The Evolution of the Consumer Movement

To the Editor: The essay “Evolution of the Antipsychiatry Movement Into Mental Health Consumerism” (1) in the June issue attempts to impose false labels and a skewed history on activists for human rights in mental health, including the nonprofit organization that I direct, MindFreedom International.

The origin of our social change movement cannot be traced to a few antipsychiatry theoreticians and campus intellectuals. Many of us actually credit the civil rights movement and our own experiences of psychiatric abuse as the original sources of our inspiration. We can and do organize on our own. The authors use the undefined term “antipsychiatry” 34 times in their essay, applying that label to many of us who do not describe ourselves or our groups in that way. There are, for example, compassionate, practicing psychiatrists who play an active role in MindFreedom.

The authors claim that psychiatry has addressed our key grievances “to some degree.” Even if some psychiatrists have reduced the dosages of neuroleptics prescribed, overall neuroleptic prescriptions are skyrocketing. Neuroleptic prescriptions for youths have shot up more than fivefold in less than a decade (2). From our perspective, both electroshock and psychosurgery have experienced a resurgence in popularity within psychiatry and the mainstream press. Many states have greatly expanded commitment criteria, and most states have implemented involuntary outpatient commitment. Courts now order some MindFreedom members who live peacefully in their own homes to take neuroleptics involuntarily.

The authors appear to observe us from afar through a flawed lens, which may explain their factual errors. The well-respected activist Leonard Roy Frank is not the founder of Support Coalition International. Support Coalition International and MindFreedom International are not two separate organizations—our name change occurred in 2005. The essay aligns the history of our movement with the “radical left” to a great extent, ignoring decades of outstanding work by conservatives and libertarians in fighting psychiatric abuse. Today, conservatives lead the grassroots opposition to mental health screening in schools.

Consider the bias inherent in this sentence: “Psychiatry continues to fight antipsychiatry disinformation on the use of involuntary commitment, electroconvulsive therapy, stimulants and antidepressants among children, and neuroleptics among adults.” The authors appear to transmogrify into “antipsychiatry disinformation” all public education efforts that are inconsistent with the American Psychiatric Association’s official position.

This is my 30th year working for human rights and alternatives in the mental health system. We have made mistakes. We are not perfect. But I am very proud of our social change movement, which includes concerned family members, advocates, attorneys, mental health professionals, and interested members of the public. The authors claim that the psychiatric profession finds it difficult to communicate with us. The fact is that the American Psychiatric Association has generally refused our repeated invitations for conversation.

Somehow, some people who have experienced serious human rights violations in the mental health system—including unscientific labeling, forced drugging, solitary confinement, restraints, involuntary commitment, electroshock, and more—have reached deep within the human spirit and found the power to speak out and unite nonviolently (3). Please reply with dialogue, not distortion.

David Oaks
Mr. Oaks is director of MindFreedom International, Eugene, Oregon.

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ing increased financing for mental health services, insurance parity, and the protection of individual rights, such as health care privacy.

The movement comprises courageous individuals who, at some risk to their own livelihoods, come out of the closet about their own experiences with mental illness and give back to their communities by forming support groups, operating drop-in centers, and educating the public against stigma and discrimination. It is unjust to discredit mental health care consumer advocates and their hard work by linking them with antipsychiatrists, including Scientologists.

Contrary to the authors’ assertions, psychiatrists are engaged in ongoing collaborations with the consumer movement, with activities that range from conducting local public awareness events to convening a national dialogue series to identify collaborative approaches to improve care (4). Past APA president Steven S. Sharfstein, M.D., reinforced this effort when he endorsed the need for “a collaborative approach with input solicited and accepted from the patient” (5).

Psychiatry recognizes that alliances with those served—whether on the clinical, community, or policy levels—are in our mutual interest: the promotion of mental health recovery.

Paolo del Vecchio, M.S.W.

Mr. del Vecchio is associate director for consumer affairs at the Center for Mental Health Services of the Substance Abuse and Mental Health Services Administration.

