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CHAPTER 7

A Mad Fight: Psychiatry and Disability Activism

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SUMMARY

The Mad Pride movement is made up of activists resisting and critiquing physician-centered psychiatric systems, finding alternative approaches to mental health and helping people choose minimal involvement with psychiatric institutions. They believe mainstream psychiatry over exaggerates pathology and forces conformity through diagnosis and treatment. In this chapter, Bradley Lewis highlights the political and epistemological similarities between the Mad Pride movement and other areas of disability studies. For instance, the social categories of normal and abnormal legitimize the medicalization of different bodies and minds and exert pressure on institutions to stay on the side of normality, or in this case, sanity.

Lewis briefly traces the historical roots of Mad Pride to show how diagnoses of insanity were often political abuses aimed at normalizing differing opinions and experiences. The movement entered into the debate to fight involuntary hospitalization and recast mental illness as a myth rather than an objective reality. Today's Mad Pride often works within mental health services systems by bringing together "consumers" (rather than "survivors" or "ex-patients") who contribute real input for psychiatric policy.

Nevertheless, Mad Pride still wages an epistemological and political struggle with psychiatry, which has undergone a "scientific revolution" that values "objective" data and undervalues humanistic inquiries. For example, biopsychiatric methods led to Prozac-type drugs being prescribed to 67.5 million Americans between 1987 and 2002. Mad Pride staged a hunger strike to protest the reduction of mental illness to a brain disease, arguing this model couldn't be proved by evidence and limited consumers' options for treatments like therapy or peer-support. By opposing mental illness screening and other policies that advance pharmaceutical interests, Mad Pride continues to work to open peer-run mental health services and reduce the coercive connections between psychiatry and state power.

In the late summer of 2003, six people gathered at a small building in Pasadena, California, and starved themselves for 22 days. The small group of hunger strikers were later joined by over a dozen "solidarity strikers" around the world. Their strike was about "human rights in mental health" and, in particular, it sought to protest the "international domination" of biological approaches to psychiatry and the ever-increasing and widespread use of prescription drugs to treat "mental and emotional crises" (MindFreedom, July 28, 2003).

The hunger strike caught the attention of the *LA Times*, *The Washington Post* and, most important for those involved, the attention of the American Psychiatric Association (APA). One of the central aims of the strike was to challenge the main institutions in psychiatry—namely the American Psychiatric Association, the National Alliance of the Mentally Ill (NAMI) and U.S. Surgeon General—and to rouse them into providing "evidence that clearly establishes the validity of 'schizophrenia,' 'depression' or other 'major mental illnesses' as biologically-based brain diseases" (MindFreedom, July 28, 2003). The fasters demanded evidence that mental and emotional distress results from "chemical imbalances" in the brain; a view that underpins the biopsychiatric medical model and which currently dominates mental health treatment in the West.

In demanding this evidence, the strikers were taking a risk. Using a hunger strike to challenge psychiatry and its scientific findings (which are now almost ubiquitously accepted throughout the medical world and wider culture), the protestors faced the possibility of being labeled "mad." After all, isn't psychiatry a science? Shouldn't scientific questions be decided in laboratories and in peer-reviewed articles filled with graphs and statistical analysis? What sense does it make to hold a hunger strike to challenge contemporary scientific beliefs?

The hunger strikers took the risk because, indeed, they are mad. They are all members of a psychiatry disability activist group known among their friends and allies as "Mad Pride." This activist group is an international coalition devoted to resisting and critiquing clinician-centered psychiatric systems, finding alternative and peer-run approaches to mental health recovery, and helping those who wish to do so minimize their involvement with current psychiatric institutions. They affectionately call themselves "Mad Pride" because they believe mainstream psychiatry over exaggerates psychic pathology and over enforces psychic conformity in the guise of diagnostic labeling and treatment—which all too often comes in the form of forced or manipulated hospitalizations, restraints, seclusions, and medications. Like the celebratory and reappropriative uses of the terms "Crip," "Queer," and "Black Pride," the term "Mad Pride" overturns traditional distinctions and hierarchies. It signifies a reversal of standard pathological connotations of "madness." Rather than pathologizing mental difference, Mad Pride signifies a stance of respect, appreciation, and affirmation.

In this essay, I discuss the relation of Mad Pride to disability studies, review the history of the movement, and work through its contemporary struggles with psychiatry. Throughout the discussion, I highlight the importance of Mad Pride's efforts to go beyond "politics-as-usual." Mad Pride, like other forms of "biocultural" activism (such as Women's Health Movement and AIDS Coalition to Unleash Power), is located at the interface of bioscience and politics. As such, Mad Pride continuously struggles with epistemological issues along with more typical political issues. In short, the people in Mad Pride struggle over *both* truth and values.

This commingling of politics, power, and truth is familiar ground for disability studies. Similar to Mad Pride, disability studies unpacks and undermines stereotyped representations of disability in science and popular culture to understand and intervene in how "representation attaches meanings to bodies" (Garland-

Thomson, 1997, 5). Michael Oliver gives a good sense of these stereotyped disability representations by dividing them into key themes of “individualism,” “medicalization,” and “normality” (Oliver, 1990, 56, 58). *Individualism* refers to the perspective that disability is a “personal tragedy.” This frame undergirds a “hegemony of disability” which views disability as “pathological and problem-oriented” (1996, 129). It leads to a ubiquitous *medicalization* that legitimizes the medical infrastructure for acquiring knowledge about the disabled individual. The logic of this medical infrastructure rests on notions of *normality* and the dichotomy between normal and pathological. The able-bodied and the disabled, the valued and the devalued, become co-constituted cultural divisions which structure medical and cultural preoccupations (Davis, 1995). One side of the binary defines the other and both operate together as “opposing twin figures that legitimate a system of social, economic, and political empowerment justified by physiological differences” (Garland-Thomson, 1997, 8).

