

# Mental Illness and the Freedom to Refuse Treatment: Privilege or Right

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The *Sell v. United States* (2003) U.S. Supreme Court decision necessitates an evaluation of forced medication, informed consent, and incompetence to stand trial. Are the criminal justice and mental health systems entwined in procedures that create unjust consequences? Charles Sell's refusal to take psychiatric medication prevented him from being tried on Medicaid fraud and resulted in his confinement in forensic institutions for more years than he would have served had he been convicted and received the maximum sentence for his alleged crime. The current reliance on drug-dominated treatment models backed by force and its historical antecedents are examined in relationship to present-day practices and prospects for recovery.

*Keywords:* consumer, survivor, ex-patient, recovery, forced medication

The right to be free from unwanted interventions that are designed to change the way one thinks is an issue fraught with passion. Many questions, strong opinions, and much bias complicate the debate and policies concerning the forced administration of mind-altering substances and their impact on equal-rights protection under the law.

Are there indisputable benefits to the individual and the community that justify forcing people to relinquish their right to choice because of assessments of mental illness and its often associated implication of global incapacity? Do policy and legal decisions rely too heavily on biochemical solutions to the complex interface of the behavioral and social issues encountered by people living in community?

In a society that can mandate treatments that conflict with a person's expressed wishes, the history and context within which potentially harmful treatments are administered must be an important component of evolving mental health policy. This article examines and expands the question the Sell petition presented to the U.S. Supreme Court (*Sell v. United States*, 2003) and explores its ramifications for people who are, or once were, the recipients of a serious mental illness diagnosis. The travails of Sell are used as an example, and they provide a springboard for an examination of the shadow cast by the large umbrella of forced treatment, a shadow that is an explicit and implicit force shaping today's mental health services.

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*Sell v. United States* asked the Supreme Court of the United States to rule on a challenge to a common treatment practice for mental illness. "The question presented is whether the Constitution permits the Government to administer antipsychotic drugs involuntarily to a mentally ill criminal defendant—in order to render that defendant competent to stand trial for serious, but nonviolent crimes" (*Sell v. United States*, 2003).

Sell, a dentist originally charged with committing 63 counts of Medicaid fraud, was determined by psychiatric evaluation to be incompetent to stand trial. The government psychiatrists recommended psychoactive drugs to restore competency. Sell, having experienced negative reactions to psychoactive drugs in the past, refused. As a result, he was incarcerated in a forensic mental institution for a longer period of time than he would have served had he received the maximum sentence for the crime with which he was charged.

On June 16, 2003, Justice Breyer delivered the Supreme Court decision:

We conclude that the Constitution allows the Government to administer those drugs, even against the defendant's will, in limited circumstances, that is, upon satisfaction of conditions that we shall describe. Because the Court of Appeals did not find that the requisite circumstances existed in this case, we vacate its judgment. (*Sell v. United States*, 2003)

Sell won his right to refuse to take psychoactive drugs, but his victory was a hollow one at substantial cost. Sell's right to a speedy trial as guaranteed in the sixth amendment to the Constitution is mocked by his more than 7 years confinement. In November 2004, U.S. District Judge Donald Stohr rejected his request to stand trial and said that as judge he would decide when Sell was capable of standing trial (Tuft, 2004). The *Sell v. United States* Supreme Court decision may not resolve conflicts surrounding competency and forced treatment, but it will provide a lightning rod and a forum for proponents and opponents of forced treatment to argue an issue that is divisive to consumers, survivors, and

ex-patients (C/S/X),<sup>1</sup> as well as mental health practitioners, family members, and policymakers.

Almost 2 years before Sell's petition wended its way up to the top of the Appeals ladder, he wrote a letter of appreciation to the Association of American Physicians and Surgeons:

Thank you very much for the excellent amicus curiae brief that you filed in support of me on behalf of the Association of American Physicians & Surgeons to the 8th Circuit Court of Appeals. I just yesterday received a copy of the brief, and the other inmates that have read it so far are raving about it. You have given us prisoners here at Springfield new hope in our efforts against the terrible practice of forced medication. Also I would like to assure you that I am not the despicable monster that the government portrays me. Thank you for your time and consideration in this matter. (C. Sell, letter to the Association of American Physicians and Surgeons, October 23, 2001, available from <http://www.aapsonline.org/judicial/sellletter.htm>)

Sell's letter to the Association of American Physicians and Surgeons, the largest entirely membership-funded physician organization, seems to demonstrate that he has enough understanding of his circumstances to participate in his own defense. Perhaps on some days he is more capable of clarity than on other days. Psychiatrist Edward Podvoll (2003), founder of the Windhorse alternative-treatment communities, describes "islands of clarity" (p. 265) in which people have periods of clear thinking even in the midst of florid psychoses. Podvoll theorized that at those times, a person is very available to make therapeutic changes. Would it be possible to work with Sell to help him to develop competency to stand trial without drugs? Suppose his condition did not improve with the drugs and maybe even deteriorated. Would Sell then be required to remain confined in a mental institution for the rest of his life?