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To the Editor: During the past 27 years, I have studied psychiatry and psychology as a student, as a patient, and as a professional, and since college I have written and edited published work in these areas. From this perspective, I would say that although the Open Forum by the Rissmillers, which claims to survey the “antipsychiatry” movement, aims for a worthy goal, it is weak because of its imprecision about concepts, its less-than-adequate research, and its rather stereotyping characterization of certain intellectual figures in the 1960s and 1970s and the significance of their more responsible ideas.

Perhaps the best way to undermine the authors’ central apparent argument—that antipsychiatry was a golden banner that started as an intellectual game among a few radicals and then, after virtual exhaustion, was picked up by a movement among obstreperous consumers that seemed nostalgic for 1960s leftist political and intellectual styles—is to quote from Dendron, a sort of samizdat newsletter that eventually provided the basis for the organization Support Coalition International, whose name was changed last year to MindFreedom International. In a 1988 interview with none other than the renowned psychiatrist R. D. Laing by David Oaks, editor of Dendron at the time and currently director of MindFreedom International, Laing was also characterizing the psychiatric survivor movement, Laing was also characterizing the most fundamental method of relating between doctor and patient. But if this was so, it may have been unintended and ironic because he definitely seemed surprised that Americans—with their homely “hands-on” efforts—could have a pragmatic way of organizing a pro-patient movement. In fact, his tone seems that of a musty old European doctor-patient fundamentalist.

So much for the Rissmillers’ claim or suggestion that there is some substantive continuity—almost on the order of a grand, insidious historical error—between Laing, Szasz, and others and between their hermetic intellectual efforts and the more modern consumer efforts, now enabled by the Internet.

The more likely reason for the growth of the consumerist movement might be today’s widespread style of practice of psychiatry and such things as the pharmaceutical industry’s medical hegemony. More fundamentally, the better reason among many people involved in the movement might simply be good sense.

Gregory Ludwig

Mr. Ludwig is a freelance editor and writer, Highland Lakes, New Jersey.

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1. Exclusive Dendron interview: R.D. Laing. Dendron, Feb 1988, pp 1,6,7

To the Editor: The description in the June Open Forum of consumer activists and their history might lead your readers to conclude that the consumer movement is a fringe group—marginalized and bent on spreading disinformation. Readers should understand that the movement to ensure the human rights of people with disabilities is international in scope.

After many years of advocacy by the disability community, the United Nations General Assembly established a committee in 2001 to develop an international convention on the

LETTERS
To the Editor: Psychiatric Services has done a disservice to any of its readers who might want an accurate picture of our movement for the human rights of psychiatric consumers/survivors. Anyone familiar with our history would have a hard time recognizing us from the bizarre and highly inaccurate article that appeared in your most recent issue.

The authors got it partly right when they mentioned two of our long-time leaders, Leonard Frank and Judi Chamberlin. If the authors had interviewed either of them, their account might have some resemblance to reality. Instead, the authors seem to have relied completely on articles and books, rather than first-hand reports from the people who have actually been involved.

As for myself, my 35 years of activity in our movement wasn’t inspired by any books written by Drs. Szasz or Laing or the other seminal thinkers named, although I respect their contributions. It came about from my ten years in a state hospital as a child, after I received electroshock treatment at age six at the hands of one of the profession’s most honored child psychiatrists. And most activists in our movement have also become involved because of their own experiences.

Though I would hardly expect a journal of the American Psychiatric Association to support our criticisms of psychiatry, I think that it would be much more useful for your readers—and more interesting—if you exposed them to accurate reports of our positions and activities. Any psychiatrist who relied on articles such as this to get a picture of our movement would be living in a dream world.

Ted Chabasinski, J.D.

Ms. Chabasinski is a patients’ rights attorney, Berkeley, California.