Together, these stereotyped disability representations direct the health care industry toward a near exclusive focus on individual biomedical cures. Rather than adjust social environments to meet differing bodily needs, medical interventions seek to cure the individual “abnormal” body. Disability activists resist these individualizing and medicalizing approaches by reframing disability as a social restriction and oppression rather than simply a medical problem. Emphasizing a social model rather than a medical model they call attention to the fact that much of the suffering of different bodies comes from social exclusion, isolation, and lack of opportunity, along with the often pernicious side effects of a medical industry bent on aggressive intervention to achieve “normal” bodies.¹

The task of undermining stereotyped representations of individualism, medicalization, and normality are also central to the Mad Pride movement. Individualistic approaches to mental difference and distress blame and punish the victim for structural problems that are often better understood as located in families, communities, and society. Medicalization, or psychiatrization, legitimizes the medical community’s expert authority over the domain of mental difference. And the binary between normal and abnormal shores up this psychiatrization by providing tremendous social and psychological pressure to stay on the side of normality, or sanity. Disability studies scholars refer to social stigma and oppression against the physically different as “ableism”; those in Mad Pride refer to social stigma and oppression against mental difference as “mentalism” or “sanism” (Chamberlin, 1977, 219; Perlin, 2000, 21).

Despite these similarities, disability activists and Mad Pride members have had difficulty forming a sustained coalition. Part of this difficulty involves the simple fact that two groups are composed of different subcultures—with different histories, different cultural artifacts, and different networks of association. But, beyond this, there are other, deeper reasons. Some disability advocates continue to harbor sanist style associations toward mental difference and do not wish to be associated or “tarnished” by Mad Pride. Likewise, many in Mad Pride (like many in the Deaf community) express discomfort with the “disability” label. They do not see their mental difference as a disability, but rather as a valued capacity. In addition, many in Mad Pride feel that disability struggles are separate from their concerns because physical disability does not involve the same level of state coercion. People with physical differences are often inappropriately confined (through limited choices and multiple manipulations), but Mad Pride activists must deal with an additional layer of state-sponsored coercion in the forms of involuntary commitment and forced medication laws.²

Like many in both movements, however, I believe it is wise to foreground the similarities between disability activism and Mad Pride. Clearly, all of the new social movements, in one way or another, have to struggle with both truth and values—largely because biomedical science has been used to justify such a broad range of subordination practices. But, more than most, Mad Pride and disability activism face a combined political and epistemological struggle. The very heart of these activisms begins with expressly biomedical assignments of impairment. This comes not in the form of a general pronouncement of inferiority, but in a direct and specific diagnosis and treatment process. Because of this, Mad Pride and disability activist efforts to reduce individualization, medicalization, and ableism require a dual struggle that goes beyond politics-as-usual. The challenge of this dual epistemological and political struggle requires all the allies you can get. When disability activist and Mad Pride work together, they can form a formidable coalition.

THE BIRTH OF MAD PRIDE MOVEMENT

Mad Pride activists have had extensive experience going beyond politics-as-usual. Their lesson of dual engagement goes back to the nineteenth century efforts of Mrs. Elizabeth Ware Packard, an early precursor to today's Mad Pride movement. In 1886, Packard, a former mental hospital patient and founder of the Anti-Insane Asylum Society, began publishing a series of books and pamphlets critical of psychiatry. Packard's writings challenged the subordination of women to their husbands and the remarkable complicity of the political and psychiatric establishment to this subordination (Packard 1868, 1874). As Gerald Grob explains, "When Packard refused to play the role of obedient [minister's] wife and expressed religious ideas bordering on mysticism, her husband had her committed in 1860 to the Illinois State Hospital for the Insane" (Grob, 1994, 84). Packard remained incarcerated for three years and only won her freedom by going to court to challenge her confinement. The trial received national publicity and eventually led to Packard being declared sane by the court and released from the asylum. She spent the next 20 years campaigning for personal liberty laws that would protect individuals from wrongful commitment and retention in the asylums.

Even in this early precursor to today's movement, the issues of epistemological struggle and political struggle are inseparably intertwined. Packard challenged pathologizing diagnostic practices that would treat people as insane "simply for the expression of opinions, no matter how absurd these opinions may appear for others" (quoted in Geller and Harris, 1994, 66). And she challenged the political abuses that occurred once the insanity diagnosis had been made. Lunatic asylums, she argued, too often left people at the complete mercy of hospital despotism where they were treated worse than convicts or criminals. Packard's dual stress on both the "facts" of insanity and the inhumane treatment of those considered to be insane reverberate into today's resistance to psychiatry.

The more proximate antecedents to today's Mad Pride movement began in the 1970s. Mad Pride activists, during these years, gained momentum from the black civil rights movement, the women's movement, and from the early stages of lesbian and gay movement and the disability movement. Like Elizabeth Packard almost a century before, the key experience that motivated Mad Pride activists was their negative treatment within the psychiatric system. Early founders of the movement shared common experiences of being treated with disrespect, disregard, and discrimination at the hands of psychiatry. Many also suffered from unjustified confinement, verbal and physical abuse, and exclusion from treatment planning.

