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Susan Stefan

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“DISCREDITED” AND “DISCREDITABLE”: THE SEARCH FOR POLITICAL IDENTITY BY PEOPLE WITH PSYCHIATRIC DIAGNOSES

SUSAN STEFAN*

*You're never the same—mental health diagnosis is an opinion and attitude. You cannot cure or have remission from others' attitudes of rejection.*¹

*Friends and family—they don't understand my illness / disability—they think I am getting away with something—that there is nothing wrong with me.*²

INTRODUCTION

Identity matters. In particular, identity matters to people who are stigmatized and stereotyped because they belong to a socially disfavored group. Although individual members of these groups may have very different ideas about how to respond to prejudice and mistreatment, the matter of identity itself—membership in the group—is generally not at issue. Justice Clarence Thomas and the Reverend Jesse Jackson may have sharply conflicting ideas about the meaning of being an African American in our society, but the identity of each man as an African American is hardly open to question.

* Staff Attorney, Center for Public Representation, Newton, Massachusetts. I began research for this Article as a professor of law at the University of Miami School of Law, where I was greatly assisted as always by the wonderful reference librarians, my secretary, Joann Manees, and by research assistant Marina Luybimova. I am also grateful for the insights of Ira Burnim, Keith Elkin, David Oaks, and Vicki Smith.

1. SUSAN STEFAN, SURVEY FOR PEOPLE WHO HAVE BEEN GIVEN A PSYCHIATRIC LABEL, unnumbered response (on file with author) [hereinafter STEFAN SURVEY]; see *infra* notes 57-59 and accompanying text for an explanation of survey methodology.

2. STEFAN SURVEY No. 92.

When it comes to disabilities, however, these distinctions begin to blur, in part because disability is as much about environmental context and social functioning as it is about any physical or mental characteristic. Asthma may or may not be a disability, depending on the presence of pollen and pollutants in the air. Mild mental retardation may be less disabling in a rural farming community than in a busy urban environment. In addition, impairments exist along a spectrum, both physical and functional, rather than representing a dichotomy between a class of clearly identified disabled people differentiated unmistakably from nondisabled people. Therefore, a person's self-identification as "disabled" is often not as automatic as self-identification with respect to race and sex. In fact, self-identification as a person with a disability is often a long, complex, and difficult process. In this respect it may resemble self-identification as gay or lesbian.

Disability, unlike race and sex, but like sexual preference, is usually not identifiable at birth,³ and often becomes salient in an individual's life after she has formed a personal identity. Indeed, one of the most hurtful aspects of disability discrimination is that newly disabled persons find it very difficult to accept that people who knew them before they became disabled can treat them so differently once they are disabled, and people with hidden disabilities are shocked when they are abandoned by old friends and even family after they reveal their disabilities.

The fact that disabilities exist along a spectrum contributes to another disparity between the identity of disabled people and the identity of people in other groups that experience discrimination. Because disabilities exist along a spectrum, it is unclear when someone actually becomes "disabled." Disability is a status that is initially identified, named, or conferred, not by the individual, but by "experts," usually medical experts, although the ramifications of disability are significantly social and political.

3. A number of articles have pointed out that gender is not always self-evident, and is sometimes assigned at birth, and that racial characteristics exist along a spectrum that permits "passing" and its attendant social issues. See, e.g., Alex M. Johnson, Jr., *Destabilizing Racial Classifications Based on Insights Gleaned from Trademark Law*, 84 CAL. L. REV. 887, 919 (1996); Chanika Phornphutkul et al., *Gender Self-Reassignment in an XY Adolescent Female Born with Ambiguous Genitalia*, 106 PEDIATRICS 135, 135-37 (July 2000). I do not dispute these contentions, but here make a general point about the majority of cases.

Furthermore, unlike race or gender, experts hold themselves out as being able to mitigate or treat disability.⁴ Although people with disabilities have challenged the claims and dominance of experts for many years, experts retain a position of primacy in defining both the categories and the meaning of physical and mental disability, and are considered the only authority on the mitigation, treatment or cure of the disability.⁵

The centrality of experts to the experience of disability has enormous social, legal, and political consequences. A large number of cases under the Americans with Disabilities Act involve claims by the plaintiff that she is disabled.⁶ Defendants dispute these claims by hiring experts to refute the plaintiff's claims to identity as a person with a disability. In many cases, the Supreme Court has rejected the plaintiff's claim to belong to the protected group—persons with disabilities.⁷ This process—permitting experts and the judiciary to determine whether an individual fits into a protected class—would be unthinkable in the case of race, gender, age, religion, or sexual orientation.

Moreover, some disabilities are not readily apparent. People with invisible disabilities confront issues about disclosure, whereas people with visible disabilities have fewer secrets to keep and

4. In the past, this was also true of sexual preference. Claims by experts to identify, categorize, and treat sexual preference, however, have lost credibility in the last twenty years, particularly since the American Psychiatric Association removed homosexuality from the *Diagnostic and Statistical Manual of Mental Disorders* in 1980. The pressure and advocacy that accomplished this deletion was clearly recognized by the gay and lesbian community as a political move, and the excision of homosexuality from the category of deviances identified and treated by psychiatric experts was indeed a political victory, because it represented an essential first step toward the normalization of this identity within society. Thus, freeing an identity from expert taxonomy may be essential to political development.

5. DEBORAH A. STONE, *THE DISABLED STATE* (1984); Matthew Diller, *Entitlement and Exclusion: The Role of Disability in the Social Welfare System*, 44 *UCLA L. REV.* 361, 416-17 (1996).

6. The Americans with Disabilities Act also allows claims on the basis of history of disability or being regarded as disabled, but the vast majority of cases involve people who claim to be presently disabled. See Americans with Disabilities Act of 1990, 42 U.S.C. §§ 12101-12213 (2000).

7. See, e.g., *Murphy v. United Parcel Serv., Inc.*, 527 U.S. 516 (1999) (holding that high blood pressure did not limit the individual's life activities); *Sutton v. United Airlines, Inc.*, 527 U.S. 471 (1999) (holding that severe myopia did not qualify as a disability because of the availability of corrective lenses).

choices to make in this arena.⁸ Issues surrounding self-revelation and "coming out" are crucial to many people with invisible disabilities. These people may go to enormous lengths to conceal their disabilities from their colleagues at work and even their families. In this respect they are also similar to those in the gay and lesbian community.

Within the contingent and malleable category of disability, psychiatric disability raises perhaps the most perplexing questions about identity. First, although almost every disability has some effect on social functioning, psychiatric disability is, from the point of view of the external observer, completely characterized by difficulties, deficits, or aberrations in social functioning. In the absence of unmistakable problems in social functioning, an individual's self-report of psychiatric disability is likely to be discredited, disbelieved, or minimized. An individual with a severe physical disability who climbs Mount Everest or performs some equivalent feat is lauded for courage and tenacity;⁹ but an individual who reports severe psychiatric difficulties yet continues to function is simply disbelieved.¹⁰ Or worse, the person is criticized for self-pity, exaggeration, or self-dramatization.¹¹

Second, psychiatric difficulties not only exist along a spectrum of impairment, as do most disabilities, but they are also temporally contingent: the same person may vary over a period of weeks between functioning extremely well and being immobilized and dysfunctional.¹² Though some people with psychiatric disabilities

8. In some cases, people with visible disabilities do make choices about keeping their disabilities secret. For example, John Hockenberry, former reporter for National Public Radio (NPR), filed stories with NPR from an Oregon affiliate for years before he had to disclose that he used a wheelchair when he missed a deadline because he could not find a telephone booth he could fit into to file a report. JOHN HOCKENBERRY, *MOVING VIOLATIONS: WAR ZONES, WHEELCHAIRS, AND DECLARATIONS OF INDEPENDENCE* 168-70 (1995).

9. Christy Hoppe, *Ready to Take on Mount Everest; "It's about the capabilities of people with disabilities,"* DALLAS MORNING NEWS, Nov. 21, 2002, at 31A; James B. Meadow, *Head in the Clouds; Blind Climbers' Dreams Lead Him to Bag World's Highest Mountain Peaks,* ROCKY MOUNTAIN NEWS, Dec. 26, 2002, at 6A.

10. WALTER OLSON, *THE EXCUSE FACTORY: HOW EMPLOYMENT LAW IS PARALYZING THE AMERICAN WORKPLACE* (1997).

11. See ALAN DERSHOWITZ, *THE ABUSE EXCUSE AND OTHER COP-OUTS, SOB STORIES AND EVASIONS OF RESPONSIBILITY* (1994).

12. EEOC, *EEOC ENFORCEMENT GUIDANCE ON THE AMERICANS WITH DISABILITIES ACT AND PSYCHIATRIC DISABILITIES*, app. question 8, at <http://www.eeoc.gov/docs/psych.html> (last

cycle between states of functioning well and disability, it is also true that many individuals experience severe psychiatric disability while *concurrently* managing to "pass" as functional.¹³

Finally, although almost everyone who receives a diagnosis of mental illness personally experiences profound emotional distress, the identification and transformation of profound distress into disability, by any of its various names—disability, mental illness, insanity—is made by an "expert," who is by definition an individual outside the group. Although some mental health professionals are also people with severe psychiatric disabilities, very few are public about their history and experiences.

The determination by experts that a person has a "mental illness," sometimes after fifteen minutes of evaluation in a hospital emergency room, unites into one category millions of people with extraordinarily divergent personal experiences who might otherwise never think to identify with each other. The classification itself is often disputed and subject to widely conflicting opinions and disagreement, both among the experts and among the persons labeled mentally ill or mentally disabled.

For example, some people for whom the diagnosis of psychiatric disability has been crucial to their identity deny that they have any mental illness at all. According to Janet Gotkin:

"That is part of our condition, to feel despair. That is what I am feeling and it is black and it wells up inside until you feel that you will explode with the heaviness of this sense of yourself, alone, in this unfeeling darkness that can be the world. Women and men have looked down into the pit that is themselves and that is life and questioned the meaning and mourned the futility of it all. No amounts of Thorazine will ever make this feeling go away."¹⁴

visited Feb. 5, 2003) ("For some individuals, psychiatric impairments such as bipolar disorder, major depression, and schizophrenia may remit and intensify, sometimes repeatedly, over the course or several months of several years.").