In this article, I write through my lens as a person diagnosed with schizophrenia who has experienced forced treatment, who has been educated and licensed as a psychologist, and who has worked with people in diverse settings. I do not try to present a balanced review that summarizes opposing positions in regard to forced treatments; those can be easily found elsewhere.<sup>2</sup> Arguments justifying force are ubiquitous; opposing positions are rarely visible in academic, professional, and public arenas. It is my hope that this article will provide an opportunity for readers to consider arguments that challenge the dominance of a one-large-size-fits-all treatment model that is rooted in biochemistry and the pursuit of the elusive magic-bullet drug. Can we develop and implement effective individual-centered mental health services that embrace creative alternatives when the complexity of the human condition is forced to yield to the parsimony of Occam's Razor?

### Forcing a Person to Take Psychoactive Drugs: What Are the Critical Issues?

Psychoactive drugs are prescribed with the intention of enabling people to exercise better judgment in dealing with their problems, to alleviate emotional pain, to regulate impulses better, to relieve unpleasant symptoms and other forms of discomfort, and to help people feel better about themselves and their lives. The benevolence of these intentions is set against the use of drugs and other forced interventions to control behavior while minimizing the unintended and unwanted consequences.

Forcing people to take psychoactive drugs relies on the following underlying assumptions:

1. The drugs will be effective in addressing targeted problems, including impaired judgment, incapacity to make important decisions, safety concerns regarding the patient and the community, other troubling symptoms, and barriers to recovery.
2. The patients' behaviors are dangerous to themselves and/or others, and the drugs will control undesirable behavior.
3. The benefits exceed the risks.
4. Alternative strategies are not effective for people with serious mental illness.
5. People with serious mental illness who are noncompliant are noncompliant because they are not aware that they are mentally ill.
6. The drugs are the first step toward, and the foundation for, enabling a person to live outside an institutional setting.

Allowing patients a choice in psychoactive drug use relies on the following assumptions:

1. Choice is an important component of recovery.
2. Forced treatment is a discriminatory violation of one's civil rights.
3. The threat of force will discourage a person from seeking treatment.
4. The patients' negative experiences taking drugs often determines their rejection of drug treatment, and the patients' subjective cost-benefit ratio assessment may be different than that of the drug prescriber.
5. The drugs seldom do what they are supposed to do, and the side effects have been responsible for creating irreversible neurological damage.
6. The drugs can be barriers to recovery.<sup>3</sup>

Emotionally charged rhetoric designed to incite and frighten the public is positioned through well-funded campaign strategies to make forced treatment the dominant answer to the mental illness problem. Supporters of forced medications argue that those with serious mental illness who refuse treatments are condemned "to rot with their rights on" (Applebaum & Guthell, 1980, p. 720).

The Treatment Advocacy Center (TAC), a splinter group of the National Alliance for the Mentally Ill, encourages supporters to use the TAC briefing papers and database to highlight the dangerousness of mentally ill people when lobbying for laws favoring force in their respective state legislatures. Disregarding its stigmatizing impact, the TAC Web site encourages followers to stoke the media's appetite for sensational stories by drawing their attention to acts of violence committed by people with mental illness (Treatment Advocacy Center, 2004). Psychiatrist and leading advocate for forced treatment E. Fuller Torrey states, "It would be probably

<sup>1</sup> Consumer/survivor/ex-patient is an inclusive generic name for people who have been treated for serious mental illness, with a few exceptions, in a psychiatric in-patient institution. The term C/S/X reflects the diversity of opinions on issues and allows for self-identification according to one's positions regarding mental illness, treatments, rights, etc. For more detailed description, see Bassman (2001, pp. 19-21).

<sup>2</sup> For views advocating forced treatment, see Frese, Stanley, Kress, & Vogel-Scibilia (2001); and Swartz and Sibert (1994).

<sup>3</sup> For reports of unwanted drug effects and challenges to their alleged benefits, see Fisher and Greenberg (1993); Gram (1994); and Healy (2004).

difficult to find any American psychiatrist working with the mentally ill who has not, at a minimum exaggerated the dangerousness of a mentally ill person's behavior to obtain a judicial order for commitment" (Torrey, 1997, p. 152).

In courtrooms the TAC position on mental illness is demonstrated by the court testimony of forensic psychiatrists R. P. Singh and Gary Rosenberg. Together they declare authoritatively that a mentally ill person, Jeremy Perkins, is "acutely psychotic even after months of treatment with medication" (Gryta, 2004, p. 1). Singh predicts that "Perkins will never be cured but, with proper medications and therapy, can eventually 'lead a functional and good life.'" He said Perkins likely would relapse into violent behavior should he stop taking antipsychotic medications. Noteworthy is their testimony that Perkins' treatment with medication has not been effective, yet they are steadfast in professing that the "proper medication," when found and administered, is the only effective treatment.

Opponents argue that such categorical statements are unproven, lack predictability, and not only lead to the discrimination and restriction of one's rights but undermine the foundation of hope that is instrumental to recovery (Fisher, 1994; Harrison et al., 2001; Steadman et al., 1998).