The testimony of Leonard Roy Frank, co-founder of the Network Against Psychiatric Assault (1972), provides a helpful glimpse into the experiences of many. After graduating from Wharton, Frank moved to San Francisco to sell commercial real estate. He was in his own words "an extraordinarily conventional person" (Farber, 1993, 191). Gradually, during his late twenties, he started discovering a new world within himself and began going through an "obvious clash between...my emerging self and that of my old self" (191). He later thought of this as a "spiritual transformation." But, at the time, he responded by doing serious reading and reflection on his emerging insights. He ended up rethinking everything in his life: "what was happening to me was that I was busy being born" (191).

A key text for Frank during his transformation was Mohandas Gandhi's autobiography. Frank took seriously Gandhi's message that one's inner life and outer life should interact and complement each other. Reading Gandhi opened his eyes to the violence of political injustice and to the power of non-violent resistance. It also raised his awareness that animals had feelings and could suffer. The more Frank thought about Gandhi's writings on meat-eating, the more he concluded it was inescapably cruel to both animals and to humans: "We can't avoid harming ourselves when we harm other beings, whether human or animal. Meat-eating was an excellent example of how this principle played out in real life. ...Because it was inherently cruel to animals and morally wrong, it affected the wrong doers by causing them to become sick and cutting short their lives" (206). This combination of insights made it difficult for Frank to continue his previous lifestyle and his work selling commercial real estate; he soon lost his job, grew a beard, became vegetarian, and devoted himself to full time spiritual exploration.

Frank was exhilarated by the process, but his parents were deeply concerned. Seeing Frank's transition through the stereotyped frames of individualization, psychiatrization, and sanism, they thought he was having a "breakdown." They tried to persuade him to see a psychiatrist, but Frank resisted. They responded by arranging an involuntary commitment. The hospital records show that Frank's psychiatrists document symptoms of "not working, withdrawal, growing a beard, becoming a vegetarian, bizarre behavior, negativism, strong beliefs, piercing eyes, and religious preoccupations" (193). The psychiatrists diagnosed him as "paranoid schizophrenia," and they started a sustained course of court authorized insulin-electroshock treatments that lasted nine months and included 50 insulin comas and 35 electroshocks.

When the psychiatrists were not giving him shock treatments, their "therapeutic" interactions with Frank

revolved around his behavior, particularly his refusal to shave or eat meat. There was never any discussion of his emerging beliefs or his spirituality. Instead, Frank's psychiatrists focused on changing overt signs of "abnormality." They even went so far as to shave his beard while he was unconscious from an insulin treatment. Frank eventually came to realize that his hospital resistance was futile, and, with the ever-increasing numbers of shock treatments, he also came to fear he was in a "life or death" situation: "These so-called [shock] treatments literally wiped out all my memory for the [previous] two-year period. ... I realized that my high-school and college were all but gone; educationally, I was at about the eighth-grade level" (196).

Rather than risk more "treatments," Frank surrendered. He played the psychiatrists' game and did what they wanted: "I shaved voluntarily, ate some non vegetarian foods like clam chowder and eggs, was somewhat sociable, and smiled 'appropriately' at my jailers" (196). After his release, it took six years to recover from his treatment. But, throughout it all, he never gave up on his beliefs, and he never saw another psychiatrist for treatment. He went on to become a major figure in early Mad Pride activism.

During the early 1970s, people like Frank began to recognize they were not alone and started organizing local consciousness-raising groups. U.S. examples include the Insane Liberation Front in Portland Oregon (1970), the Mental Patient's Liberation Project in New York City (1971), and the Mental Patients' Liberation Front in Boston (1971). These groups built support programs, advocated for hospitalized patients, lobbied for changes in the laws, and educated the public through guest lectures and newsletters. In addition, they began the process of developing alternative, creative, and artistic ways of dealing with emotional suffering and psychological difference outside the medical models of psychiatry. The publication of Mad Pride activist Judi Chamberlin's book *On Our Own* (1977) in the mainstream press was a milestone in the development of peer-run alternatives (Van Tosh and del Vecchio, 2000, 9). Chamberlin used the book to expose her own abuse at the hands of psychiatry and to give a detailed account of burgeoning consumer-run alternatives. The eloquence, optimism, and timing of the book was a critical catalyst for many in the movement. As ex-patient Mary O'Hagan puts it: "When my mood swings died away I was angry and amazed at how the mental health system could be so ineffective. There had to be a better way. I searched the library not quite knowing what I was looking for. And there it was, a book called *On Our Own* by Judi Chamberlin. It was all about ex-patients who set up their own alternatives to the mental health system and it set me on my journey in to the psychiatric survivor movement" (quoted in Chamberlin, 1977, back cover).

The newly formed local Mad Pride groups also organized an annual Conference on Human Rights and Psychiatric Oppression to help connect local members with the wider movement. At these meetings, activists from across the country gathered to socialize, strategize, and share experiences. They gained solidarity and increasing momentum from the experience of being with like-minded activists. Between meetings local groups communicated through a newspaper forum. The San Francisco local newsletter, *Madness Network News*, evolved into a newspaper format which covered ex-patient activities across North America and around the world. This publication became the major voice of the movement, with each issue containing a rich selection of personal memoirs, creative writing, cartoons, humor, art, political commentary, and factual reporting—all from the ex-patient point of view (Hirsch, 1974; Chamberlin, 1990, 327).