13. See KATHY CRONKITE, *ON THE EDGE OF DARKNESS: CONVERSATIONS ABOUT CONQUERING DEPRESSION* (1994) (interviewing Mike Wallace, Joan Rivers, Rod Steiger, and others); ELIZABETH WURTZEL, *PROZAC NATION: YOUNG AND DEPRESSED IN AMERICA* (1995).

14. JANET GOTKIN & PAUL GOTKIN, *TOO MUCH ANGER, TOO MANY TEARS: A PERSONAL TRIUMPH OVER PSYCHIATRY 377* (1975) (quoting Janet Gotkin).

She continues:

This was not an illness. I was not being "sick" and having symptoms. This was me—living....

"There is no such thing as schizophrenia, not outside some psychiatrist's imagination. There is pain and people's odd convoluted ways of trying to survive in the world. That's real. Not mental illness."¹⁵

This perspective is different from people with physical disabilities who refuse to concede that their illness or impairments have rendered them disabled. In the case of psychiatric disability—and only psychiatric disability—a significant number of people with psychiatric diagnoses deny that they have a medical impairment at all, as opposed to denying that the impairment disables them.¹⁶ However, it is important to note the general fallacy of the charge by some psychiatrists that people with psychiatric disabilities deny that they have any problems at all, and that this "lack of insight" itself requires treatment. It is far more accurate to say that some people with psychiatric diagnoses deny that they have a medical impairment suitable for diagnosis and treatment by psychiatric experts. Virtually all the written accounts by former psychiatric patients who reject psychiatry acknowledge that they have experienced fundamental personal emotional crises.¹⁷ Sometimes these crises are called spiritual, and sometimes existential, according to the philosophy of the individual. People with this perspective speak of recovery and healing rather than treatment, and it is clear that for many of them, the social consequences of those crises—involuntary commitment and forced treatment—are political issues, and their political identity as a former psychiatric patient plays as crucial a role in forming their personal and political identity as race, gender, or sexual preference.

15. *Id.* at 383.

16. JUDI CHAMBERLIN, *ON OUR OWN: PATIENT-CONTROLLED ALTERNATIVES TO THE MENTAL HEALTH SYSTEM* (1978); GOTKIN & GOTKIN, *supra* note 14, at 383.

17. *See, e.g.*, BEYOND BEDLAM: CONTEMPORARY WOMEN PSYCHIATRIC SURVIVORS SPEAK OUT (Jeanine Grobe ed., 1995); CHAMBERLIN, *supra* note 16; CRY OF THE INVISIBLE: WRITINGS FROM THE HOMELESS AND SURVIVORS OF PSYCHIATRIC HOSPITALS (Michael A. Susko ed., 1991); SETH FARBER, *MADNESS, HERESY, AND THE RUMOR OF ANGELS: THE REVOLT AGAINST THE MENTAL HEALTH SYSTEM* (1993); GOTKIN & GOTKIN, *supra* note 14.

Others who concede that their lives have been profoundly affected by psychiatric disability appear to deny that it plays any part in their continuing personal identity. William Styron, author of *Darkness Visible*, says at the end of the book that "[s]ave for the awfulness of certain memories it leaves, acute depression inflicts few permanent wounds."¹⁸

Still another group of people believes that psychiatric disability is central to its identity, but considers it an illness with no political meaning:

Before [these episodes of depression] happened, I would identify myself [as] a white male. Now I identify myself as a mentally ill white male. I don't know if it makes a difference, that's how I see myself, how I describe myself. Maybe in a way it's kind of self-defeating to look at myself that way. If the first thing that I use to identify myself is an illness, that kind of perpetuates the depression. It's not honest to ignore it, or to say that the power of positive thinking will somehow make it go away. I definitely—it's been the most defining thing in my life for the last two years, and it's affected all areas of my life, so I don't know how I couldn't lead off with that descriptor. I wouldn't call myself a white male with depression, maybe in the future if it's not so pervasive I can change. There really is a tremendous amount of guilt about it, somehow that it's my fault, if I'm discriminated against, that I deserve it, that's part of being depressed.¹⁹

These very different reactions to the experience of emotional suffering, the experience of diagnosis and treatment, and the issue of identity itself create a difficult situation for a group that decades of social science research confirms is subject to enormous discrimination. In order to assert that one is being discriminated against because of membership in a certain group, one must both accept membership in the group and externalize negative experiences. In other words, one must be able to recognize such experience as discrimination, rather than deserved treatment. This acceptance and externalization are crucial to seeing one's identity

18. WILLIAM STYRON, *DARKNESS VISIBLE: A MEMOIR OF MADNESS* 75 (1990). It did, however, have enough impact on him to lead him to write a book.

19. Interview with K.E. (Mar. 15, 2002) (on file with author).

in a political context. Externalization, however, requires that one have sufficient self-esteem and internal resources to believe that social difficulties are primarily the result of unfair and unjustified treatment by others, and that the generalizations made by those in power about the group to which one belongs are at best mistaken and at worst purposeful oppression. A claim of discrimination is obviously a political claim of unjustified treatment on the basis of membership in a certain group. Both the recognition that the treatment is unjustified and the question of identity (defining who is a member of this group) are critical to a political movement.²⁰

Translating membership in a particular stigmatized group into a political movement requires that (1) its members be willing to publicly claim the identity; (2) its members organize to dispute the stereotypes and social meaning surrounding the identity that is imposed by the majority; and (3) ultimately, members of the group successfully assert the prerogative to reshape the social meaning and consequences of the identity.²¹

For most groups traditionally protected by antidiscrimination law, the first step is not an issue. Although there may be disagreement about the social meaning of a characteristic such as race, gender, religious affiliation, or sexual preference, a substantial degree of social consensus both within and outside the group exists as to whether any given individual is a member of the group. By contrast, the question of who does or does not have a psychiatric disability is a highly contested one on both individual and systemic levels.²² There is even some debate about whether mental illness exists as a medical or biological condition.²³

Even if an individual claims identity within the group of people with psychiatric disabilities, the question remains whether the

20. William N. Eskridge, Jr., *Social Movements and Law Reform: Channeling: Identity-Based Social Movements and Public Law*, 150 U. PA. L. REV. 419 (2001).

21. I am grateful to Ira Burnim of the Bazelon Center on Mental Health Law for this insight.

22. Compare CHAMBERLIN, *supra* note 16, DERSHOWITZ, *supra* note 11, GOTKIN & GOTKIN, *supra* note 14, and OLSON, *supra* note 10 (contesting diagnoses of mental illness on individual and systemic levels), with PAUL S. APPELBAUM, *ALMOST A REVOLUTION: MENTAL HEALTH LAW AND THE LIMITS OF CHANGE* (1994), and KAY REDFIELD JAMISON, *AN UNQUIET MIND: A MEMOIR OF MOODS AND MADNESS* (1997).

23. See THOMAS SZASZ, *THE MYTH OF MENTAL ILLNESS: FOUNDATIONS OF A THEORY OF PERSONAL CONDUCT* (1961).

individual sees any political connection between her disability and its social consequences. While groups whose social stigma arose on the basis of visible characteristics have generally been more successful in forming political movements than groups where the unifying characteristic is invisible or deniable,²⁴ people with psychiatric disabilities have long represented an interesting amalgam of both categories—unavoidable visibility in some cases, and lifelong invisibility in others. Forty years ago, Erving Goffman described people with a stigmatizing characteristic as either "discredited" or "discreditable."²⁵ The discredited person assumes that whatever characteristics make her different are evident on the spot, and known by the community. By contrast, the discreditable person is the person who may be able to pass, whose difference is neither known by those present nor immediately perceivable by them.²⁶ Although neither Goffman nor subsequent commentators developed the political implications of these categories,²⁷ this Article theorizes that the difficulties that the ex-patient movement has had in organizing the millions of people who have suffered from discrimination as a result of receiving psychiatric treatment, and the related problems of identity discussed at the beginning of this Article, result from the split between people in these two categories.

24. Some assert that the gay rights movement only gained momentum in earnest after the AIDS epidemic forced many gay men, especially prominent gay men, into painful and involuntary public disclosure. See Richard Lacayo, *The New Gay Struggle*, TIME, Oct. 26, 1998, at 32 (linking the AIDS epidemic to the "cutting edge of gay politics").

25. ERVING GOFFMAN, *STIGMA: NOTES ON THE MANAGEMENT OF SPOILED IDENTITY* 4 (1963).

26. *Id.*

27. A search of LEXIS revealed five law review articles that incorporate the "discredited/discreditable" dichotomy. See Benjamin Baez, *The Supreme Court and Affirmative Action: Narratives About Race and Justice*, 18 ST. LOUIS U. PUB. L. REV. 413 (1999) (discussing the dichotomy as it relates to affirmative action); Dennis Chong, *Values Versus Interests in the Explanation of Social Conflict*, 144 U. PA. L. REV. 2079 (1995-96) (looking at the dichotomy in terms of law and economics); Jane Byeff Korn, *Cancer and the ADA: Rethinking Disability*, 74 S. CAL. L. REV. 399 (2001) (analyzing the construction of disability with an emphasis on cancer, but including no discussion of psychiatric disabilities or the politics of an organized group identity); Robert C. Post, *The Social Foundations of Defamation Law: Reputation and the Constitution*, 74 CAL. L. REV. 691 (1986) (discussing defamation); Note, *Making Docile Lawyers: An Essay on the Pacification of Law Students*, 111 HARV. L. REV. 2027 (1998) (discussing the experience of law students at Harvard Law School). A search of the medical and health literature on NEXIS returned two articles that each simply explained Goffman's theory. See Sana Love, *The Involuntary Civil Commitment of Mentally Ill Persons in the United States and Romania: A Comparative Analysis*, 23 J. LEGAL MED. 211 (2002); Graham Scambler, *Stigma and Disease: Changing Paradigms*, 352 LANCET 9133 (1988).

Experiences of stigma and discrimination, identity, and political agendas presently vary greatly between people in the "discredited" and "discreditable" categories. Ultimately, social structures play each group off the other, rendering both categories politically weaker than they would be if they were to unite and proceed as one bloc of millions of people.