### Government, Law, Health, and Mental Illness

The U.S. Department of Health and Human Services (DHHS) operates with the motto "Leading America to Better Health, Safety and Well-Being" (<http://www.hhs.gov>). It is the largest grant-making agency in the federal government, with a \$581 billion budget and 67,444 employees (U.S. Department of Health and Human Services, 2005). The National Institutes of Health (NIH) and the National Institute of Mental Health (NIMH) are its subordinate agencies respectively responsible for implementing physical and mental health policies and funding. "The NIH mission is to uncover new knowledge that will lead to better health for everyone" (Steve Benowitz, NIH executive officer and director of human resources management, as quoted in Garnett, 1998, Knowledge Is Power section, ¶ 3). The NIMH mission is "to reduce the burden of mental illness and behavioral disorders through research on mind, brain, and behavior" (Insel, 2004, ¶ 2). People who have fought to overcome the internal and external barriers associated with a diagnosis of serious mental illness are acutely sensitive to the devaluing implicit in the contrast between upbeat and positive language focusing on health for one group (e.g., "better health for everyone") and the government's use of the word "burden" in addressing mental illness.

Although the policy-making and regulatory roles of government in physical health and mental health share similarities, there are disparities in rights protection. In both areas, the government is responsible for limiting the risk of harm. When dealing with a communicable disease like tuberculosis, the government's authority may supersede an individual's rights, but only if the person will not comply with treatment protocols necessary to prevent the spread of the disease to others. However, a person with a communicable disease like AIDS, which is spread by specific controllable behaviors, is not subject to forced treatment and isolation unless that person deliberately exposes others to the disease. In physical health, the assumption is that the person has the capacity to make

the choice to reject treatment even if health practitioners recognize that treatment as necessary. The person's Constitutional rights take precedence unless that person deliberately exposes others to the communicable disease. On the basis of decisions such as *Rennie v. Klein* and *Rogers v. Okin*, competency is the presumed state even with persons involuntarily committed to mental hospitals (Ennis, 1972; Farr, 1999; Gelman, 1999).

A major problem with the *Sell v. United States* decision is that its logic is based on an acceptance of the medical model's premise that psychoactive drugs are a reasonably safe and effective treatment for scientifically proven diseases. An absolute faith in the efficacy of a shaky diagnostic model, built through consensus, makes research to develop nondrug alternatives politically and financially unattractive (Brown, 1990; Kaplan, 1995; Mosher, 1999). DHHS, through its agencies, is the major source of research funding. Since DHHS is committed to the brain-disease model, investigators have little financial incentive to explore research paths that do not promote "better living through chemistry." Much of the research on outcomes involves time-specific snapshots measuring recidivism and symptom reduction while ignoring the demonstrated nonlinear path of recovery. Funding decisions that favor research to find ways to improve drug-taking compliance limit the prospects for studies that reflect the richness and complexity of the human condition. The high value placed on quantitative research should not warrant the dismissal of patients' narratives as anecdotes unworthy of serious investigation (McAdams, 1993; Rappaport, 2000; Salzer, 1998).

### Rights, Privileges, and the Implementation of Forced Treatment

In the mental health arena, if persons diagnosed with a major mental illness are judged to be dangerous to themselves or dangerous to others, they can be legally forced to undergo various treatments against their will. In some jurisdictions, a person can also be forced to undergo treatments if they are determined to be at risk of becoming gravely disabled without treatment intervention. Mental illness evaluations focusing on such criteria rely on subjective interpretations of current and past behavior, not the pathology tests or physical markers common to physical health problems.

In real-life practices involving mental illness, in which mental patients must prove to a judge that they have the capacity to understand the consequences of their choices, the patient is too often confronted with an impossible task. One can develop an informed opinion on the fairness of this process by attending commitment hearings in any big city. My personal best and worst story features a hearing I witnessed in which a young man was brought for his appearance in chains and dressed in hospital pajamas. The judge shortened the judicial process by repeatedly saying to the attorneys, "enough . . . get on with it . . . we all know that." Then, waving off all objections and further testimony with a sweep of his hand and a smile that announced his attempt to be witty, the judge said to the wide-eyed man in pajamas, "If you don't go along with treatment this time, I will sentence you to

outpatient's devil's island."<sup>4</sup> Few people are able to receive a fair and impartial hearing when confronted with the presumed authority of mental health experts and the bias of impatient judges who avoid potential criticism by being extremely cautious.

Most people are allowed to make extremely foolish life decisions without facing government intervention. You can choose to smoke until you die. You can eat so much that you cannot get through the doorway to leave your home. Being a member of a recognized religion allows you to make a health decision based on a tenet of your religion even if it may put your life in danger. But if you are a mental patient, there is an automatic bias to believe that you are incapable of making good decisions. Therefore it is necessary for the court to determine what is in your best interest regardless of your beliefs.

The freedom to make poor choices is a privilege that is denied to the person who is labeled mentally ill. Chronicity means always having to prove that you have the capacity to make appropriate independent choices. To comply with the requirements of your supported group-living arrangement, you may be forced to attend a day treatment program from morning until evening. Your money, and how you spend it, can be controlled by a court-appointed payee or guardian. When being a mental patient is the overriding explanation of who you are, you must endure others' suspicion and monitoring of your personal decisions.