Effective treatment should be the first demand of psychiatry’s critics (2). To attack what is wrong, which is the approach taken by the antipsychiatry movement, is necessary but not sufficient. The Rissmillers’ focus on Foucault, Laing, and Szasz, and their omission of respected professionals, such as Loren Mosher and Peter Breggin, erroneously imply that antipsychiatry’s criticisms have come almost entirely from a small, marginal, Left-wing group. The authors do not, for example, mention either the Internationals and Survivors of Psychiatry.
To the Editor: In the June issue, Rissmiller and Rissmiller provide an interesting report on the development of alternative perspectives on the nature of mental illness and the role of treatment. The authors describe two movements: the intellectually and academically based antipsychiatry movement and the community-based–populist “consumerist” movement. They contend that as the antipsychiatry movement lost momentum in the early 1980s, it was essentially transformed and incorporated into the more mainstream “consumerist” movement. They believe that antipsychiatry tactics had a significant impact on the course followed by the “consumerist” movement and that it became more radicalized as a result.

Although there may be some controversy with regard to this view, their report does provide an accurate assessment of the reforms that these two movements, alone or in combination, brought about. Their concluding remarks are unfortunate, however, stressing divisions between psychiatrists and consumer activists. Although it is true that some psychiatrists have had difficulty interacting with the more hostile elements of the consumer movement, and these elements have likewise had difficulty softening their perception of psychiatry, psychiatrists and consumers have made great strides in creating a dialogue in recent years, regardless of sometimes divergent viewpoints. Failure to acknowledge this evolution misses the key to the transformation that is currently under way.

Wesley Souers, M.D.
Dr. Souers is president of the American Association of Community Psychiatrists and medical director of the Office of Behavioral Health, Allegheny County Department of Human Services, Pittsburgh.

To the Editor: I am writing in regard to the Open Forum essay, “Evolution of the Antipsychiatry Movement Into Mental Health Consumerism.” From a historical perspective the essay was interesting and provocative. However, I was left with a hollow feeling. I wondered about patients and psychiatrists who work hard every day and toward greater understanding of mental illness and recovery. I especially wondered about the hesitancy a patient may have to take the first step for help, either in a self-help program or a psychiatrist’s office.

The authors’ conclusion was profoundly concerning in that it maintains a crude and cold separation between patient and doctor that does not further the relationship on which so many depend. In fact, it could easily drive help-seeking consumers from the development of a therapeutic relationship. This relationship must be seen as key to consumers who wish to delve further into analysis or clinical interventions that are required for many of us to maintain lives rooted in recovery values.

At a time when consumers are most vulnerable, we must foster the clinical dialogue, not drive a wedge that creates a problem to which there is really no solution. The authors’ message, while academically controversial, merely emphasizes this schism. Yes, some psychiatrists and consumers may be at war over ideology, but it is the struggle and eventual healing that can result in ultimate recovery. In this most fundamental instance, psychia-
trists and consumers can make a new history that is based on mutual understanding and compassion.

Laura Van Tosh

Ms. Van Tosh, who is an editorial consultant for Psychiatric Services, is director of consumer affairs at Western State Hospital, Tacoma, Washington.

In Reply: We appreciate the numerous letters regarding our article, “Evolution of the Antipsychiatry Movement Into Mental Health Consumerism.” We apologize for erroneously listing Mr. Frank as the founder of Support Coalition International. We also acknowledge that a fundamental problem was the need to summarize in 3,000 words three decades of history. This required limitation necessitated, as Mr. Oaks points out, “the authors appearing[s] to observe us from afar.” Mr. del Vecchio writes, “Today’s consumer movement is not ‘radical.’ It is a mainstream, cornerstone approach to improve mental health care quality.” We disagree. Quoting from the eighth edition of Kaplan and Sadock’s Comprehensive Textbook of Psychiatry, “it is important to distinguish between the mental health ‘consumer movement,’ which has been positive through empowering patients . . . and the ‘consumer/survivor’ movement, which has advanced a radical reform.”

Mr. Oaks, Mr. Ludwig, Dr. Lehrman, and Mr. Chabasinski all maintain that our basic hypothesis is false. They maintain that the survivor movement had nothing to do with the antipsychiatry movement. We dispute this point of view. As Tomes (1) noted, “The modern consumer/survivor movement arose in the wake of a radical restructuring of the U.S. mental health system between 1950 and 1970, resulting from deinstitutionalization, new psychotrophic drug treatments, the widening ‘legal’ conceptions of patients’ rights, and the intellectual critiques associated with the antipsychiatry movement.” We maintain that the antipsychiatry ethos, as disseminated by its seminal thinkers, was maintained as the antipsychiatry movement declined. It significantly affected two other movements: the consumerist movement that had been in existence since the late 19th century and the survivor movement, which dates back to worldwide deinstitutionalization. Many of the resultant hybrid radical consumer-survivor coalitions have carried forward, to this day, a message almost identical to that of the earlier antipsychiatry movement: that organized psychiatry is a self-serving guild that oppressively sacrifices consumers’ needs and has little basis in science.