This early period of the Mad Pride movement was also the most radical in its epistemological critique. Early leaders of the movement drew philosophical support from high-profile critical writers that, as a group, came to be known as "anti-psychiatry." Writers such as Erving Goffman (1961), R. D. Laing (1967), Thomas Scheff (1966), and Thomas Szasz (1961) may have differed widely in their philosophies, but collectively their main tenets were clear. Mental illness is not an objective medical reality but rather either a negative label or a strategy for coping in a mad world. As Laing put it, "the apparent irrationality of the single 'psychotic' individual" may often be understood "within the context of the family." And, in turn, the irrationality of the family can be understood if it is placed "within the context of yet larger organizations and institutions" (Laing, 1968, 15). Put in context in this way, madness has a legitimacy of its own which is erased by medical-model approaches that can only pathologize it. For many anti-psychiatry writers, mental suffering can be the beginning of a healing process and should not be suppressed through aggressive behavioral or biological interventions.

The most epistemologically radical of the anti-psychiatry writers, Thomas Szasz, had the most influence on U.S. activists. Szasz, a dissident psychiatrist, was shunned within his own field, but his prolific writings (over 25 books) and forceful prose gave him tremendous influence outside psychiatry (Leifer, 1997). Throughout his work, Szasz's argument was always two-fold: (1) mental illness is a myth and (2) there should be complete separation between psychiatry and the state. As Szasz put it in a summary statement, "Involuntary mental hospitalization is imprisonment under the guise of treatment; it is a covert form of social control that subverts the rule of law. No one ought to be deprived of liberty except for a criminal offense, after a trial by jury guided by legal rules of evidence. No one ought to be detained against their will in a building called 'hospital,' or any other medical institution, on the basis of expert opinion" (Szasz, 1998).

Consistent with others in the Mad Pride movement, Szasz combined his epistemology and his politics. Szasz's insistence on the autonomy of mental health clients rested directly on his epistemology, which he based on a strong positivist philosophy of science that emphasized a sharp demarcation between observation and conjecture. For Szasz, *physical illness* was real because it was based on actual observation, but *mental illness* was at best a metaphor. A broken leg is real because you can see the X-ray, but a "broken brain" is a myth because there is no X-ray that will show it. For Szasz, to see mental illness as "real" rather than as a metaphor was to make a serious category mistake. "Mental illness" is not objectively observable; it is a myth.

MAD PRIDE TODAY

During the last 30 years of their struggle, Mad Pride has increasingly infiltrated the mental health system rather than simply criticizing it from outside. Despite the fact that institutional psychiatry continues to ignore and denigrate their efforts, important government agencies involved in mental health policy have begun to pay attention. Mad Pride activists have been particularly successful in increasing consumer participation in treatment planning and facility governance. In addition, they have gained increasing respect for the work developing peer-run treatment alternatives.

The most important agency to pay attention to Mad Pride perspectives has been the national Center for Mental Health Services (CMHS). This little known public agency is “charged with leading the national system that delivers mental health services” (Center for Mental Health Services, 2002). Following on the success of Chamberlin’s *On Our Own*, the agency worked with a local California peer group to publish *Reaching Across: Mental Health Clients Helping Each Other*, a “how to” manual for peer-run services (Zinnman, Harp, and Budd, 1987). For too long, CMHS explains, “decisions about mental health policies and services were made without any input from people who have mental illnesses or their families. As a result, some policies and programs failed to meet the needs of the people they were intended to serve” (Center for Mental Health Services, 2004). CMHS worked to change this by sponsoring peer-run research, training, and technical assistance centers, and producing federally mandated documents encouraging states to include consumer-operated alternatives to traditional treatment programs. Since 1985, CMHS has also sponsored an annual, national level, Alternatives Conference that brings together consumers and ex-patients to network and to share the results of their scholarship and program development.

These political successes have gradually necessitated a change in Mad Pride’s epistemological critique. Szasz’s strong epistemological critique of psychiatry was useful in the early days of the movement, but it became less so as Mad Pride shifted into its more contemporary formations. The early anti-psychiatry literature set up an either/or relation between consumers and providers. People had to either be with psychiatry or against it. Szasz’s rigid positivist epistemology left little room for contradiction and coalition politics. As sociologist and Mad Pride activist Linda Morrison points out, with increasing infiltration of the mental health system, many members no longer took a hard-line approach to psychiatry. These members identified themselves more as “consumers” than “survivors” or “ex-patients.” Consumers, by definition, were critical of aspects of psychiatry but were willing to legitimize and participate in other aspects (Morrison, 2005). Mad Pride needed to embrace these contradictions and adopt coalition politics to avoid losing these members.

Contemporary Mad Pride members have made just this kind of epistemological shift. Though activists still reference Szasz favorably, they now draw more on his political values (of autonomy and separation of psychiatry and state) than on his epistemology. Mad Pride members mark this shifting epistemology by referring to themselves as “consumer/survivor/ex-patient” groups. This hyphenated designation, usually shortened to “c/s/x” or “consumer/survivors,” highlights that today’s Mad Pride is a coalition of critical activists—some of whom have a more radical epistemological critique than others (Morrison, 2005).

This shift has set the stage for additional coalitional possibilities between Mad Pride and critical psychiatrists. Increasingly, critical psychiatrists are moving beyond the narrow approaches of their training and drawing from interdisciplinary theory in science studies, disability studies, and the humanities. Like Mad Pride, they are developing alternative perspectives on psychiatry that emphasizes the importance of social models and of democratic research and treatment. In Britain, an influential Critical Psychiatry Network (www.critpsynet.freeuk.com/critpsynet.htm) has recently formed, bringing together a coalition of critical providers and consumer/survivors (Double, 2004).³

Contemporary Mad Pride’s political success at getting a seat at the table of mental health policy has also necessitated a change in the more radical infrastructure of the movement. The Conference on Human Rights and Psychiatric Oppression no longer meets and has now been replaced by the Alternatives Conference sponsored by CMHS. The different name of the conference is consistent with a shift in emphasis from psychiatric oppression to peer-run support and service involvement. The change is subtle as both oppression and support remain paramount for Mad Pride, but the change does mark a shift of the emphasis within the movement.