When judging whether a person with a serious mental illness diagnosis has the capacity to understand the cost-benefit ratio for making a decision, an underlying assumption of global incapacity often guides that determination. In health decisions, Gert (1997) advises that capacity evaluations for a particular decision should always be situation-specific. Other medical ethicists want capacity determinations to be based on assessments that reflect general reasoning ability rather than being situation-specific (Freedman, 1981). Also, there are ethicists who argue for the inclusion or exclusion of risk and consequences as primary factors to consider in capacity evaluations (Wicclair, 1991). Ethicists do agree that significant efforts need to be made to include a person's preferences and values in the decision-making process regardless of disability. Substituted judgment that is deemed to be in the best interest of the patient occurs too frequently for people with mental, physical, sensory, and cognitive disability (Mitchell & Snyder, 2000; Prilleltensky & Nelson, 1997). The complexity of these decisions demands more than the loose and arbitrary practices that a person faces today.

The state assumes special authority and responsibility for people diagnosed with major mental illness. At the core of this authority are perceived safety issues and inconsistently assessed and applied principles and policies:

1. A person with a major mental illness who meets specific legal criteria for insanity may be excused from responsibility for the commission of a crime and faces different legal consequences than someone who does not meet the criteria for insanity.

2. A person with a major mental illness can be incarcerated (allegedly for their own good) without committing a crime. By exhibiting annoying behavior, unusual appearance, or repellent personal hygiene that fit the stereotypes of mental illness, a person can be detained, and depending upon compliance with evaluations and treatment (medications), may be involuntarily confined to a jail or mental institution. The underlying premises are (a) a person

who breaks the law is arrested and punished, and (b) a person who is mentally ill can be detained or arrested before a law is broken because he or she needs treatment. Unfortunately, both paths demonstrate poor outcomes for community reentry and integration.

There is a public perception that the criminal justice system grants preferential treatment to people with mental illness. Former mental patients who have been involved with law enforcement and the judicial system know from personal experience that they are treated differently from others who have been arrested, but not in ways that they might choose. Should people with mental illness who do not have the capacity to understand that they have violated the law be held legally responsible for their actions? The diverse group that is subsumed under the term C/S/X does not have a uniform, single position on legal responsibility for one's actions and its relevancy to forced treatment.<sup>5</sup> My peers, psychiatric survivors, say yes to assuming responsibility for violating the law, no to questionably preferential treatment, and no to forced treatment for purposes of rehabilitation. When someone does harm, the reasons for the commission of that harmful act can only be effectively factored into judicial decisions if the court refrains from using recipes that mix punishment, rehabilitation, deterrence, and community safety. Many psychiatric survivors consistently express the belief that people, regardless of their emotional or mental state, should be held responsible for their actions. A violation of the law should be dealt with in the criminal justice system, not the psychiatric system. My peers have no illusion that life would be easier in a prison, and they are well aware that forced drugging, humiliation, victimization, and assaults on the spirit await them in both systems. In many states, the secure forensic hospital has the added disincentive of indeterminate commitment time. In the current circumstances, the selection of prison or hospital offers only the choice between terrible and horrible. A civilized society has the obligation to create better alternatives.

### History's Lessons

When discussing differential decision-making rights and limitations on personal liberty, one cannot ignore the well-documented outrageous treatment practices and brutal abuses that brand the history of psychiatry with shame.

The criteria for the designation of mental illness severe enough to require confinement in a criminal or civil institution expand and contract depending on political and economic trends reflective of shifting community attitudes and standards (Foucault, 1988; Scheff, 1966; Whitaker, 2001). The general public's fear of those who are different in appearance, behavior, or ability, coupled with government sanction, has permitted horrific treatments to be forced on those who differ from the norm in cognitive, sensory, physical, and mental abilities (Mitchell & Snyder, 1997).

Historian and psychiatrist Joel Braslow conducted research of treatment practices at California's Stockton State Hospital in the

<sup>4</sup> The judge was referring to Kendra's Law, which allowed involuntary outpatient treatment. Kendra's Law had just become a law in New York.

<sup>5</sup> For further discussion of the differing positions of consumers and psychiatric survivors regarding forced treatments, see Bassman and Frese (1999).

early 1950s and reveals, "Physicians believed that masturbation in the female was a troubling symptom and one of the indications for lobotomy. (The) women ranged in age from 29 to 49 and were operated on between September 1947 and February 1950" (Braslow, 1997, p. 171). Not in the distant past but in my lifetime, psychiatrists measured the success of lobotomies by the extent to which they vanquished subjective desires and needs—spirit breaking in its most devastating form.

An oral interview of an occupational therapist who worked at New York's Willard psychiatric hospital until it closed is chilling. N.C., employed at Willard from 1958 to 1989, provides a profound example of how workers can see appalling practices, recognize the horror of it, and yet be unaware of its contradiction with their own image of being a kind and caring person. Excerpts from the recorded interview follow (Penney & Perriard, 2003; D.P. and S.P. are the interviewers):

N.C.: I started working there back when they used to line up for shock treatments and you probably know all about that, how they used to set the chairs in the hallway. They had what they called the blitz, and you'd go in and you had your shock treatment. That's when people broke their backs and everything when they had shock because they weren't sedated or anything. And they'd line up the chairs in the hallway and there'd probably be 15 or 20 people. And they'd take this one in and give her shock and then she'd go to the end of the line and they would blitz them two or three times that day if they were violent.

D.P.: And people didn't try to avoid shock treatment? They just accepted it?

