well-adjusted," he does not feel the need to offer any other

particular qualifications for her experience and his argument to challenge psychiatry

and psychiatrists.   Psychiatrists, in Caughey's argument, may be able to exercise

control over other people in certain circumstances, but they are fundamentally just

people who have certain perspectives. Therefore, whereas Caughey was able to treat

the question of the validity of psychiatry's definitions of madness/mental illness as

one that was open to at least some debate, today, that argument seems closed.[216] The

dominance of medical authority and the popular perception of scientific knowledge as

absolute is now so complete that those who write about their experiences with

madness/mental illness must testify to the pathology of the experience and the

validity of the medical model *in order to borrow back enough cultural authority to be*

reconstituted as credible witnesses to their own experience. The entire context of

engagement has shifted; biological psychiatry has so effectively deployed modernist

narratives of scientific progress and absolute validity that controls the terms on which

any discussion may occur. It seems to me that, in this particular arena at least, the

disability rights project has *lost* ground over the last twenty-five years.

    That, in turn, suggests that the strategies for resistance need to change. The

disability studies project's emphasis on identity and inclusion, born from a civil rights

era-type consciousness, simply does not translate as a strategy for resistance in the

madness/mental illness arena because there is such a broad popular acceptance of

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[216] Concern with cultural rather than biological explanations of mental illness continues in the work of some psychological anthropologists. See, for example, Roland Littlewood and Simon Dein, eds., *Cultural Psychiatry and Medical Anthropology: An Introduction and Reader* (London; New Brunswick, NJ: Athlone Press, 2000).

medical models of madness/mental illness, even among those who experience it firsthand. Therefore, this research suggests that other approaches, namely those that deconstruct and critique the policy-shaping structures that directly affect people's lives, may be more successful in the long term in promoting new ideas in both scholarship and social change, not only as pertain to madness/mental illness, but for disability studies as a whole. People are not likely to demand change unless they perceive that a real problem exists, so it is up to scholarship to illuminate the problem. Given that there are so many ways to illustrate generally that science is not absolute, and specifically that biological psychiatry is much less "scientific" and much more political than it purports to be, I argue that the disability rights/disability studies project should instead focus on showing how the biological psychiatry system works to perpetuate and protect its own authority, at the expense of those it claims to help.

This study (excluding the literature review) offers examples of three kinds of arguments that address medical discourses, their implementation in their immediate context, and their implications for broader popular discourses. The first type is the one that Joshua Wolf Shenk argues quite eloquently in *Lincoln's Melancholy*, in which he contests the interpretation of the experience of depression as uniformly pathological and instead suggests that the experience is more complex and may in fact have certain "good" features. The second is my revival and application of Thomas Szasz' critique, in which he argues that the idea of mental illness represents a degradation of scientific rigor because the criteria for establishing a diagnosis of mental illness are behavioral rather than physiological, and no somatic evidence of

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pathology can be demonstrated. This, in short, is a refutation of the validity of the idea of "mental illness" on intellectual grounds, a charge that this notion of illness lacks sufficient evidence according to general principles and standards of scientific practice. The third is my broadly Marxist examination of the WPATH *Standards of Care for Gender Identity Disorder* of the way in which the medical industry, broadly interpreted, is careful to protect the line between "medical professional" and "patient," to preserve the appearance of medical authority even when there is little credible evidence of real expertise, and to obscure financial relationships behind rhetorics of professional responsibility.

More broadly, this study argues that it is not only desirable but is in fact absolutely necessary for the humanities to actively engage other disciplines, especially those in science and medicine.   As described above, this study has attempted to provide examples of how a humanities-based disability studies project might profitably redirect its efforts. But my argument for engagement is much larger than that; it is a contention that one of the reasons that the dominant narrative of biological psychiatry has become so powerful is because the humanities have failed to fully engage and critique modernist narratives of scientific progress in their practical embodiments. Instead, I believe, disciplines in the humanities have tended to fold into themselves, perhaps engaging other humanities or social science disciplines in exploring postmodern ideas as they have materialized in those areas, but leaving the hard sciences largely untouched.

I argue for the humanities to engage science, technology, engineering and math (STEM) disciplines, which I interpret here to include medicine, for multiple

mutual benefits. First, I contend that there is a pressing need for a humanities-based critique and counterbalance to the activities being pursued in STEM fields, a need that has begun to be engaged by scholars in science studies. A vigorous philosophy of science activity (e.g., an expansion of science studies) will help to productively critique and strengthen thinking about the application of these fields, and to increase scrutiny on the way that science-related activities are being performed and supported, much as a friendly argument with a good opponent will sharpen and refine one's own ideas. Second, the potential usefulness of external critique goes in both directions, and can serve equally to hone the thinking of scholars in the humanities. Third, and most important, a vigorous engagement of the STEM fields would help to address the problematic popular acceptance of "Science" as having absolute, universal validity— what I understand to be the reason that the dominant model of biological psychiatry has enjoyed such an enormous expansion in power and authority.

For the disability rights project in general, and for people with illness-related disabilities in particular, this contribution has the potential for enormous utility. The more that science and medicine are approached as political constructions, rather than discoveries, the greater the potential for them to be interrogated accordingly and for both the disability rights and disability studies projects to fulfill their respective goals.

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