In addition, the newspaper *Madness Network News* is no longer being published. Today’s Mad Pride connects its members largely through the activities of the Support Coalitions International (SCI) which brings together 100 international local groups. Under the leadership of David Oaks, SCI has become “the epicenter of the Mad Movement” (“Windows into madness,” 2002). It runs a website (www.mindfreedom.com), an email list, a magazine (*MindFreedom Journal*), and an on-line “Mad Market” (where interested parties can

find “a little library of dangerous books”). Much of the success of the center comes from Oaks’ capacity to build a coalition of consumers, survivors, and ex-patients. Like Packard, Frank, and Chamberlin before him, Oaks’ motivation for mental health activism comes from his experiences of psychiatric abuse: including forced hospitalization and forced treatment. Like so many others, he has taken those experiences and turned them into political action.

RECENT STRUGGLES WITH PSYCHIATRY

Despite the successes Mad Pride has had within the mental health system, their epistemological and political struggle with psychiatry continues. These struggles are often complicated, and they require impressive political savvy. In this section, I work through some examples of these struggles to give a sense of the political terrain and the critical importance of today's consumer/survivor activism. The 2003 hunger strike is a good example of Mad Pride's contemporary epistemological battles. To understand the context of the strike, it is important to note that during the same time Mad Pride has complicated its epistemology, psychiatry has gone in the exact opposite direction. The last 30 years have seen a "scientific revolution" in psychiatry that primarily values quantitative, positivistic protocols for research (Lewis, 2006). The emphasis on "objective" data has created a preference for neuroscience and genetics at the expense of an array of cultural and humanistic styles of inquiry. This new scientific psychiatry, working in tandem with pharmaceutical funding, has gone on to create today's dominant clinical model of psychiatry, "biopsychiatry"—whose emphasis is almost exclusively biomedical style diagnoses and pharmacological treatments.

The blockbuster medication, Prozac, gives a window into biopsychiatry's dominance. Between 1987 and 2002 (the year Prozac came off patent), new prescriptions for the drug reached over 27 million. Combined with the multiple "me too" drugs it inspired—the class of antidepressants known as "selective serotonin inhibitors" (SSRI)—that total reached 67.5 million in the U.S. alone (Alliance for Human Research Protection, 2004). That means almost one in four people in the U.S. were started on a Prozac-type drug between 1987 and 2002. These same one in four people were dealing with sufficient emotional issues that someone thought they needed help.

For some of these people, the SSRIs may have been the best choice. But was it the best choice for 67.5 million people? Psychiatry's professional literature, its patient hand-outs, and the popular press all tell us "yes." They tout "scientific progress in the treatment of depression" as the main reason for the SSRIs extensive use (Gardner, 2003; Metzl, 2003; Lewis, 2006). But, if we scratch the surface, we find that the SSRIs are highly controversial, and researchers have not been able to agree on even simple questions like: Do the drugs work? or, Are they safe? The *Handbook of Psychiatric Drug Therapy*, typical of most clinical reviews, claims with great authority that the SSRIs are highly effective and that they have a mild side effect profile (Arana and Rosenbaum, 2000, 57, 76). But critical analysts conclude just the opposite: that the SSRIs are not much better than sugar pills and that they have major side effects—including sexual dysfunction, suicidality, and even violence (Breggin, 1994, 65; Fisher and Fisher, 1996; Kirsch and Sapirstein, 1998; Glenmullen, 2000; Healy, 2004). Going further, scientific opinion is also at odds regarding the question of explanation. Some argue that the SSRIs have effects because they treat biological disease. But others argue these drugs are simply stimulants like cocaine and amphetamines. These researchers conclude that SSRIs are mood brighteners and psychic energizers because they work on the same neurotransmitters as other stimulants (Breggin 1994; Glenmullen, 2000).

When we take these controversies surrounding the Prozac-type drugs into account, it seems highly questionable that the SSRIs were the best choice for 67.5 million people. For most of these people, alternatives like psychotherapy, peer-support, and personal and political activism would have likely been better options than taking drugs that are expensive, are possibly no better than placebo, have multiple side effects, and may be little more than a dressed-up version of speed. But, because of the hype of biopsychiatry, these controversies are not well known and alternatives are not given a chance. The SSRIs are seen as quick and easy solutions backed by advances in psychiatric science and individual medical recommendations. For most people thrown in that situation, they are seen as the only viable option.

Mad Pride's hunger strike was directed squarely at this so-called "biological revolution" in psychiatry. The fasters, organized by David Oaks and Support Coalition International, demanded evidence that emotional and mental distress can be deemed "biologically-based" brain diseases, and also evidence that psychopharmaceutical treatments can correct those "chemical imbalances" attributed to a psychiatric diagnoses (MindFreedom, July 28, 2003).

The strikers were not trying to show that the biopsychiatric model of mental illness is myth, and they were not touting another model of mental distress as better or more accurate. The protestors stated from the outset that they were aware that psychopharmaceuticals work for some people, and that they were not judging individuals who choose to employ biopsychiatric approaches in an effort to seek relief. For Oaks and his fellow protestors, there are

many ways to help people experiencing severe mental and emotional crises. ... We respect the right of people to choose the option of prescribed psychiatric drugs. Many of us have made this personal choice. ... However, choice in the mental health field is severely limited. One approach dominates, and that is a belief in chemical imbalances, genetic determinism and psychiatric drugs as the treatment of choice.