N.C.: Oh, no. Some people were petrified of shock treatment. It was a real scary thing. It was scary to watch. You had people holding you down, trying to hold you down because the neck would arch up and they had this big thing they put in their mouth. Now, if you have shock treatments, they give you a sedative. Back then, they didn't. They gave them nothing. Back then they convulsed terrible. It was real scary to see. And it was kind of scary to even walk through the wards, you know. People were put into their little rooms naked. And in 32 years, I never saw anybody mistreated. That was one thing about being like a family I think. City people are kind of transient people and they come and go. Here they all lived here. They got their livelihood here and they treated people with compassion, I think.

D.P.: Do you know if they did lobotomies at Willard?

N.C.: Yes, a lot of people came from other places. I never knew them to do lobotomies here. Some people were like vegetables and some like Cecelia were just loud and funny. You know, they weren't violent. I guess it was supposed to stop the violence anyway. Some people were very lethargic afterward. They just kind of sat like a lump. The holes were deep enough so you could put your fingers in them.

S.P.: You could see the holes?

N.C.: Oh, yes. It was like somebody had drilled through the skull and you could stick your fingers in the hole.

Will the most current and popular state-of-the-art treatment later be judged by history to violate medicine's cardinal tenet, "to do no

harm"? Many patients did not escape as Janet Frame narrowly did and live to say, "'For your own good' is a persuasive argument that will eventually make a man agree to his own destruction" (Frame, 1982). Frame, author of two dozen books and one of New Zealand's most prominent authors, drew subject matter from her experiences of mental illness. At the time that she won a literary prize for one of her first published works, *The Lagoon and Other Stories*, Frame was scheduled to have a lobotomy. She had not been aware of the prize until a doctor at the hospital brought it to her attention. The lobotomy was quickly canceled. Later she wrote in *An Angel at My Table*, "It is little wonder that I value writing as a way of life when it actually saved my life" (Bernstein, 2004).

Although the treatments may have become less punitive and less painful to the outside observer, the belief that desperate conditions demand desperate treatments continues. Critical psychiatrist Ken Barney writes that after three decades of critique, oppressive and dehumanizing practices continue unchanged (Barney, 1994). Barney lists those who in the 1960s challenged the pretensions of psychiatry to portray itself as a science: Ernest Becker (Becker, 1964), Erving Goffman (Goffman, 1961), R. D. Laing (Laing, 1967), Thomas Scheff (Scheff, 1966), and Thomas Szasz (Szasz, 1961). Barney states that the ongoing accumulation of critiques of the medical model was unable to stimulate change. He argues that wider sociopolitical factors have provided a protective shield for the medical model's "imperviousness to compelling critique" (Barney, 1994, p. 20).

Many of my peers, those of us who have been treated for serious mental illness, are not comforted by the popular belief that we have moved far beyond the days of lobotomies, insulin shock, metrazol shock, electroshock, teeth extractions, and organ amputations. Though the sojourns of mental patients into community life freed them from confining institutions, if you listen, you will hear talk of the chemical lobotomies which have become their new prisons with invisible, yet substantial walls (Blanch, Fisher, Tucker, Walsh, & Chassman, 1993; Chamberlin, 2002; Ridgway, 2001).

### Why Do People Resist Taking Psychoactive Drugs?

Some people in pain will try to ease their suffering with alcohol; others may try illegal street drugs, almost anything that promises relief. So why do people refuse to take the psychoactive drugs that are supposed to help them? The easy, too-glib answer is that they are mentally ill and don't know it or deny it. Why then do people prefer to use alcohol or street drugs? Is it more socially acceptable? Does it work better, or does it allow them to continue to deny that they are mentally ill? Does it point to the importance of self-determination and the exercise of choice?

It is easy to be seduced by the promises of the physical sciences. Readers of weekly news magazines like *Time* or *Newsweek* could search their old issues and see the frequency of magazine covers hailing miraculous discoveries. Such breakthrough research studies proclaim that we are on the verge of discovering the means to cure and prevent diseases like schizophrenia and manic depression. Richard Lewontin, Alexander Agassiz Professor of zoology and professor of biology at Harvard University, writes,

The concentration on the genes implicated in cancer is only a special case of a general genomania that surfaces in the form of weekly

announcements in *The New York Times* of the location of yet another gene for another disease. The revealing rhetoric of this publicity is always the same; only the blanks need to be filled in: "It was announced today by scientists at [Harvard, Vanderbilt, Stanford] Medical School that a gene responsible for [some, many, a common form of] [schizophrenia, Alzheimer's arteriosclerosis, prostate cancer] has been located and its DNA sequence determined. This exciting research, say scientists, is the first step in what may eventually turn out to be possible cure for this disease." (Lewontin, 1997, p. 29)

Among most mental health professionals, the value of psychoactive drugs has been accepted as a foregone conclusion. Even nonmedical clinicians defer to the primacy of drug treatments when confronted with illogical, disordered thinking and behavior that is beyond their comfort zone. The continuation of this trend may result in future clinicians getting little if any exposure to nontraditional perspectives during their formal education. Today, the undervaluing of the nondrug approach is apparent in the lack of attention paid to the contributions of pioneer mental health professionals such as Loren Mosher, Edward Podvoll, John Weir Perry, Frieda Fromm-Reichmann, Harry Stack Sullivan, and Bert Karon. Alternative treatment settings such as Mosher's Soteria House, Perry's Diabasis, and Podvoll's Windhorse are just about absent from mainstream educational programs. The therapy of persons with schizophrenia as championed historically by Frieda Fromm-Reichmann and Harry Stack Sullivan and as practiced today by Bert Karon receive little mention in the training of most clinicians. Students learning to become clinicians are required to learn diagnostic and treatment models constructed from expert consensus that is passed off as research-based evidence. A prime example of consensus substituting for evidence is Medication Management, one of the six evidence-based practices supported by the Federal Center for Mental Health Services (Mellman et al., 2001). Much more genuine evidence is needed before we promote such a limited number of practices.