Mr. Haan and Ms. Hill state that the survivor movement is “not ‘anti-psychiatry’” but is against “the way the profession treats people” and against “psychiatric oppression,” which Ms. Hill defines as “any language or action that would allow for mental health treatment . . . to be forced upon any individual.” Her listed doctrine could have been taken directly from the 1960s antipsychiatry manifesto, which contended that society deals with undesirables by locking them away. Foucault, as noted in our article, argued against society’s pressing need to sequester members who would not comply with its definition of “Reason.”

Mr. Oaks notes that survivor organizations encompass many disciplines, including psychiatrists. We never asserted otherwise. As Dain (2) notes, “Over the years psychiatry has been a target for antipsychiatry groups competing for influence or authority over the mentally ill. At various times these groups have included neurologists, social workers, new religions, consumers, and psychiatrists themselves.” The authors of several letters state that members of their movements do not consider themselves antipsychiatrists. However, many members do. Weitz (3), in an article titled “Call Me Antipsychiatry Activist—Not ‘Consumer,’” made the point, and organizations such as the Antipsychiatry Coalition emphasize it.

Mr. Oaks disputes our contention that in response to pressure from the antipsychiatry movement, psychiatry marginalized electroconvulsive therapy and psychosurgery, and he states that both are now resurging. In 1991 Fink (4) noted, “In spite of its acknowledged efficacy and safety . . . electroconvulsive therapy remains a controversial treatment, with limited use . . . the controversy results from attack by the antipsychiatry movement.” The demise of psychosurgery following the antipsychiatry movement has also been documented by Feldman (5). He noted that after the turbulent 1960s, “Public and political scrutiny severely restricted, or actually banned, the use of psychosurgery in many American states, as well as in other countries such as Germany, Australia, and Japan.”

Finally, the authors respectfully disagree with Ms. Van Tosh, who maintains that our essay widens an already existing schism and “could easily drive help-seeking consumers from the development of a therapeutic relationship.” We believe our essay offers a balanced view of the antipsychiatry movement’s evolution. However, we applaud and close with her sentiment, “Yes, some psychiatrists and consumers may be at war over ideology, but it is the struggle and eventual healing that can result in ultimate recovery. In this most fundamental instance, psychiatrists and consumers can make a new history that is based on mutual understanding and compassion.”

David J. Rissmiller, D.O.
Joshua H. Rissmiller

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Not Only a Rural Issue

To the Editor: The two reports by Willging and colleagues (1,2) in the June issue documented disparities in rural mental health services for sexual and gender minorities. However, the problem is more widespread. There is evidence that it is an endemic problem, not only a rural issue, in psychiatric treatment settings. For example, Lucksted (3) has documented that such disparities are far more generic than is realized. Moreover, in response to many of the same concerns that have now been documented in the rural setting, I have previously discussed the development of treatment services for persons from sexual minority groups who have mental illness and live in the heart of New York City (4,5). Institutional reforms are clearly needed at all levels of care no matter the population density.

Ronald E. Hellman, M.D.

Dr. Hellman is director of the LGBT Affirmative Program at South Beach Psychiatric Center, Staten Island, New York.

References


In Reply: We agree with Dr. Hellman’s assertion that the problem of disparities in mental health services for lesbian, gay, bisexual, and transgender (LGBT) people is widespread. We are also frustrated that as federal and state governments increasingly mandate culturally relevant care, political efforts have sought to limit services for and research regarding the health and mental health of sexual and gender minorities—a move which can only intensify existing inequities.