In demanding evidence, the strikers hoped to show that the “chemical imbalance” theory of mental distress is not watertight, and to therefore challenge the overinvestment in this “biopsychiatric approach” by the mental health institutions.

In the early days of the strike, the APA brushed off the strikers’ demands for evidence and told them to consult introductory textbooks on psychiatry. The strikers responded by persisting in their demands and by sending a letter to the APA written by a panel of 14 critical scholars. The letter showed that within the very textbooks that the APA had recommended there were numerous statements that invalidated the notion that mental illnesses have specific biological bases (MindFreedom, August 22, 2003). Using psychiatry’s own knowledge against itself, the hunger strikers prompted the APA to respond more fully, and a follow-up communiqué from APA finally conceded that “brain science has not advanced to the point where scientists or clinicians can point to readily discernible pathological lesions or genetic abnormalities that in and of themselves serve as a reliable or predictive biomarkers of a given mental disorder” (American Psychiatric Association, 2003). This reluctant admission from the APA marked an important epistemological victory for Mad Pride. In an interview, Oaks said: “They acknowledged that they didn’t have the biological evidence [of mental illness], so that’s on the record” (Davis, 2003). The hunger strike vividly demonstrated how problematic it is to accept without question the “truths” of biopsychiatry.⁴

Despite this small success, Mad Pride’s epistemological struggle continues to be a tough one. They are battling against a veritable superpower whose main ally is the hugely profitable and very influential pharmaceutical industry. As David Davis reports in his *LA Times* article on the hunger strike, Mad Pride is up against both an American Psychiatric Association, whose conventions bustle with “brightly colored” booths of the drug companies, and a booming pharmaceutical industry whose “sales of psychotherapeutics reached \$21 billion in 2002, almost double the \$11 billion in sales in 1998” (Davis, 2003).⁵

Because of the influence and clout of biopsychiatry, Mad Pride knows all too well that skirmishes over epistemology are only part of the struggle. While it is vital to strike at the heart of mainstream psychiatry’s “knowledge” and “truths,” it is just as vital to realize that the epistemology game is hard to win. Science studies scholar Bruno Latour explains that dissenters of science can only go so far by using scientific literature against itself. For alternative perspectives to successfully join in the process of science (and truth) in the making, they must build their own “counter-laboratories,” which of course requires tremendous resources (Latour, 1987, 79). Mad Pride clearly does not have the resources to compete laboratory for laboratory with the institutions of psychiatry and their pharmaceutical supporters. Thus, while Mad Pride continues to play the game of epistemology, and continues to have some successes destabilizing psychiatry’s biomedical model, it also struggles with psychiatry on the more typically political and economic terrain.

This was particularly evident in 2002 when President George W. Bush’s administration initiated what David Oaks dubbed “the Bush triple play,” which prompted Mad Pride to mobilize swiftly and energetically to fight on the political front (Oaks, 2002–2003). The triple play included (1) the planned appointment of a controversial conservative psychiatrist, Dr. Sally Satel, to the important National Advisory Council for Mental Health, (2) the announcement of budget cuts to key government-sponsored consumer/survivor technical support centers, and (3) the creation of a New Freedom Commission to study U.S. mental health services. All aspects of this triple play posed direct threats to Mad Pride and the consumer/survivor movement, and they threatened the freedoms and rights of those suffering mental and emotional crises.

The first part of the triple play began with a White House leak, with word coming out that Dr. Sally Satel was being selected by the Bush administration for a position on the advisory council for the CMHS (the very organization which has been most receptive to consumer/survivor initiatives). Dr. Satel—a fellow at the American Enterprise Institute (a conservative political think tank)—is the author of the controversial book *P.C., M.D.: How Political Correctness is Corrupting Medicine* (2000). She is not only a vociferous advocate of the biopsychiatric model of mental illness; she is also an outspoken critic of the consumer survivor movement, and an insistent lobbyist for involuntary commitment and treatment laws. In *P.C., M.D.*, under a chapter titled “Inmates Take Over the Asylum,” Satel names the leaders of the Mad Pride movement and attacks their hard fought efforts to increase peer-run services and reduce involuntary treatments. She denigrates mental health administrators who have taken Mad Pride seriously: “Tragically, they [mental health administrators] seem to be willing to sacrifice the needs of those with the most severe illnesses to political correctness and to the expediency of placating the vocal and annoying consumer/survivor lobby” (76). And she even goes so far as to describe the Alternatives Conference as the “guinea pig rebellion” (50).

For Mad Pride, Satel’s appointment and her public vilification of consumer-run organizations signaled an overall Bush administration strategy to aggressively push a controversial biopsychiatry paradigm, to abandon

consumer-run self-help and peer-support programs, and to increase forced psychiatric medication.

These concerns were reinforced by the second part of the Bush triple play. Soon after the leak about Dr. Satel, the Bush administration announced budget cuts to CMHS-sponsored consumer/survivor technical assistance centers. Although the cuts totaled only \$2 million out of the total CMHS budget, they were targeted directly at consumer/survivors. Three out of five of these centers were consumer run, which represented a clear about face for CMHS. Joseph Rogers, director of one of the programs to be cut, the National Mental Health Consumer Self-Help Clearinghouse, commented that “We had no warning. The cuts just came out of the blue, and we’ve had no explanation since that makes any sense” (Mulligan, 2002).