In her book *The End of Blackness* (Dickerson, 2004), Debra Dickerson explains how blackness is a construct that needs to be discarded in order to progress toward racial equality and full integration. The construct of mental illness and its numerous derived assumptions would be well served by a similar examination.

Treatments that deny people freedom of choice and restrict one's liberty are framed in language that soften its impact. *Assisted outpatient treatment* is helpful and kind, whereas *court-ordered involuntary outpatient commitment* conveys the use of force. Whether one calls electricity applied to the brain *electroshock* or *electroconvulsive therapy*, or just *ECT*, reveals one's opinion about the procedure. Psychoactive drugs are called psychiatric medications, and when shortened to *meds*, they sound almost warm and fuzzy. The names for classes of drugs change to become what manufacturers and prescribers tell us they do for people. The drugs directed at controlling hospitalized mental patients were first identified as major tranquilizers, then as neuroleptics. When politically expedient, the drugs' control function morphed into psychosis treatment, and the drugs were thus marketed as antipsychotics. After the major debilitating side effects of the drugs were documented, pharmaceutical companies named their latest creations "new atypical antipsychotics."<sup>6</sup>

The damage caused by drugs and other harmful somatic treatments is not a problem securely buried in the past. Serious side effects are common to the psychoactive drugs and include death (neuroleptic malignant syndrome), blood disorders, liver and kidney disease, neurological movement disorders, diabetes, obesity, sedation, loss of sexual desire, neo-parkinsonism, lethargy, depression, disruptions in memory, cognitive deficits, and drug-induced psychoses.

Sonja Kjaer has lived for many years with painful and debilitating tardive dyskinesia and dystonia (TD).<sup>7</sup> Since co-founding the Tardive Dyskinesia/Tardive Dystonia National Association in 1988, she has received thousands of letters and inquiries. Some sample comments:

Tremors and spasms make my arms do a sort of jitterbug. Spasms in my neck pull my head to the side. My tongue sticks out as often as every 30 seconds. (TD survivor, Washington, DC)

Having TD is being unable to control my arms, fingers and sometimes my facial muscles; having a spastic digestive tract and trouble breathing. Getting food from my plate to my mouth and chewing it once there can be a real chore. I've bitten my tongue so severely it's scarred. I often bite it hard enough to bleed into the food I'm trying to eat. I no longer drink liquids without drooling. (TD survivor, New York)

I've always tried to feel better and I felt how could any prescribed medicine meant to help me, do more damage than the illness itself. (TD survivor, Louisiana)

The spirit-breaking component of forced drugging is reflective of the rationale used to justify past psychiatric treatments. A review of the history of psychiatry reveals that spirit-breaking was an important first step in treatment and a major justification for the psychic and physical torture of patients.

In 1951 the California Department of Mental Hygiene reported that lobotomies were used "chiefly to pacify noisy, assaultive and uncooperative patients" (Braslow, 1997, p. 168). Benjamin Rush, considered the father of American psychiatry wrote, "Terror acts powerfully on the body, through the medium of the mind, and can be employed in the cure of madness. . . . FEAR, accompanied with pain, and a sense of SHAME, has sometimes cured this disease" (Frank, 1978, p. 11).

#### In Support of Freedom of Choice: Philosophy, Politics, Ethics, and Morals

John Stuart Mill's classic 1859 essay *On Liberty* confronted a question that remains unresolved to this day: In a democratic state, how can the individual be protected from the tyranny of the majority (Mill, 1859/1975)?

Politics demands that government present solutions to community problems. In my education as a psychotherapist, I was taught that therapy was both an art and a science; so too is the field of

<sup>6</sup> The number of these disorders was increasing at an alarming rate, and law suits were threatening to become a serious concern.

<sup>7</sup> Tardive dyskinesia, dystonia, and akathisia are late-appearing neurological movement disorders caused by psychoactive drugs and some drugs that are prescribed for nonbehavioral disorders.

politics as depicted to the student of political science. A successful outcome for a politician may be confidently assessed: to maintain and advance the power of one's office through election. Treatment providers, lacking an ideal model of mental health, must rely on the absence of identified negatives such as symptoms or recidivism to indicate treatment success. To be needed by the client no longer might be the ideal. Who decides what is desirable and what needs to be controlled?

Most people conform to the status quo; their actions, thoughts, and even most of their feelings (the ones of which they are conscious) are conventional. Criminals, revolutionaries, artists, scientists, and eccentrics violate the status quo. They usually get punished for it; most quit or hide, and some persevere (T. Scheff, personal communication, January 5, 2004).