Yet, the worlds of the discredited and the discreditable have much more in common than either might imagine. If people from both worlds could come together, they would constitute a potent political force. In Part I, I examine and describe the two worlds of people with psychiatric disabilities. I will compare and contrast their perspectives, their literature, and their goals. In Part II, I consider the significant social and political consequences of the dichotomy between the world of the discredited and the world of the discreditable. In Part III, I briefly discuss whether this apparent dichotomy is characteristic of all such groups. I conclude by offering a theory that unifies these apparently diametrically opposed groups, and suggest strategies that would enable them to combine to create a political force unlike any that has previously existed.

I. "DISCREDITED" AND "DISCREDITABLE": THE TWO WORLDS OF PEOPLE WITH PSYCHIATRIC DISABILITIES

Erving Goffman differentiated between people whose stigmatizing features are public knowledge—the discredited—and people who can conceal their stigmatizing characteristic—the discreditable.²⁸ A discredited person is one who has ended up being what Sue Estroff called "a full-time crazy person."²⁹

The political movement by people with psychiatric disabilities has largely been organized on behalf of the discredited.³⁰ Members and opponents of the ex-patient movement understand the movement as representing people whose conditions are unavoidably subjects of public policy, because they are in public hospitals, clients of the public mental health system, or receiving government disability benefits. When psychiatrists decried the effort to establish a right

28. See *supra* notes 25-26 and accompanying text.

29. SUE E. ESTROFF, *MAKING IT CRAZY: AN ETHNOGRAPHY OF PSYCHIATRIC CLIENTS IN AN AMERICAN COMMUNITY* 255 (1981).

30. See *infra* note 37 and accompanying text.

to refuse treatment as leading to patients "rotting with their rights on," they certainly were not describing upper middle class and wealthy patients in private hospitals.³¹ The books written by upper middle class people about their experiences with mental illness in the private sector reflect the unquestioned assumption, shared by their mental health professionals, that they had the right to make treatment decisions, including treatment refusal.³² In *An Unquiet Mind*, Kay Redfield Jamison, a professor of psychiatry with bipolar disorder, reproduces her doctor's notes: "Patient has elected to resume lithium.... Patient has stopped lithium again.... Patient is not taking lithium.... Patient has resumed lithium."³³ Although her psychiatrist observed the serious and adverse consequences of Jamison's decision to stop taking medication, he did not tell her that she was rotting with her rights on, or make any move to force her to take lithium.³⁴ Thus, the ex-patient movement's concern with minimizing or halting forced psychiatric treatment³⁵ is essentially irrelevant to the millions of people who are discreditable.

The ex-patient movement is also focused on substandard state institutional conditions,³⁶ which discreditable people will never experience. The ex-patient movement protests the abuses of seclusion and restraint, injury, and death at the hands of institutional workers.³⁷ These issues barely exist for people who are discreditable. The people who lead the ex-patient movement are people who once were discredited, recovered, and could have made the leap from discredited to discreditable by passing as nondisabled. Instead, their experiences have led them to champion the cause of their discredited brothers and sisters.³⁸

31. Paul S. Appelbaum & Thomas G. Gutheil, "Rotting with Their Rights On": *Constitutional Theory and Clinical Reality in Drug Refusal by Psychiatric Patients*, 7 BULL. AM. ACAD. PSYCHIATRY L. 306 (1979).

32. See, e.g., JAMISON, *supra* note 22, at 100-01.

33. *Id.*

34. *Id.* at 102-03.

35. The Internet sites of the leading organizations of the ex-patient movement concentrate on eliminating forced treatment. See MindFreedom Online, at <http://www.mindfreedom.org> (last visited Jan. 29, 2003); MadNation: People Working Together for Social Justice and Human Rights in Mental Health, at <http://www.madnation.cc> (last visited Jan. 29, 2003); National Empowerment Center, at <http://www.power2u.org> (last visited Jan. 29, 2003).

36. See CHAMBERLIN, *supra* note 16; GOTKIN & GOTKIN, *supra* note 14.

37. See sources cited *supra* note 35.

38. Psychiatrist Daniel Fisher helped to found the National Empowerment Center

The world of discreditable people with psychiatric disabilities is both much larger and much less visible than the world of discredited people. People who are discreditable have psychiatric disabilities, but they are not represented by mental health lawyers in civil rights cases. When researchers and scholars study and discuss mental illness, they rarely, if ever, study people who are discreditable. Although millions of the discreditable suffer a great deal of discrimination, they prefer to stay out of political activity identified with issues relating to mental illness. Unlike people with physical disabilities, not one well-known discreditable person testified before Congress at hearings on the ADA, nor have they testified to state legislatures.

People with diagnoses of severe psychiatric disability who are discreditable are not organized into any significant political movement. Indeed, their frame of reference regarding their experiences with psychiatric disability virtually ensures that they rarely see it as raising political issues at all. To the extent that discreditable persons who have gone public have concerns that could be described as political, they revolve around the impact of stigma on career and family, and discrimination in insurance coverage, professional education, and licensing. To the extent that they have organizations at all, their organizations, like the Depression and Bipolar Support Alliance, concentrate on medical issues, such as the use of placebos in research, or on insurance parity.³⁹ Sometimes, however, they are willing to tell their stories to the media.⁴⁰

For the most part, we know people who are discreditable as people with psychiatric disabilities only when they choose to come forward, which they generally do individually, primarily through books and magazine articles. Their literature is substantial: a series

because of his experiences as a patient in the mental health system. See <http://www.power2U.org/who.html> (last visited Jan. 24, 2003). Dr. Patricia Dugan, a psychologist, has similarly devoted her life to exposing ways in which the mental health system can damage patients. See www.bu.edu/resilience/examples/recovery-conspiracyofhope.txt (last visited Jan. 24, 2003).

39. For more information, see <http://www.ndmda.org> (last visited Jan. 18, 2003).

40. See, e.g., Oliver Poole, "Curse? It's the Luck of Superman" "I have nothing to hide now. Once you have been labelled as the outcast of society, you have nowhere to go but up," LONDON DAILY TELEGRAPH, Dec. 9, 2002, at 13 (interview with Margot Kidder); Alex Treniowski et al., *Finding Daylight NFL Star Ricky Williams Breaks Free of the Anxiety that Nearly Ruined His Life*, PEOPLE, Oct. 7, 2002, at 103.

of books over the last twenty years or so by people of greater or lesser degrees of fame and accomplishment detail their struggles with and eventual recovery from mental illness.⁴¹ These authors publish their books after recovery and recount stories that are relentlessly medical and apolitical on talk show interviews.

These two worlds of discredited and discreditable people with psychiatric diagnoses appear to exist in virtually parallel universes with no apparent intersections. In fact, the discreditable world is, by definition, largely invisible. People who are discreditable emerge to tell their stories voluntarily, in their own time and on their own terms. Because the experiences of discreditable people with psychiatric disabilities are at odds with our social and legal understanding of disability and discrimination, their experiences are erased and unaccounted for in research about mental illness, academia, and in case law. Despite the popularity of the literature of discreditable people, they are never considered to be part of the group society calls "the mentally ill." When the media reports that someone with a history of mental illness has committed an act of violence, one rarely associates the offender to Buzz Aldrin,⁴² Kay Redfield Jamison,⁴³ William Styron,⁴⁴ Patty Duke,⁴⁵ Mike Wallace,⁴⁶ Rod Steiger,⁴⁷ or any of the myriad other celebrities who have courageously and candidly recounted their experiences with emotional crises and disabilities.

This absence creates a profound failure to understand both the nature of psychiatric disability and the nature of discrimination against people with psychiatric disabilities. Until these misunderstandings are corrected, the political movement for people with psychiatric disabilities will gain little ground.

41. See generally CRONKITE, *supra* note 13; NORMAN S. ENDLER, HOLIDAY OF DARKNESS: A PSYCHOLOGIST'S PERSONAL JOURNEY OUT OF HIS DEPRESSION (Rev. ed. 1990); JAMISON, *supra* note 22; MARTHA MANNING, UNDERCURRENTS: A LIFE BENEATH THE SURFACE (1994); ANDREW SOLOMON, THE NOONDAY DEMON: AN ATLAS OF DEPRESSION (2001); STYRON, *supra* note 18; TRACY THOMPSON, THE BEAST: A RECKONING WITH DEPRESSION (1995).

42. See EDWIN E. "BUZZ" ALDRIN, RETURN TO EARTH (1973).

43. See JAMISON, *supra* note 22.

44. See STYRON, *supra* note 18.

45. See PATTY DUKE & GLORIA HOCHMAN, A BRILLIANT MADNESS: LIVING WITH MANIC DEPRESSIVE ILLNESS (1993).

46. See CRONKITE, *supra* note 13, at 14-20.

47. See *id.* at 46-48.

It is important to note that the distinctions between discredited and discreditable individuals do not arise from differences in severity of diagnosis, symptomatology, or bizarreness of behavior. Like the discredited, discreditable people have hallucinations and delusions, attempt suicide, cut themselves, have multiple personalities, and experience mania and hospitalization. Although it is a common belief that well-known professionals who have suffered from debilitating psychiatric problems, such as Rod Steiger, Mike Wallace, William Styron, and Kay Jamison, could not really have been as badly off as the person blankly watching television day after day in the state hospital, their accounts tell a different story. Mike Wallace recounts watching the sky shake,⁴⁸ and Rod Steiger reports clawing his skin and pounding on the wall for three days.⁴⁹

It would also be misleading to assume that the primary distinctions between the first world (the discreditable) and the second world (the discredited) are class and economics. The fact that children of the upper middle class become members of the first world was one of the chief reasons that their parents formed the National Alliance for the Mentally Ill. The best known advocates and spokespeople for the first world come from middle class and upper middle class families. David Oaks, a leader of the ex-patient movement, was radicalized by involuntary commitment and treatment while he was at Harvard (although he came to Harvard from a working class family with a strong union/labor background). By the same token, thousands of poor and lower class people with severe psychiatric disabilities toil and pass every day in minimum wage jobs.

If the distinction between the two worlds is definitely not one of symptomatology or behavior, and not principally one of class, what is the source of the distinction? I can only speculate. Years of research have led me to the following conclusions.

First, race is relevant to one's perspectives on emotional difficulties. In a fascinating study by Sue Estroff and her colleagues, people who were considered to be "chronically mentally ill" were asked for their interpretations of the condition that had resulted in repeated hospitalizations. Just under half of the white men and

48. *Id.* at 17.

49. *Id.* at 46.

women and black women reported that they had an illness; only four percent of black men considered themselves ill.⁵⁰ All of the books and articles written from the discreditable point of view are written by white people. People of color write uniformly from the discredited perspective.