The third part of the Bush triple play was the creation of a New Freedom Commission on mental health. Bush hailed the Commission as a major step toward improving mental health services, and he charged it with the ambitious goals of reviewing the quality of mental health services, identifying innovative programs, and formulating federal, state, and local level policy options. The administration stipulated that the Commission be composed of 15 members and that these members be selected from a range of stakeholder groups, including providers, payers, administrators, consumers, and family members (Bush, 2002). Although all of this sounded laudable enough, but true to Mad Pride concerns, when the New Freedom Commission’s 15 members were made public, only one person self-identified as having personally experienced the mental health system or as involved in the consumer/survivor movement. The New Freedom Commission’s choice of members appeared not to be about true stakeholder inclusion, but only a crude form of tokenism.

For many consumer/survivors, the Bush triple play was not only an outrage, it was a serious danger. These three deft moves threatened to undo all the gains consumer/survivors had made over the past 30 years. Oaks put it this way: “Mental health consumers and psychiatric survivors have experienced fierce repression. But to have a well-funded think tank unite with a Presidential administration to openly attack our movement in such a way is unprecedented. As the enormity of the attacks set in, several activists said they were numb with disbelief” (Oaks, 2002–2003).

Mad Pride activists could have reasonably given up at this juncture. Instead, they held a strategy meeting with colleagues from the international movement, and they decided to directly oppose each part of the Bush triple play. Opposition to Dr. Satel’s appointment and the cuts to CHMS programs took the form of a blitz of emails to consumer/survivor list-servs, active lobbying of mental health administrators, and a barrage of critical faxes to Secretary Tommy Thompson of the US Department of Health and Human Services. And, rather than being dismayed by the non-democratic message of the New Freedom Commission’s selection process, consumer/survivors took full advantage of the Commission’s plan to hold public hearings on psychiatric services. Four days before the first scheduled hearing, consumer/survivors gathered for an emergency meeting with a network of physical disability activists. Judi Chamberlin, who has been a longtime advocate of disability and Mad Pride coalitions, explained the rationale for involving the larger disability movement, “When a wolf wants to target a whole flock, it looks for the most vulnerable lamb. The Bush administration is targeting psychiatric survivors today, but the whole disability movement is the target tomorrow” (Oaks, 2002–2003).

The meeting turned out to be a major inspiration for consumer/survivors. The first speaker that night was Justin Dart, who many call the “Martin Luther King” of the disability movement. Dart, struggling with the last stages of terminal illness (he died just eight days later), gave a rousing speech which set the tone for the meeting. Dart proposed that:

we in the disability communities must unite with all who love justice to lead a revolution of empowerment. A revolution, to create a culture that will empower every single individual including all people with psychiatric disabilities, to live his or her God given potential for self determination, productivity and quality of life.

Empowerment means choices—individual choices about where we live, how we live, where we work, choices about health care. We have a right to complete quality health care of our own choosing.

NO FORCED TREATMENT EVER.

We choose our own doctors and medication. We choose the places of care. No denial of treatment ever.

NO FORCED TREATMENT EVER.

(Oaks, 2002)

The combined presence of Dart and several other disability representatives created the strategic capacity to get the word out and rally support and resistance far beyond the usual consumer/survivor community. It also further advanced a cross-disability activist connection between the disability movement and consumer/survivors.

On the day of the New Freedom Commission’s first public meeting, consumer/survivor activists and their disability activist comrades made their presence known. Not only did they hand out their own press release and talk individually to members of the Bush Commission, they also made public announcements. Judi Chamberlin’s testimony was typical. Announcing that she was a “psychiatric survivor” and “an advocate” on

consumer/survivor issues for more than 30 years,” she pointed out:

A basic premise of the disability rights movement is simply this: Nothing About Us Without Us. The makeup of the Commission violates this basic principle. Just as women would not accept the legitimacy of a commission of “expert” men to define women’s needs, or ethnic and racial minorities would not accept a panel of “expert” white people to define their needs, we similarly see the Commission as basically irrelevant to our struggle to define our own needs.

(Chamberlin, 2002)

Chamberlin argued that the Commission lacked the “expertise on the consumer/survivor experience” and also the “expertise of disability rights activists, those knowledgeable about the legal and civil rights of people diagnosed with mental illness, and experts in community integration.” And she went on to detail how the Commission should get the extra expertise it needed.

Unlike the results of the hunger strike, however, the results of Mad Pride’s efforts to resist the Bush triple play can only be described as mixed. With regard to part one of the triple play, Mad Pride was unable to stop Sally Satel’s appointment to the advisory board. Once on the board, she predictably advocated for more forced treatment and for discontinuation of consumer-run programs. But part two of the triple play, the planned budget cuts to peer-support programs never materialized. The three technical centers sponsored by CMHS continued to be funded.

The New Freedom Commission results were also contradictory. On the one hand, the Commission ended up quite friendly to Mad Pride concerns. It agreed with Mad Pride that the mental health system is fundamentally broken, that it needs extensive overhaul (not just piecemeal reform), that mental health services must be consumer and family centered, that modern psychiatry overemphasizes reductionist biomedical approaches, and that consumers must be protected from unjust incarceration and the use of seclusion and restraints. Together these recommendations signified an impressive success for Mad Pride’s and their disability allies’ efforts to reach the Commission and have their voices included in their report.