Sadly, people diagnosed with serious mental illness are trained to take the one role available to them: lifelong mental patient who requires psychoactive drugs to survive.

Government and mental health professionals have become entangled in alliances in which psychologists and psychiatrists are credited with the ability to predict the future behavior of an individual. These experts are paid handsomely to express opinions that demonstrate very little predictive validity. Their guesses are supported only by reputation and professional credentials.

The unproven link between mental illness and violence is a red herring that diverts attention from a more likely cause of crime and violence: living in poverty with no hope of improving one's prospects. Actuary data drawing on demographics of income, age, marital status, and gender are better predictors of criminal justice involvement than mental illness diagnoses (Dawes, 1994; Monahan, 1984). Will the designated average mentally ill person attack you at a higher rate than the average 18–26-year-old male or the average person going through divorce while burying their problems in alcohol? Because we cannot change the age and sex of offenders, and lacking the political will to address inequities in resources, it is simpler to reassure a frightened citizenry that the threat of violence is reduced by developing mandated interventions for people labeled mentally ill. Stepping into an arena with numerous shades of gray, competing attorneys vie to hire the most convincing charismatic doctor to persuade the court to heed his or her Solomon-like judgments.

In their critique of the courts' use of mental health expert witnesses, Faust and Zisken (1988, p. 31) tried to answer two important questions: (a) Can expert witnesses in psychology and psychiatry answer forensic questions with reasonable accuracy and (b) can experts help the judge and jury reach more accurate conclusions than would otherwise be possible?

The authors concluded from their investigation that clinicians are wrong at least twice as often as they are right. The life experiences of psychiatric survivors corroborates another of Faust and Zisken's observations: "Clinicians typically expect to find abnormality, and a search for supportive evidence will almost always 'succeed' regardless of the examinee's mental health" (Faust and Zisken, 1988, p. 33).

In Sell's case, forced drugging in order to stand trial served the interests of the criminal justice system, rather than those of Sell. The medicalization of moral and spiritual questions complicates legal issues. Both Sell and the court representatives were aware that the drugs were not being suggested as a genuinely viable

treatment for what was diagnosed as his delusional disorder. It is doubtful that anyone believed that he would be grateful for a newfound ability to process information more realistically. In the proceedings, the potential for debilitating painful side effects and the unwanted manipulation of his thought processes were problems only to Sell.

Clinicians, lawyers, judges, administrators, policymakers, advocates, and activists take conflicting stands on the issue of who retains the right to refuse treatment, and on what basis. If treatment is directed at relieving pain, only the recipient of the treatment is able to evaluate the outcome of the treatment and its desirability. If the government or the community determines that a person's behavior is obnoxious or stretches the limits of tolerance without a law being violated, are there legitimate grounds for intervention? Extreme and rare examples become the justification for government to formulate overreaching mental health regulations and policies driven by political purposes. The lengths to which the government is permitted and encouraged to extend its range of interventions has consequences for people's right to maintain sovereignty over their own minds and bodies. Lessons drawn from the former Soviet Union inform us that a state should not be empowered to declare its critics and dissenters insane or incompetent. When the boundaries, principles, and needs of treatment, rehabilitation, punishment, and government are porous and enmeshed, the pain and loss of opportunities suffered by mental patients will continue unabated.

Preparing to give a speech to an audience of state labor arbitrators about patient abuses in state psychiatric facilities, I asked a friend for her thoughts on the topic. She told me that it is only patients who see the reality of life in the institution. The workers have lost their ability to see or question the appalling conditions and practices. The years of continuous exposure make the inhumane treatment seem normal and allow staff to maintain their view of themselves as compassionate caring people. Only the patients who leave the institution have the fresh eyes to see the abuses that staff take for granted.

Anyone with mental-illness experience, either as a patient or worker, has been exposed to stories trumpeting the value of psychoactive drugs. There was the early Thorazine "miracle" that was supposed to have cleared out the back wards and enabled those former inhabitants of the "snake pit" to return to their communities. Today, we hear of the miracle cures of Clozaril and other new atypicals. Advance promotions from the pharmaceutical industry announce the introduction of better drugs without the side effects that were underestimated until the arrival of the newest breakthrough drugs. If you are involved with mental illness at any level, you have heard the personal stories of lives changed or saved by medication. I am aware of too many of the untold stories.

At outpatient day-treatment programs, I see why I remain suspicious of the benefits of psychoactive drugs. The day treatment programs offer an assortment of social skills, personal hygiene, and current events groups. Some individuals amiably attend groups, but seem more interested in the availability of cookies and coffee. Most of the attendees alternate between pacing, sleeping in chairs, and shuffling outside to smoke. The day treatment centers are predictable and safe, one day or week or month is indistinguishable from another. The glazed eyes, the missing teeth, trembling hands, distended stomachs, slurred speech, and other drug-

related side effects will not be remarkable there. I look and see squelched dreams and resignation. I wonder what their lives were like and what could have been. Before they became mental patients, how did they envision their futures? Can we say that psychoactive drugs improved their lives? Were there no other possibilities? Isn't there something better we can do for them now? Others have transformed their experiences. Why not these people?