Second, the autobiographical literature suggests that the attitude of a troubled individual's parents and the treatments they seek for their children make an enormous difference. I am not suggesting that we return to the world of schizophrenogenic mothers, but one has only to contrast the tales of women who were sexually abused by their fathers, stepfathers, or other relatives, with the accounts of Kay Redfield Jamison, Tracy Thompson, and other successful professionals who recite their parents' love, patience, and enduring support, to at least wonder whether this may not make a decisive difference.

Third, mainstream employment tends to be a distinguishing feature of people in the first world. This is not to say that people in the second world cannot handle employment, even difficult, stressful employment. Many people in the second world are employed, but their employment tends to mirror their primary identity as consumers of mental health services. They are the "consumer" representatives in state government, in managed care companies, in departments of mental health. They receive grants to run drop-in centers and coordinate conferences. Rarely, they are scholars who research and study people with psychiatric disabilities;⁵¹ or attorneys who represent people with psychiatric disabilities.⁵²

By far the greatest determinant, however, is the experience of force. Discredited people write of "being stripped and locked in a cold room or being beaten during physical restraint,"⁵³ or of being

50. See Sue Estroff et al., *Everybody's Got a Little Mental Illness: Accounts of Illness and Self Among People with Severe Persistent Mental Illness*, 5 MED. ANTHROPOLOGY Q. 331 (1991).

51. Professor Jean Campbell has done pathbreaking research on people with psychiatric disabilities. See, e.g., Jean Campbell & Caroline L. Kaufman, *Equality and Difference in the ADA: Unintended Consequences for Employment of People with Mental Health Disability*, in MENTAL DISORDER, WORK DISABILITY, AND THE LAW 221 (Richard J. Bonnie & John Monohan eds., 1997).

52. Jeannie Matulis, an attorney formerly employed by the California Protection and Advocacy System, is one example.

53. Coni Kalinowski & Pat Risser, *Identifying and Overcoming Mentalism*, in INFORMED PUBLISHING AND TRAINING 1, available at <http://home.att.net/~PatRisser/spirituality/>

[sexually] molested on the psychiatric unit.”⁵⁴ One discredited person explained:

[T]hey took me to the “quiet room” and they ripped my clothes off, and they stuck me in the bum with needles very painfully and roughly because I was struggling to get away from them.... I was tied to the bed naked, and then they left me in the dark with these drugs happening that they had injected in me, and I was terrified.⁵⁵

It is the dehumanizing and traumatizing impact of force, often administered by mental health aides and professionals who are supposed to help and treat, that is at the core of the anger and disillusionment of the movement by discredited people. According to David Oaks, “[t]he identity of psychiatric survivors is as experiencers of human rights violations.”⁵⁶ This experience of force communicates and reinforces their diminished status and stigma, their powerlessness to resist indignities and bodily intrusion, their lack of credibility, and the futility of complaint. No one would strap down Mike Wallace and inject him with Haldol in his buttocks, no matter how bizarrely he was behaving. For the most part, this is because people with celebrity and high income can maintain an enormous private realm that insulates and erases their erratic behavior from public view. When a celebrity behaves bizarrely in public, and attributes a political rather than a medical meaning to the treatment received, the media coverage is almost comically uncertain.

The stories of discreditable people, though vivid with the emotional suffering associated with psychiatric disability, contain no references to force or coercion, and in fact virtually uniformly identify the mental health professionals who treated them as allies, sometimes indispensable allies.

identifyingmentalism.html (last visited Feb. 6, 2003).

54. Laura Prescott, *Women Emerging in the Wake of Violence*, in PROTOTYPES SYSTEM CHANGE CENTER 13 (1998).

55. Barbara Everett, *Something is Happening: The Contemporary Consumer and Psychiatric Survivor Movement in Historical Context*, 15 J. MIND & BEHAV. 55, 62 (1994) (quoting participant in radio broadcast hosted by Irit Shirifat (CBC Radio 1989)).

56. E-mail from David Oaks to Susan Stefan (July 22, 2002) (on file with author).

I came upon the distinctions between these two groups of people by accident. In writing a book about discrimination against people with psychiatric disabilities, I decided to conduct a survey of people who perceived themselves as psychiatrically disabled, who had a diagnosis of serious mental illness, or who thought others perceived them as psychiatrically disabled.⁵⁷ The survey asked people if they believed they had been discriminated against, and if so, on what basis and in what areas of life.⁵⁸ I conducted this survey by distributing it through a wide variety of networks that I thought would tap the full spectrum of people with psychiatric disabilities. I sent it to fifty-one protection and advocacy agencies,⁵⁹ which provide legal and advocacy services for people with psychiatric disabilities in institutions and in the community. I sent it to a number of groups such as the Mental Health Association, the National Alliance for the Mentally Ill, and the National Manic-Depressive Association. I sent it to ex-patient support groups, distributed it at mental health conferences, and most importantly for the results I will be discussing, posted it on the Internet. In my attempt to make the survey as widely available as possible, I essentially concentrated on outlets serving people who are discredited.

I expected the surveys to reflect stories that constituted discrimination according to my understanding of it as both a lawyer and a citizen: exclusion, underestimation of abilities and strengths, and stigma associated with stereotypes such as dangerousness or violence. In fact, the surveys reflected many accounts of precisely this kind of devaluation: termination of parental rights or loss of

57. I received a total of 408 responses over the two and a half years that the survey was available. Of these, eleven were incomplete. I used the answers that they had included. One was from Australia and six reported only physical disabilities. I received relatively few responses that some might consider garbled or delusional. I included these responses in the survey data.

58. I have appended a copy of the survey to this Article.

59. In 1986, Congress passed the Protection and Advocacy for Mentally Ill Individuals Act, which provided federal funds for legal aid to persons who suffered from abuse and neglect in psychiatric institutions, or within ninety days of discharge. *See* Pub. L. No. 99-319, 100 Stat. 478 (1986). The Act has since been renamed the Protection and Advocacy for Individuals with Mental Illness Act, and its scope has been broadened to include individuals with psychiatric disabilities in the community. 42 U.S.C. § 10801 (2000); *see also* Children's Health Act of 2000, Pub. L. No. 106-310, 114 Stat. 1101 (2000) (amending the statute to reflect the name change).

access to children because of a diagnosis of mental illness;⁶⁰ termination of employment upon discovery that the individual had a history of hospitalization or was taking medications;⁶¹ rejection by schools,⁶² landlords,⁶³ churches,⁶⁴ and families; mistreatment by the medical system, especially emergency treatment;⁶⁵ and rejection by insurance companies.⁶⁶ These traditional stories of discrimination involved people insisting on their ability to raise children, compete in employment, be part of the congregation, succeed in school, and generally be equal members of the social and political community in the face of assumptions and stereotypes that magnified their diagnoses and ignored their strengths. In large part, these people did not want accommodations for their disability. They simply wanted to be treated equally—to be allowed to stay in rental housing because they paid the rent and were good tenants, rather than being evicted because the landlord was afraid that mentally ill people set fires; to be allowed to worship in the congregations of their faith rather than being ejected because their voices were characterized as demons; to be allowed to study, work, or be part of

60. STEFAN SURVEY No. 24; *id.* No. 263 (stating that the worst discrimination experienced was "loss of access to my kids").

61. *Id.* No. 104; *id.* No. 283.

62. *Id.* No. 112; *id.* No. 115; *id.* No. 130; *id.* No. 145 (stating that, after being committed to a psychiatric unit, the student was barred from returning to student housing and was not permitted to retrieve belongings from the dormitory room); *id.* No. 186 (stating respondent was "denied entrance to graduate psychology program shortly after interview with department head when I openly mentioned I had psychotherapy").

63. *Id.* No. 6; *id.* No. 13.

64. *Id.* No. 17; *id.* No. 41 (stating that respondent was rejected by church because respondent's voices were considered "demons").

65. One respondent reported:

[W]hen [I was] taken to the emergency room for a physical emergency, ... the Dr. demanded to perform a psychiatric exam before releasing me, intercepted a call between my psychiatrist & me, insisted that the advocate who was with me leave the examining room or he would not do the psychiatric exam ... I was overmedicated because those in charge didn't believe that I knew about my disorder and about how medications affect me—If you have a mental illness, you must also be childish & unreliable, unpredictable, unknowledgable.

Id. No. 248.

66. *Id.* No. 269 ("[M]y husband wanted to take out insurance on me; & the agent said we couldn't because of my mental illness. I thought this isn't fair—I was really angry."); *id.* No. 274 ("[I]nsurance not covering psychiatric (a biological disease) treatment, therapy and meds as other illnesses").

a community without being treated with suspicion, hostility, or wariness.

These accounts also often revealed that the worst discrimination that respondents suffered was the treatment they received at the hands of mental health professionals and psychiatric hospitals. The stories were written with an anger, bitterness, and eloquence that leapt off the page:

On the basis of my EX-fiance's assertions, I was **HANDCUFFED, LOCKED UP**, and treated as though I was an imbecile not worth communicating with. In fact, I have a university degree in math, never lost my intellect, never lost touch with reality—I was sad and overwhelmed by horrendous life events I was also at that time locked up in an "isolation" cell—and was told after so sorry, it had nothing to do with me, it was simply normal procedure for everyone. Is this supposed to be therapeutic? What sense is there in taking someone emotionally distressed and severely traumatizing them? I will never ask for help of the psychiatric profession because I no longer trust them. They are the **LAST** people I would tell if I were depressed. That scares me, too—not being able to trust people for help.⁶⁷

Another account answered a question about the worst discrimination experienced by the respondent as follows:

In the mental health area, forced detention in a psychiatric hospital. Made me lose my job, also forced to take neuroleptics threatened with physical violence if I did not take them. Also I was **TORTURED** with sleep deprivation when I refused to take neuroleptics by the staff banging loudly on my door and yelling loudly room check every fifteen minutes which made me physically sick and I suffered emotional distress.⁶⁸

Yet another individual responded:

I was discriminated against in mental health treatment The [mental health professionals] label [my] exhaustion "depression"

67. *Id.* No. 164.