But, on the other hand, all was not rosy with the Commission’s report. In addition to the above recommendations, the New Freedom Commission also recommended nationwide mental health screenings in schools, primary care offices, prisons, and the welfare system. The ominous dimension of this plan was pointed out in the *British Medical Journal* (BMJ) in an exposé titled “Bush plans to screen whole US population for mental illness.” The BMJ explained that the New Freedom Commission recommendation for nationwide screening was linked to their recommendation for “evidence-based” treatment protocols. In psychiatry, these protocols are code words for the Texas Medication Algorithm Project (TMAP). TMAP was started in 1995 as an alliance between the pharmaceutical industry, the University of Texas, and the mental health system to set up expert guidelines for psychiatric practices. But a whistle blower at TMAP, Allen Jones, revealed that key officials received money and perks from the drug companies to unnecessarily promote expensive on-patent drugs. As Jones explained “the same political/pharmaceutical alliance” behind TMAP is also behind the New Freedom Commission. This alliance is “poised to consolidate the TMAP effort into a comprehensive national policy” of over-treating mental illness with expensive medications (Lenzer, 2004). When you add to this state of affairs the recent National Institute of Health conclusion that half of all Americans will meet the criteria for a *DSM-IV* disorder some time in their life, the profiteering possibilities of the New Freedom Commission’s political/pharmaceutical alliance is easy to imagine (Kessler, 2005).

Of course, none of this screening will go forward without resistance. In quick response to the BMJ exposé, MindFreedom sent out a news release “What You Gonna Do When They Screen For You” and set up a section of its website titled “President Bush and the Shrinking of the USA” (see www.mindfreedom.org/mindfreedom/bush_psychiatry.shtml). This news board gives access to breaking stories and commentary, plus it provides answers to frequently asked questions concerning the controversy. In addition, the Mad Pride advocacy group Alliance for Human Research Protection (AHRP) has begun to monitor closely the outcomes of the New Freedom Commission (see www.ahrp.org/about/about.php). At the time of this writing, AHRP reports that lawsuits are already being filed in Indiana to resist the effects of “TeenScreen Depression”—a program funded partly with new federal grants initiated by the New Freedom Commission.⁶

CONCLUSION

These recent conflicts with psychiatry provide an important window into Mad Pride's ongoing epistemological and political struggles. Against tremendous odds, the movement has worked impressively to expose psychiatry as a limited field of inquiry, to open up its clinical services to more peer-run alternatives, and to reduce coercive connections between psychiatry and the state. Their fight to reduce individualization, psychiatrization, and sanist approaches to psychic life is arduous, and at times a little "mad." But the stakes are high and the struggle must continue. With the increasing coalition with the broader disability movement and the emergence of a critical psychiatry network, the fight is becoming more and more mainstream. Soon the battle will be one about which we all know and in which we can all participate. Active biocultural citizenship regarding mental difference and distress requires nothing less.

As the editors of *Abusters* sum up in their issue on Mad Pride, in a culture of hardening isolation, status, materialism, and environmental degradation,

Mad Pride can be a broad embrace. It is a signal that we will allow ourselves our deep sorrow, our manic hope, or fierce anxiety, our imperfect rage. These will be our feedback into the system. We reserve the right to seek relief from both our most troubling symptoms and from society's most punitive norms. The sickness runs deep; without madness, there is no hope of cure.

("Deep sadness, manic hope," 2002)

NOTES

1. Public health scholar Barbara Starfield estimates that the combined effect of medical adverse effects in the United States are as follows:

- 12,000 deaths/year from unnecessary surgery
- 7000 deaths/year from medication errors in hospitals
- 20,000 deaths/year from other errors in hospitals
- 80,000 deaths/year from nosocomial infections in hospitals
- 106,000 deaths/year from nonerror, adverse effects of medications.

That comes to a total to 225,000 deaths per year from iatrogenic causes—which constitutes the third leading cause of death in the United States. Just after heart disease and cancer (Starfield 2000, 484).

2. For an extended discussion of confinement and disability see the “Confinement” entry in the *Encyclopedia of Disability* (Lewis, 2005).
3. The Critical Psychiatry Network organizes its members less under the banner of “anti-psychiatry” and more under the banner of “post-psychiatry” (Thomas and Bracken, 2004). The epistemological underpinning of post-psychiatry avoids the either/or problems of anti-psychiatry. Relying on the philosophy of Michel Foucault, a post-psychiatric perspective blurs the binary between truth and myth as all forms of human knowledge making are understood to be both material and semantic (Foucault, 1965 and 2003; Bracken and Thomas 2001; Lewis, 2006). This shift moves the legitimacy question of psychiatric knowledge from “truth” to “consequences.” The issue is not whether psychiatric knowledge magically mirrors the world, but who is allowed to participate in making the knowledge? What kinds of consequences (and for who) will follow from the knowledge?
4. For an extended analysis of the exchange between Mad Pride and the APA see critical psychiatrists Duncan Double’s review: “Biomedical Bias of the American Psychiatric Association” (Double, 2004).
5. See former editor-in-chief of the *New England Journal of Medicine* Marcia Angell’s book, *The Truth about Drug Companies: How They Deceive Us and What to Do About It* (2004), for an extended discussion of the influence of the pharmaceuticals on medical research and practice. Also see Pulitzer Prize finalist Robert Whitaker’s book, *Mad in America: Bad Science, Bad Medicine, and the Enduring Mistreatment of the Mentally Ill* (2002) for an historical perspective specific to psychiatry.
6. Theresa and Michael Rhoades, who filed the first suit, claim that TeenScreen sent their daughter home from school telling her she had been diagnosed with obsessive compulsive disorder and social anxiety disorder. The Rhoades “claim that the survey was erroneous, improper, and done with reckless disregard for their daughter’s welfare and that they did not give the school permission to give the test” (Pringle, 2005). High-profile attorney John Whitehead calls the situation an “Orwellian Nightmare” and has agreed to take on the Rhoades case. However, “because of the financial backing of pharmaceutical companies and the Bush administration’s support through the New Freedom Commission,” even Whitehead is concerned and considers his opposition to be formidable foes (Alliance for Human Research Protection, 2005).

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