I am not opposed to using a substance to deal with pain. I am opposed to the subtle coercions and the misrepresentation of information presented to people when they are in vulnerable situations. A person in extreme psychic or physical pain will most likely choose to take the quickest, most effective, least harmful substance for relief. "Will it work?" is the key.

I believe the mind, the soul, that ghost in the machine, has a remarkable capacity to thwart predictability and positively transform seemingly impossible mental knots. The spirit is remarkably resilient. Applying disease language to ethereal constructs like schizophrenia justifies the for-your-own-good argument and wraps capacity assessments in false objectivity. When people lose their freedom and are forced to take drugs because they are judged to be mentally ill, it prevents them from doing little other than proving that they are indeed mad. In a model where biochemistry is the latest gospel, psychologists are unable to take on the leadership roles necessary to create meaningful innovations.

#### Implications for Practitioners

The percentage of people treated for mental illness has increased significantly since the introduction of psychoactive drugs, as evidenced by the dramatic increase in the number of people with a psychiatric disability who are receiving social security benefits (Jans, Stoddard, & Kraus, 2004). Research shows that people diagnosed with schizophrenia who live in developing countries with less access to drug treatments and mental health services have a significantly higher rate of recovery than people living in industrialized nations like the United States (Harrison et al., 2001). Such findings call out for changes in the way we provide services to people dealing with severe and confusing emotional states.

Psychologists can do much more than limit their practices and research to developing adjunct treatments that work in combination or as a supplement to the primary drug treatment.

What would psychotherapy practice look like without legal entanglements or drug considerations? When people who have been treated for serious mental illness are asked what has been helpful, at or near the top of their lists was a relationship with someone who believed in them (Bassman, 2000; National Council on Disability, 2000; Onken, Dumont, Ridgway, Dornan, & Ralph, 2002). A full, trusting therapeutic relationship is difficult to establish when the threat of government intervention is a palpable presence hovering in the consulting office. Wouldn't it be freeing to be able to work with an individual without the specter of control and reporting requirements limiting the exchange of trust and restricting one's creativity?

If the therapeutic alliance is fundamental to the delivery of effective psychological services, then we must be exquisitely sensitive to how inextricable motivation is from personal autonomy. Once freedom is lost and force is implemented, suspicion grows sturdy roots that will choke off trust. I often have heard people say,

"I'm mentally ill but I'm not stupid; I know what I shouldn't say to the doctor if I want to stay out of the hospital."

Consumers, survivors, and ex-patients have repeatedly identified key concepts in studies (Campbell & Schraiber, 1989; Onken et al., 2002) that they cite as important to their self-development:

1. Hope must be cultivated.
2. Forced treatment is harmful and antagonistic to recovery.
3. Choice and motivation are inseparable.
4. The threat of force makes us avoid services.
5. We speak for ourselves and define our experience.
6. We are more than our labels and diagnoses.
7. Relationships with peers and self-help are often the catalysts and validators of progress.

What is the best fit for practitioners? In a biochemical brain-disease model of mental illness, the physician will always be primary. For the psychologist who values learning, creativity, personal growth, and the possibility of making a positive difference in the lives of marginalized people, the emotional rewards can be substantial. With a C/S/X-centered model, the approach is person-to-person collaboration in which power inequities are minimized. The client must be the hero of his or her transformative journey (Duncan & Miller, 2000). Psychologists who can collaborate as partners with C/S/X will discover exciting possibilities to experience the satisfaction of helping people access long-dormant abilities.

Perhaps it is time for practitioners to reconnect with the exciting beginnings of their helping profession, in which there was belief in the transformative power of thinking, sharing, feedback, and understanding known as talk therapy. Is it not possible to help persons in extreme emotional states to reconstruct their stories? People diagnosed and treated for serious mental illness should not be arbitrarily dismissed as incapable of benefiting from talk therapy.

I urge practitioners to consider the following questions when embarking on such therapeutic work:

1. Will my client's attempts to grow be supported even if he or she faces the risk of failing?
2. Will I be able to risk failure and to what extent?
3. Will the whole person be the focus?
4. Will my client's world view be respected even if it is different than mine?
5. Can I be honest and genuine with someone who is struggling with madness?
6. Will I be flexible and creative?
7. Will my client's spirituality be respected and not automatically pathologized?
8. Will I be cognizant of cultural differences and be sensitive to the role that clients play in the therapy?
9. Will my work with a client reflect my understanding that seemingly irrational behavior is not independent of one's history and the context within which one lives?
10. Will I be able to resist fixing my client and allow that person own his or her own pain?
11. Will I support my client's hopes and dreams and at the same time help him or her develop new ones?
12. Will I be able to let myself be fully there and experience the disease of not having the answer?

Human growth and development thrives in an environment in which there is support, encouragement and a dynamic balance of risk and safety. When providing mental health services to people in extreme emotional states—even after those states have lost most of their energy—the optimal balance for growth and progress is weakened by the extreme emphasis on safety. I urge practitioners to look at possibilities for therapeutic work with fresh eyes and to challenge a currently ascendant paradigm which stifles progress.

It is time to debunk the myths and allow those who struggle the opportunities to find their way to the help of their choice, to allow them the risk of transforming their pain and conflicts into strengths, not as deviants to be feared and controlled, but simply as part of the human family.

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