68. *Id.* No. 142.

because they're too dishonest to admit they're threatening survivors with a seemingly unlimited array of forced "treatments" which are nothing but assault, and those threats have the same effect on me as the snowmobiles that run wolves to exhaustion.... I've sat in the courtroom while a judge decided that a man was innocent of rape because the young girl he'd raped was in psychiatric treatment and therefore the judge could not be sure she had refused sex. So that means once I'm labelled, anyone can do anything to me, because my word will not be accepted in court.⁶⁹

These accounts of discrimination are reminiscent of accounts of rape, sexual assault, beatings, and lynchings based on gender and race discrimination: the use of brute force to enforce a dominant political hierarchy against stirrings of resistance. For most of society, accustomed to the image of voluntary interactions with sympathetic therapists, the analogy would seem absurd. As mentioned above, however, this analogy goes far to answer the questions about identity asked at the beginning of this Article.

These accounts of "traditional" discrimination and forcible commitment and treatment amounted to just more than half of the responses I received. What I had not expected was that nearly an equal number of people identified their experiences with discrimination in what seemed to be precisely the opposite way. Virtually all of these "different" responses were submitted in response to the Internet posting, and many came from people currently employed as lawyers, social workers, academics, and in other professional fields. These respondents experienced discrimination as the failure of others to take seriously their reports of suffering and difficulty. Their experience of discrimination was of being treated as an ordinary, normal person who was oversensitive or subject to hypochondria. They were told to cheer up, to stop being lazy, or to stop goldbricking. For example, one survey respondent wrote:

I've tried to "cure myself" in many ways and some people still believe if I would only "get to the bottom of my neurosis" I would be "normal." I am not a passive person. I am not lazy. We are

69. *Id.* by V.B. (on file with author).

just like normal people, except for the ways our brains work, not violent, not cruel, usually more scared than anything else.⁷⁰

Another told of her husband's family's suggestion that she put pressure on her depressed husband to shape up:

[W]hen my husband was unable to work due to mental health problems his family refused to acknowledge his inability to hold a job and at one point requested that I threaten to leave him so that he would go to work. When I refused, they became angry at me There were several incidents where family and my therapist encouraged me to leave my husband because of his mental health problems. I felt isolated and abandoned myself. Eventually I became clinically depressed myself.⁷¹

When I read the surveys, I saw what had been before my eyes all along: the numerous autobiographical accounts of individuals whose families or coworkers had insisted that they were just down in the dumps or needed a rest,⁷² and my own law students' accounts of their families' unwillingness to acknowledge that they were dealing with more than typical first-year law student travails.⁷³

In fact, many of the ADA employment discrimination cases that I had been studying involved emphatic rejection by employers of employees' reports of psychiatric disabilities.⁷⁴ One fairly typical account involved a grocery store employee who revealed to his manager that he suffered from clinical depression. Shortly thereafter, the manager and the district manager

70. *Id.* No. 231.

71. *Id.* No. 92.

72. See MANNING, *supra* note 41, at 75-76; THOMPSON, *supra* note 41, at 110-12.

73. Over ten years as a law professor, I heard numerous stories of students warned by their families and friends not to seek professional help because it would have to be disclosed to the Board of Bar Examiners when they sought to be admitted to practice. These stories were so continuous and problematic that Jim Green of the ACLU and I brought a lawsuit on behalf of three law students and a lawyer from another state that successfully challenged questions regarding mental health treatment on bar applications. See *Ellen S. v. Fla. Bd. of Bar Exam'rs*, 859 F. Supp. 1489 (S.D. Fla. 1994).

74. See, e.g., *Steele v. Thiokol*, 241 F.3d 1248, 1250 (10th Cir. 2001) (noting that when plaintiff told his supervisor he had a psychiatric disability, the supervisor responded by saying, "Bullshit, you do not have a disability").

told him they did not believe he was depressed and urged him to tell them what his real problem was. [The district manager] told [the plaintiff], "you're within a gnat's ass of losing your job, what's really your problem?" ... [T]he managers threatened him with termination and accused him of lying about the extent of his depression.⁷⁵

In another case, a federal court reasoned that when a person with a psychiatric disability claimed harassment based on his disability, the supervisor's failure to intervene because he believed the employee could handle the problem on his own showed that the supervisor did not perceive the employee as disabled.⁷⁶

Discrimination based on the defendant's refusal to believe that an individual is a member of the protected class is an incongruous concept for those trained in earlier formulations of antidiscrimination law. From this perspective, the cases would be equivalent to an African American claiming race discrimination because the employer thought he was white, or a woman claiming sex discrimination because the employer believed she was a man. These stories find no home in the social understanding of discrimination, or in traditional antidiscrimination jurisprudence. The principles of antidiscrimination law assert that people should be treated equally, and that differences such as race, and, to a lesser extent, sex, are not salient and should be ignored.⁷⁷ Treating a person's age, ethnicity, or religion as relevant to his or her ability to profit from education or to perform capably in employment is seen as discriminatory.⁷⁸

To insist on difference in the face of social assertions that do not exist, and to characterize those assertions as discriminatory, thus flies in the face of our most fundamental understanding of the

75. *Lee v. Publix Supermarkets, Inc.*, No. 95-40474-RH, 1998 U.S. Dist. LEXIS 8921, at *4-5 (N.D. Fla. Mar. 16, 1998) (citations omitted).

76. *Mork v. Manpower, Inc.*, No. 97 C 4866, 1998 U.S. Dist. LEXIS 11312, at *14 (N.D. Ill. July 23, 1998) (holding that "[i]f anything, their inaction suggests the opposite: that Mork's supervisors believed he was fully capable of taking care of himself and resolving any conflicts with his co-workers").

77. *Compare Adarand Constructors, Inc. v. Peña*, 515 U.S. 200, 222 (1995) (deciding that race-based classifications should receive the most searching judicial examination), *with United States v. Virginia*, 518 U.S. 515, 531 (1996) (requiring gender-based government action be supported by an "exceedingly persuasive justification").

78. *See* 42 U.S.C. § 2000e-2(a)(i) (2000); *id.* § 2000d.

meaning of discrimination. In a larger sense, of course, this is one of the major problems with implementing the ADA: Its recognition of difference and mandate that reasonable accommodations be provided as a prerequisite for equality places it outside traditional antidiscrimination jurisprudence. This is especially the case for people with certain kinds of invisible disabilities. The social perspective that these people are the same as anyone else dooms their legal claims of discrimination, both their claims that they actually were disabled and their claims that they were perceived as disabled.

At first, examining these two accounts of discrimination in my surveys, I was struck by the distinctions between them, and the different issues each group faced. I attempted to come up with a structure to categorize these differences in order to better understand these accounts of discrimination. The crucial differences that separate the two groups, the discredited and discreditable, appeared to fall into five major categories.

A. Identity and Disclosure

The group of people who told the traditional discrimination story of being marginalized and excluded were, for the most part, discredited people who were publicly, visibly labeled as mentally ill; they were either institutionalized in a state facility, clients of the public mental health system, or recipients of disability payments. In the eyes of most people, they were grouped with, or, to be blunt, segregated with other people with psychiatric disabilities.

These discredited people rarely struggled with disclosure of their psychiatric difficulties. They recounted their difficulties and experiences based on a premise that all the significant people in their lives, as well as society, represented by government agencies, police, and social service workers, were not only fully aware of their psychiatric disabilities, but were unable to see them as anything but a collection of symptoms or as a diagnosis. Their identity as psychiatrically disabled swallowed all other aspects of who they were—their sexuality, their religious identity, and their racial or ethnic identity. Their struggle was to be seen as more than simply a diagnostic category.

Conversely, disclosure was a crucial issue for the group of people whose sufferings were ignored—the group I now identify as discreditable. They tended to be employed in competitive jobs, to use private mental health professionals, and to have mainstream social networks. Although they had obviously disclosed their conditions to some people and thereby suffered the discrediting of their accounts of discrimination, their survey responses frequently made reference to issues of disclosure and nondisclosure. When asked, “What do you want other people to know about psychiatric disability, perceptions of psychiatric disability, discrimination, or law ...?”, many people urgently warned others not to disclose their diagnoses.

The concern of the survey respondents with disclosure is reflected in both the national media and case law. Many literary and news accounts testify to the considerable lengths to which some people with psychiatric disabilities will go to keep their conditions secret from their colleagues, friends, and even their families. An article in *Newsweek* described businessmen who borrowed their secretaries' cars to go to appointments with their therapists and paid for the appointments in cash.⁷⁹ Disclosure is frightening because of the potential for social ostracism and exclusion. It can have real effects on employment, educational and professional opportunities, child custody, and medical care.

Of course, this dichotomy corresponds to Goffman's predictions that discredited people struggle with “impression management” whereas discreditable people focus on “information management.” For discreditable people, “passing” among “normal” people becomes the crucial task of managing stigma.⁸⁰

B. Identity and Segregation

One of the reasons that disclosure is perceived as perilous by some people with psychiatric disabilities is the possible consequence of involuntary institutionalization. The stigma of institutionalization, so great that Erving Goffman concluded that it “spoiled” the identity of the institutionalized person,⁸¹ is still one that is rigidly enforced by social norms and social legislation. For many

79. Jolie Solomon et al., *Breaking the Silence*, NEWSWEEK, May 20, 1996, at 20.

80. GOFFMAN, *supra* note 25, at 42.

81. *Id.* at 51-62.

people with psychiatric disabilities, the experience of institutionalization, especially involuntary institutionalization in a state psychiatric facility, represents a key dividing line with respect to identity and one of the first steps toward being discredited. Often, disclosure is no longer an issue. Institutionalization leads to loss of housing, loss of employment, difficulty obtaining new employment, and thus a seemingly inevitable new career as a mental patient, a client of the state mental health system. This new identity is in turn crucial to receiving housing, transportation assistance, health care benefits, and public services. Individuals associate with providers and other people who are clients of the state mental health system.

One reason that discredited people live such disclosed and public lives is that many of them are part of the public mental health system, and most have a history of involuntary institutionalization. One cannot underestimate the significance of institutions created specifically for people with mental disabilities. State institutions for people with mental disabilities were usually built explicitly to keep persons with mental disabilities out of society.⁸² Far from the concept of "asylum" envisioned by early reformers, institutions have been the sites of experimentation, forced labor, deaths in restraints, sexual assault, and dehumanizing treatment.⁸³

In fact, one measure of the degree to which society dreads and rejects a particular disability or identity is whether it builds institutions or structures in which to isolate people with that condition from the rest of society. These institutions may vary from explicitly murderous to callously indifferent, but all serve the purpose of segregation. From leper colonies to internment camps to institutions for mental retardation where researchers conduct radiation experiments on children,⁸⁴ it is infallibly a mark of

82. *City of Cleburne v. Cleburne Living Ctr. Inc.*, 473 U.S. 432, 462 (1985) (Marshall, J., concurring) ("Massive custodial institutions were built to warehouse the retarded for life; the aim was to halt reproduction of the retarded and 'nearly extinguish their race.'") (citation omitted). The same is true of institutions for people considered to be mentally ill. See DAVID ROTHMAN, *THE DISCOVERY OF THE ASYLUM: SOCIAL ORDER AND DISORDER IN THE NEW REPUBLIC* (1971).

83. See SUSAN STEFAN, *UNEQUAL RIGHTS: DISCRIMINATION AGAINST PEOPLE WITH MENTAL DISABILITIES AND THE AMERICANS WITH DISABILITIES ACT 107-10* (2001).

84. Michael J. Loscialpo, *Nontherapeutic Research Experiments on Institutionalized Mentally Retarded Children: Civil Rights and Remedies*, 23 *NEW ENG. J. CRIM. & CIV. CONFINEMENT* 139 (1997).

increasing stigma when institutions are created to segregate people from society, and correspondingly, decreasing stigma is reflected when the institutions are eradicated and people are once more allowed to live among us. People with epilepsy and tuberculosis used to be routinely institutionalized, and now, for the most part, they are not.⁸⁵ Several states have closed all their institutions for people with mental retardation, but forty-nine states still have state mental hospitals.⁸⁶

People who are discreditable are integrated into society; they “pass,” and they explicitly identify institutionalization as the rite of passage into the world of the discredited, a dreaded event to be avoided at all costs. Journalist Mike Wallace, who has written a candid account of his own struggle with psychiatric difficulties, put it succinctly: “For years, depression meant the crazy house.”⁸⁷ William Styron reported: “[My psychiatrist] told me once or twice during out sessions (and after I had rather hesitantly broached the possibility of hospitalization) that I should try to avoid the hospital at all costs, owing to the stigma I might suffer.”⁸⁸ When Martha Manning, a psychologist, decided she needed ECT for her depression, and discovered that her insurance company would only cover the treatments on an inpatient basis, her reaction was, “I can’t go into the hospital. I just can’t.”⁸⁹ She forced herself to at least visit the unit, where she saw her name on a patients’ bulletin board. She went on to describe her reaction:

I panic and can’t quite catch my breath. I tear out of the place, through the double doors, down strange-smelling halls, and

85. When the Supreme Court decided *Jackson v. Indiana*, 406 U.S. 715 (1972), Indiana’s commitment statutes, like those of many other states, permitted involuntary commitment of people with epilepsy. *Id.* at 822. In *Bell v. Wayne County*, 384 F. Supp. 1085 (E.D. Mich. 1974), the court noted that “Michigan employs three standards for civil commitment: mental illness, mental handicap, and epilepsy.” *Id.* at 1095 n.8. Almost all states have deleted epilepsy from the list of conditions for which a person can be involuntarily institutionalized. At least four states—Florida, Arizona, New Jersey, and West Virginia, as well as New York City—permit involuntary institutionalization of a person with tuberculosis. See STEFAN, *supra* note 83, at 127-32.

86. Only Rhode Island no longer has a state psychiatric hospital. See the National Association of State Mental Health Program Directors, at <http://www.nasmhpd.org/hlsthtml.htm> (last visited Jan. 30, 2003).

87. CRONKITE, *supra* note 13, at 17.

88. STYRON, *supra* note 18, at 67-68.

89. MANNING, *supra* note 41, at 111.

finally through an exit door. I climb into my car, lock all the doors, and try to calm myself. I resolve to avoid the hospital at all costs. I will handle my problems. It is a matter of determination. I will make it work. The most important thing is that I am free—to walk out, to drive home, and never to return.⁹⁰

C. Identity and Coercion

Despite this basic understanding of the terror of involuntary hospitalization, neither Manning nor the millions of potentially discreditable others in her situation have made coercion a priority issue in mental health care, nor is the experience of coercion a significant part of their identity as people with psychiatric problems.

Discreditable people seem to ignore or avoid their own brushes with coercion. An individual who works for a major Midwestern university described his first hospitalization:

I was feeling really bad and I called up the EAP [Employee Assistance Program] at the University to see if there was anyone I could talk to. They said no, but I can't remember if they put me through to the police or to the hospital, but somehow a university police officer took me to the psych ER at the [university] hospital.⁹¹

This individual believed that the police officer gave him no choice but to go to the emergency room, but he also stated that he did not feel coerced.⁹²

When discreditable people end up in coercive situations in which they feel oppressed and wronged, their reaction is often to blame it on the individuals involved, rather than generalize the episode as typical of the mental health system. People who do not generalize in this way may become outraged, but they rarely become politicized.

It seems fairly obvious that people rarely make a specific choice to become discredited, to be part of the public mental health system. The path to being a discredited person is filled with milestones of identity which are tremendously stressful and significant, and

90. *Id.*

91. Interview with K.E. (Mar. 15, 2002) (on file with author).

92. *Id.*

which are almost always brought about by well-meaning family members, friends, and professional helpers. Thus, informal, well-meaning coercion often leads to coercion formalized by legal status and court orders. Sue Estroff writes of the determinants of the decision to seek disability benefits on the basis of psychiatric disability.⁹³ Her research confirms my anecdotal experience that the decision to apply for disability benefits is rarely made by an individual alone, but rather is encouraged, and sometimes coerced, by either family members or the mental health system. Estroff and her colleagues found that neither diagnosis, severity of symptoms, nor even work history was predictive of the decision to apply for disability benefits.⁹⁴ Rather, they found that people who applied for benefits were "urged to apply or assisted with application" by hospital workers and family members, and they conclude:

Our view is that for the most part, application for SSI/SSDI is something that happened to respondents, not with their help or by their initiative. Pragmatic rather than clinical or more philosophical concerns drive the process, and what this move means to the individual in terms of stigma, loss of self-esteem or giving up is less important at the time than the material resources that SSI/SSDI can provide for applicants and their social network members.⁹⁵

The discredited are often sharply aware of the coercion associated with their experiences of psychiatric disability. Because of their experiences with involuntary commitment and institutionalization, discredited people are deeply suspicious of the mental health system and consider the diagnostic system one of labeling that does the unfortunate recipient more harm than good.

Discreditable people, on the other hand, have not been coerced. They have been told, and they believe, that their problems are biological rather than political. They regard mental health professionals as their allies. They believe in medication, although the level of this belief has been exaggerated. William Styron was

93. Sue E. Estroff et al., *"No Other Way to Go": Pathways to Disability Income Application among Persons with Severe Persistent Mental Illness*, in *MENTAL DISORDER, WORK DISABILITY, AND THE LAW* 55 (Richard J. Bonnie & John Monahan eds., 1997).

94. *Id.* at 92.

95. *Id.*

attacked after he reported that the drug Halcion contributed to his suicidal tendencies.⁹⁶ Kay Jamison acknowledges that medications dull her experience of the world.⁹⁷ For that matter, many discredited people find some medications helpful; their chief complaint is being forced to take medications that do not help them. Haldol, Prolixin, and Thorazine figure chiefly among medications that are feared, hated, and forced on discredited people. Interestingly, my anecdotal experience is that these medications are rarely, if ever, prescribed for people who have choices about the medications they take.

D. Identity and Literature

The literature of each world reflects these different perspectives. Virtually all ex-patient literature, whether discredited or discreditable, revolves around the authors' experiences with psychiatric disability, diagnosis, and treatment, but the authors' reactions to this treatment and their conclusions are distinctly different.

The literature of discredited persons is the literature of the public mental health system. Judi Chamberlin's *On Our Own* and Janet and Paul Gotkin's *Too Much Anger, Too Many Tears* recount the emotional turmoil of two upper middle class American women whose experiences take them first to private hospitals, and then to state facilities. These books are beautifully written, classic examples of an understanding of the mental health system as political, and an identification with others who are trapped in it. These authors angrily and eloquently blame psychiatrists and the mental health system for misunderstanding their needs and damaging rather than helping them. Both conclude that people with psychiatric disabilities are better off receiving help and support from peers rather than from the established mental health system. As Janet and Paul Gotkin write in their introduction:

Our own book, and the ideas behind it, grew out of our involvement with what was called, in the language of the times, the Mental Patients Liberation Movement. This was a loose federation of former "mental patients," who believed, as we did,

96. STYRON, *supra* note 18, at 70-71.

97. JAMISON, *supra* note 22, at 94-95.

that the institutional system was fundamentally oppressive and that all involuntary confinement and "treatment" should be abolished.⁹⁸

On the other hand, William Styron's *Darkness Visible*, and Kay Redfield Jamison's *A Mind Apart*, although equally eloquent and beautifully written, are clearly intended to be stories about the authors' own experiences rather than a call to political action. The authors credit mental health professionals, medication, and hospitalization with saving their lives. Although they honestly discuss failures and mistakes in their medical treatment, and discrimination that they experienced or feared because of having a psychiatric diagnosis or receiving psychiatric treatment, these books are not indictments of the present mental health system in any sense.

Somewhere in the middle, and harder to categorize, are Sylvia Plath's *The Bell Jar*, Elizabeth Wurtzel's *Prozac Nation*, and Susanna Kaysen's *Girl, Interrupted*, each of which candidly relates the tale of an adolescent girl who is labelled or considers herself crazy. Each of these authors recognize the damage the mental health system can inflict, and therefore they do not project the gratitude and alliance with mental health professionals of authors like Jamison and Styron. However, the disillusionment of Plath, Wurtzel, and Kaysen does not lead them to political conclusions, generalizations, or even action. A typical moment occurs in *Girl, Interrupted*. The author describes Lisa, a girl she knew in the hospital as defiant, oppositional, and rebellious. Lisa escaped frequently, and was kept on one-to-one surveillance. Kaysen meets Lisa and her child years later by chance in Harvard Square. They speak for a few minutes. Lisa turns as she is about to leave and says:

"You ever think of those days in there, in that place?"

"Yes," I answered. "I do think of them."

"Me too." She shook her head. "Oh, well," she said rather jauntily. Then the two of them went down the stairs, underground.⁹⁹

98. GOTKIN & GOTKIN, *supra* note 14, at xiv.

99. SUSANNA KAYSEN, *GIRL, INTERRUPTED* 164 (1993).

Kaysen's and Plath's accounts reflect the fact that private hospitalization can be as damaging as hospitalization in a state facility. However, both were adolescents and theoretically voluntary patients. Although they were undoubtedly coerced,¹⁰⁰ because they were in private hospitals they did not associate the experience with state oppression, as do discredited patients. Perhaps state action, or state supported force and coercion, are usually necessary for an experience in the mental health system to lead to political organization and action.

E. Identity, Agendas, and Allies

Each group has distinct policy and political agendas. The agenda of the discredited, who have formed the ex-patient movement, revolves around choice and the end of coercion and force, whether legal or hidden in state institutions. They oppose involuntary outpatient commitment, forced electroshock, and support the recovery model and voluntary psychosocial treatment in the community.¹⁰¹ In seeking alternatives to forced institutionalization, they support legislation that would permit Medicaid money to be used for home health care rather than nursing homes, legislation that would make it easier to keep Medicaid benefits while employed, and legislation limiting the use of restraints.¹⁰² Their natural allies are groups of people with physical disabilities, groups protecting the rights of the poor, human rights groups, civil rights groups, and senior citizens' lobbies.

To the extent that they are politically involved at all, people who fit the discreditable model are concerned with disparity in insurance coverage and confidentiality of mental health records. They deplore the degree to which the stigma associated with mental illness forces them to secrecy and deception, and may litigate when they are excluded from institutions of higher education, professional schools, and by licensing organizations.¹⁰³ They often suffer from

100. Sylvia Plath's recounting of being subjected to electric shock treatments against her will is unforgettable. SYLVIA PLATH, *THE BELL JAR* (1971).

101. See *supra* notes 35-38 and accompanying text.

102. See sources cited *supra* note 35.

103. See SUSAN STEFAN, *HOLLOW PROMISES: EMPLOYMENT DISCRIMINATION AGAINST*

employment discrimination when they disclose their psychiatric diagnoses, no matter how brilliantly they perform their jobs.¹⁰⁴ This group resents constraints placed on psychiatric treatment by health maintenance organizations and managed care. They want to be able to choose therapists who can help them over the long term, and have those therapy sessions covered by insurance. The discreditable are concerned about the confidentiality of psychiatric records. Their natural allies are associations of mental health professionals, who also resent limitations on reimbursements and intrusions by managed care.

II. THE CONSEQUENCES OF THE DICHOTOMY BETWEEN DISCREDITED AND DISCREDITABLE

The dichotomy between the discredited and discreditable, and especially the erasure of the experiences of discreditable people in the social understanding of mental illness, is reflected in the media and in public opinion polls, and has extraordinarily serious policy and legal consequences.

A. *Research on Employment*

Research findings on people with mental illness are almost entirely based on studies involving only discredited people. Statistics on the employment of people with psychiatric disabilities are artificially low because the studies to which scholars and the media cite are almost universally based on populations that are easy for researchers to study—people receiving vocational rehabilitation benefits, people recently discharged from state psychiatric hospitals, and other clients of the public mental health system. For example, one article states that “as many as 85% of persons with psychiatric disabilities remain unemployed.”¹⁰⁵ However, the source for this dismal figure is an article about

PEOPLE WITH MENTAL DISABILITIES 14 n.68 (2001).

104. See DEPRESSION AND BIPOLAR SUPPORT ALLIANCE, PUBLIC POLICY AND LEGISLATIVE POSITIONS, at http://www.ndmda.org/media/DBSA_Positions.html (last visited Jan. 30, 2003).

105. Edward Diksa & E. Sally Rogers, *Employer Concerns About Hiring Persons with Psychiatric Disability: Results of the Employer Attitude Questionnaire*, 40 REHAB. COUNSELING BULL. 31 (1996).

supported employment, an intervention that many people with diagnoses of serious psychiatric disabilities do not need to remain employed.¹⁰⁶

As I have noted in other writings, statistics about unemployment among people with psychiatric disabilities are fraught with difficulty, because it is unclear from the statistics how employment is defined.¹⁰⁷ Some studies include part-time employment, others include volunteer jobs, state-sponsored sheltered employment, or supported employment, and still others are limited to full-time jobs.¹⁰⁸ But the more frequently cited studies, which list unemployment rates of between sixty-five and ninety percent, imply that mental illness precludes employment. These studies are often limited to participants in psychosocial rehabilitation programs, who are by definition of their participation in those programs, already discredited.¹⁰⁹

More reliable studies, including the Epidemiological Catchment Area survey, which used cities such as Baltimore, St. Louis, and Los Angeles as sources for its study, show much higher rates of employment, marriage, and other indices of community integration.¹¹⁰ The only employment-related study I could find in which the respondents were discreditable rather than discredited examined the work experiences of five hundred professionals and managers with serious psychiatric conditions.¹¹¹ Of the group, seventy-three percent were employed full time, eighty-three percent had college degrees or higher, and sixty-four percent had been hospitalized more than three times.¹¹² The famous people and celebrities who candidly discuss extremely serious episodes of psychiatric disability are seen as exceptions, even though their

106. See William Anthony & Andrea Blanch, *Supported Employment for Persons who are Psychiatrically Disabled: An Historical and Conceptual Perspective*, 11 *PSYCHOSOCIAL REHAB. J.* 5 (1987).

107. See STEFAN, *supra* note 103, at 12-13.

108. *Id.*

109. See *id.*

110. *PSYCHIATRIC DISORDERS IN AMERICA: THE EPIDEMIOLOGICAL CATCHMENT AREA SURVEY* (Lee N. Robins & Darrel A. Regier, eds. 1990).

111. Marsha Langer Ellison & Zlatka Russinova, *A National Survey of Professionals and Managers with Psychiatric Conditions: A Portrait of Achievements and Challenges*, (Center for Psychiatric Rehabilitation, Boston, Mass. 1999), available at http://www.bu.edu/SARPSYCH/research/rtc1999/si_3.html (last visited Feb. 6, 2003).

112. *Id.*

numbers are quite large. Kay Jamison,¹¹³ noted author and expert on bipolar disorder, journalists Elizabeth Wurtzel¹¹⁴ and Tracy Thompson,¹¹⁵ William Styron,¹¹⁶ Mike Wallace,¹¹⁷ Rod Steiger,¹¹⁸ Joan Rivers,¹¹⁹ Roseanne Barr,¹²⁰ Patty Duke, Lawton Chiles,¹²¹ Tipper Gore,¹²² Buzz Aldrin,¹²³ and Art Buchwald¹²⁴ have all reported serious bouts of mental illness, but they are not included in studies of employment rates among people with mental illness.

B. Employment Discrimination Litigation

The discreditable also lose—in litigation, in higher education, in licensing—because those in authority, accustomed to an understanding of mental illness that encompasses only the discredited, cannot fathom that a professional could be employable and simultaneously experience serious psychiatric disabilities. The cloak of secrecy that permits discreditable people to enter into mainstream employment and pass as “normal” cannot be easily shed. Almost all Title I ADA cases appear to be brought by discreditable people who have an episode of psychiatric disability they cannot hide.¹²⁵ Employment discrimination litigation under the ADA routinely results in a finding that the plaintiff is not psychiatrically disabled because she got another job after being fired as a result of her diagnosis—disabled people presumably could not be reemployed so easily.¹²⁶ Other judges find that plaintiffs are not disabled by virtue of the fact that they made it into work day after day.¹²⁷

113. See JAMISON, *supra* note 22.

114. See WURTZEL, *supra* note 13.

115. See THOMPSON, *supra* note 41.

116. See STYRON, *supra* note 18.

117. See CRONKITE, *supra* note 13, at 14-20.

118. See *id.* at 46-48.

119. *Id.* at 40-41.

120. ROSEANNE BARR, *ROSEANNE: MY LIFE AS A WOMAN* (1989).

121. L.N. Strout, *Politics and Mental Illness: The Campaigns of Thomas Eagleton and Lawton Chiles*, 18 J. AM. CULTURE, Fall 1995, at 67.

122. Tipper Gore, *Strip Stigma from Mental Illness*, USA TODAY, May 7, 1999, at 15A.

123. See ALDRIN, *supra* note 42.

124. ART BUCHWALD, *LEAVING HOME: A MEMOIR* (1993).

125. See, e.g., ANDREW CHAIKIN, *A MAN ON THE MOON* (1994).

126. STEFAN, *supra* note 103.

127. *Id.* at 74-75, 80.

C. Social Policy on Homelessness

The perception that mental illness leads to homelessness derives from focusing solely on the much smaller population of discredited people. It is probably untrue even as to them; the salient characteristic that leads people with mental illness to homelessness is poverty rather than the mental illness itself. If the concept of mental illness in our society were broadened to include the discreditable, people with serious psychiatric disabilities who pass the misconception that severe psychiatric disability is associated with homelessness would probably collapse.

D. Media Portrayals of Mental Illness

Media portrayals of people with severe mental illness center on the discredited, except on the rare occasions when celebrities reveal their battles with the illness, who seem to instantly be regarded as exceptions.

When people in our society speak of the mentally ill, they are referring only to the visible second world. This has consequences not only for the second world, but also for the first. Because the entire array of people with psychiatric disabilities is not visible, people in the second world are not credited with the strengths and capacities they have. They are subject to stereotyping and mythology. It is hard to think that mentally ill people are incapacitated or unpredictably violent and think of Mike Wallace and Tipper Gore as mentally ill people at the same time.

III. THE "TWO WORLDS" THEORY APPLIED TO OTHER GROUPS

Once I understood the nature of the two worlds, I began to look at other groups of people who have been discriminated against in America. I thought of the contrast between women who call themselves feminists and those who firmly reject the word, between closeted gay men and those who march in gay pride parades.

Is the “two worlds” theory simply another way of saying that in any group suffering discrimination, only a minority are politicized or radicalized, whereas most prefer to assimilate and minimize their distinctions from the groups in power, aspiring to a life as ordinary and untroubled as possible in the context of the roles assigned to their group by the majority? Is it true that, as Vicki Smith of MadNation puts it, “just as the gay pride folks had to make room in their coalition both for Queer to the Left and for Log Cabin Republicans, we also need to find a way to band together as a diverse and effective group?”¹²⁸

I would argue that the distinction between discredited and discreditable people with psychiatric disabilities is qualitatively different from the distinctions among African Americans, women, and gays and lesbians. Although within these groups sharp disagreements exist about both aspirations and the approaches that work best to reach those aspirations, there is not the same fundamental disagreement about identity itself that divides people with psychiatric disabilities. The very reason that some African Americans are disappointed with Justice Clarence Thomas is that they identify him as African American. The question of whether his values, actions, and behaviors advance their cause presupposes that he and they share the identity “African American.” This is not so clearly true among the millions of Americans with psychiatric disabilities.

The better and more compelling analogy is to the chasm between deaf people who experience deafness as a disability and those who experience deafness as a culture. This is not merely a disagreement about goals and strategies. The two groups of people with psychiatric disabilities—like the two groups of deaf people—differ dramatically in their experience of their own condition and its meaning. This difference in the experience of identity is qualitatively different than that of ethnic minorities or women. It makes it far more difficult for different subsets of the group to work for broadly similar goals of equality and recognition of rights. Rather, the struggle for the definition of identity—the answer to the question of what deafness or psychiatric disability is—are threshold

128. E-mail from Vicki Smith to Susan Stefan (May 8, 2002) (on file with author).

questions that determine what various experiences mean and what should be done in response to them.

For example, for people who believe that deafness is a culture, the use of cochlear implants demeans or even destroys identity; for those who believe deafness is a disability, they are seen as a benefit, a path to integration.¹²⁹ This raises very difficult questions, especially where children are concerned. Decisions about whether a child should receive cochlear implants, or the deliberate decision to conceive a deaf child through artificial insemination, have caused a great deal of controversy.¹³⁰ In this debate, professionals who treat deafness are, not surprisingly, annoyed by those who see deafness as a culture to be protected.¹³¹

There is a similar, natural tension between mental health professionals who see a patient with a medical problem, and many in the ex-patient movement, who see the terminology of diagnosis and treatment as masking fundamental political and human rights issues.

Some mental health professionals regard people in the throes of mental illness as no more able to make decisions on their own behalf than children, and use much the same rhetoric in supporting forced treatment as are used to support cochlear implants in children. Many people with psychiatric disabilities, however, reject the framework of incompetence, and although they acknowledge great difficulties, they may prefer to struggle through their troubles rather than be forced to accept ECT or mind-altering medications.

Women were also once considered incapable of making their own treatment decisions. As recently as twenty years ago, when some women turned to midwives and natural childbirth, demedicalizing the experience, medical professionals forecast death and injuries, and sought to prevent midwives from practicing.¹³² When the disasters that were forecast did not occur, the medical profession began offering more natural settings for childbirth in hospitals.

129. Bonnie Tucker, *The ADA and Deaf Culture: Contrasting Precepts, Conflicting Results*, 549 ANNALS AM. ACAD. POL. SOC. & SCI. 24, 32-33 (1997).

130. See, e.g., Faith McLellan, *Controversy over Deliberate Conception of Deaf Child*, 359 LANCET 1315 (2002).

131. E. Katherine Russell et al., *Cochlear Implants and the Deaf Child: A Nursing Perspective*, 4 PEDIATRIC NURSING 396 (1999).

132. Julie Harmon, Note, *Statutory Regulation of Midwives: A Study of California Law*, 8 WM. & MARY J. WOMEN & L. 115, 122 (2001).

The different conceptions people with psychiatric disabilities hold about identity are created by the huge disparities in their experiences with mental health professionals and force—a single, unitary experience from the point of view of many discredited ex-patients. For them, the medical *is* the political. They have experienced force constructed as medical care in the same way that women subject to forced sterilization and forced cesarian sections have, but far more universally. They also experience force more subtly, in the lack of options and alternatives to standard treatment and in the enormous financial incentives connected to institutional rather than community care.

However, although the groups are divided in their experience of force and their desire to demedicalize emotional distress, they share the common bond, of social stigma and the discrediting of their accounts of their own experience. Discredited people are not believed when they say they can parent their children and engage in responsible employment, and discreditable parents and employers are not believed when they assert the excruciating struggles they face on a daily basis to maintain these roles.

CONCLUSION

The more that I considered these two apparently polar opposites, the more it became clear that they actually expressed two sides of the same coin, and that this unity explained much about the way discrimination against people with psychiatric disabilities works in this country. Neither group is believed or credited when they report their own perceptions of their situations. The discreditable group's suffering is erased, and attempts to explain it are discounted; true agony is marginalized and true heroism goes unseen. The group of discredited people, who insist on their strengths and capacity, are equally ignored in favor of an emphasis on symptoms and dysfunction. Both groups in effect plead with society and the law for recognition of the complexity of their situations: that disability and devastating suffering can coexist with accomplishment and resilience; that people who appear to be successful can be suicidal, self-injuring, manic, immobile, can suffer anguish or hear voices; and people who appear to be delusional or disoriented can master

employment, parenthood, and the challenges of life in the community.

But the nature of the law, and the broader nature of discrimination on the basis of psychiatric disability, is to insist on two separate and always dichotomous categories: insane or sane, disabled or nondisabled, incompetent or competent. If people fall into the latter categories, their claims of emotional and psychiatric suffering are not cognizable at law; if they fall into the former categories, their appeals for rights, independence, and autonomy often fall on deaf ears in the legal system.

Is there any hope for unifying the two worlds, or, to state a more limited and realistic goal, for finding common ground among the discredited and discreditable? As noted above, both groups have shared the experience of not being believed. Ironically, one of the chasms between the two groups is that they do not believe each other. Many of those who reject the medical model and psychiatry have historically rejected the accounts of former patients who believe in the illness model. Many of those who believe in the illness model refuse to believe that articulate spokesmen, such as Dr. Dan Fisher, were psychiatrically disabled in the first place.

But a new movement is taking shape based on respect for people's stories and accounts, and in support of the right to make voluntary and uncoerced choices, whatever those choices may be. Whether one is discredited or discreditable, the issue of credibility is still a primary issue. Each group has much to gain by emphasizing the credibility of the other. Discredited people who wish to be believed on the issue of their own strengths and capacities can point to executives, professionals, and celebrities with severe psychiatric disabilities to emphasize that functioning may be more a matter of social and income supports than diagnosis. Many of these people have engaged in behaviors that are the currency of discredit—suicide attempts, cutting, self-injury—and have reported hearing voices or seeing hallucinations. Asking these people to speak publicly about what helps them to cope, and listening respectfully to the array of answers, may increase the public understanding of the need for alternatives, and the need for treatment to focus on what works for the individual.

By the same token, discreditable people suffer enormously from isolation and loneliness. In their world of silence and denial, no one

may understand what they experience. They could benefit from reaching out to discredited people, who often have communities and support unknown to discreditable people. The discredited also can be extremely informative about resources, networks, and political activity. Again, discreditable people need to hear the stories of the discredited respectfully, and understand the force and coercion that has shaped their political vision.

Both groups have strength, resilience, and coping skills that are heroic, given what they have suffered. Neither group can expect to be heard by society with credibility if it denies credibility to the stories of those who, ultimately, share some form of common experience, if only that of being disbelieved.

APPENDIX A
Survey

Susan Stefan is writing a book about discrimination against people with diagnoses or labels of psychiatric disability. She would like to learn more about the perspectives and experiences of people who have these diagnoses and labels. Please take a few minutes to fill out this form. As you can see, it is anonymous, and it will help her a great deal. Please return the survey to Susan Stefan, University of Miami School of Law, P.O. Box 248087, Coral Gables, FL 33124-8087. Thank you very much.

1. Do you believe you have a disability?

___ Yes ___ No.

1a. How would you define or describe "having a disability"? _____

2. Do you believe that other people regard you as having a disability?

___ Yes ___ No.

3. Do you believe that you have a physical or mental impairment?

___ Yes ___ No.

3a. If yes, does the impairment substantially limit you in one or more major life activities?

___ Yes ___ No.

3b. If you answered yes to 3a, please describe: _____

4. Are you vulnerable to abuse because you have or are perceived as having a disability?

___ Yes ___ No.

If yes, explain and/or give examples. _____

5. Have you ever been discriminated against?

Yes No.

5a. If yes, please check all the categories that apply:

- | | |
|---|---|
| <input type="checkbox"/> Housing | <input type="checkbox"/> access to stores, movies, etc. |
| <input type="checkbox"/> access to medical care | <input type="checkbox"/> how people treated you |
| <input type="checkbox"/> employment | <input type="checkbox"/> courtroom situations |
| <input type="checkbox"/> insurance | <input type="checkbox"/> institutional settings |
| <input type="checkbox"/> education | <input type="checkbox"/> other (specify below) |
-
-

5b. Did you feel as though you were discriminated against because of

- | | |
|--|---|
| <input type="checkbox"/> Race | <input type="checkbox"/> religion |
| <input type="checkbox"/> sex | <input type="checkbox"/> sex preference |
| <input type="checkbox"/> age | <input type="checkbox"/> psychiatric disability or perceived disability |
| <input type="checkbox"/> physical disability | <input type="checkbox"/> a combination of one or more of the above |

6. In what areas of your life have you experienced the worst discrimination?

7. Please give examples of the worst discrimination you have encountered.

8. Please explain how you felt afterward, for how long this effect lasted, and what impact it had on the way you lived your life after that.

9. What do you think is the best thing that can be done to make sure these kinds of things don't keep happening? _____

10. Do you think the Americans With Disabilities Act can prevent these things from happening to people?

____ Yes ____ No. ____ Yes, if _____

11. Do you know anyone who sued or was sued under the Americans With Disabilities Act?

____ Yes ____ No.

If yes, what was the case about? What happened? _____

12. Do you feel part of the community where you live? Why or why not?

13. I am writing a book about discrimination, law, and psychiatric disability, including perceptions of psychiatric disability. What do you want to know about that I should include?

14. What do you want other people to know about psychiatric disability, perceptions of psychiatric disability, discrimination, or law that I should include?

May I quote from your responses to this survey in my book? The quote would be anonymous. Unless you want me to use initials, I will simply number all the survey responses and cite the response by its number.

____ Yes, you may quote from this.

____ I would like you to use my initials, which are ____.

____ I prefer that you cite my survey by its number.