We find that conducting in-depth research among segments of the LGBT population offers concrete examples of how LGBT individuals are subjected to disparities. This concentrated view can challenge dominant notions of the “LGBT experience” and help determine the compounding factors that prevent LGBT individuals from obtaining high-quality mental health care. Similarly, Hellman (1,2) and Lucksted (3) have cast critical attention upon the unique needs of individuals with serious mental illness, who constitute a stigmatized, underserved, and neglected segment of the broader LGBT population.

Our research involving 38 rural and 38 urban New Mexicans points to important commonalities in their help-seeking narratives, such as lack of insurance and financial resources, limited access to LGBT-friendly services, and homophobic-transphobic encounters in treatment settings. Nevertheless, our ongoing analysis of these narratives suggests that disparities associated with rural life in New Mexico make it even harder for rural LGBT individuals to access mental health care either from specialty providers or in informal settings. The most obvious example is that some 80 percent of psychiatrists, 70 percent of psychologists, 47 percent of social workers, and 53 percent of mental health counselors are based in New Mexico’s two largest urban centers (4). Rural LGBT people are thus greatly restricted in both access to basic services and the ability to choose their providers.

Another difference worth noting is the isolation that rural LGBT people feel from informal mental health resources. Compared with their urban counterparts, rural LGBT people have substantially less access to LGBT-friendly environments, including religion-based social networks, other community support systems, and LGBT-specific support groups, organizations, and help-lines. This isolation is exacerbated by conditions of poverty and complicates the already difficult living situations of many LGBT people who seek help for mental health issues. Such difficulties were tackled in the seminal article on mental health care for rural LGBT people almost two decades ago (5), and we find that they continue to occur unabated.

We advocate for research and reform that attends to all LGBT people but that also considers the context-specific reality of rural LGBT individuals who, much like people with serious mental illness, experience extensive stigmatization and are an underserved and neglected segment of a larger population. Voices of rural LGBT people—and of rural residents in general—are not typically represented in mainstream mental health literature. The narratives of our rural LGBT participants reinforce the efforts of other researchers and demonstrate that the barriers to culturally relevant services discussed by Dr. Hellman in his 1996 Psychiatric Services article (2) remain salient today. And, as he concluded in that article, “A change in attitudes and practice is overdue.” We might add that such a change now is disturbingly long overdue.

Cathleen E. Willging, Ph.D.
Melina Salvador, M.A.
Miria Kano, M.A.

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3. Lucksted A: Lesbian, gay, bisexual and transgender people receiving services in the public mental health system: raising issues, in Handbook of LGBT Issues in Com-
Language and Stigma

To the Editor: Language is an important consideration in trying to beat the stigma of mental illness. It is, therefore, with dismay that I read Koekkoek and colleagues’ paper (1) “‘Difficult Patients’ in Mental Health Care: A Review” in the June issue. How might the term “difficult patient” be stigmatizing? It frames a person’s experience in the pejorative. It implies that people with mental illness are responsible for the symptoms and disabilities that they face. It is patriarchal and suggests that the service provider, not the person, knows what is best. It chastises the person with mental illness for having a poor relationship with the health care provider. True, some of the relationships between consumer and provider may be difficult. But the difficulty lies between the two parties and should not be blamed solely on the person with mental illness. Research has shown that resolution of difficult relationships requires equal interactions by all parties.

What services does this term provide for various mental health stakeholders? After reviewing more than 90 papers, the authors admit that there is little empirical data that lead to meaningful conclusions. “Difficult patient” does not suggest directions for treatment. The theoretical explanations are all over the place: models of chronicity, dependency, countertransference, and sociological factors. The review conflates “difficult” with “diseased.” In short, the term “difficult patient” is stigmatizing and adds little to nosological, etiological, or treatment research. If researchers are to continue a prominent role in the antistigma agenda, we need to be critical in our use of language.

Patrick W. Corrigan, Psy.D.
Dr. Corrigan is professor of psychology at the Illinois Institute of Technology, Chicago.

Reference

In Reply: Dr. Corrigan’s comments on our review of literature about “difficult patients” offer us the opportunity to clarify our view on the delicate matter of stigmatizing. We agree with Dr. Corrigan that the term “difficult” can be pejorative and even dangerous, so we used the term in quotation marks in our article. Nevertheless, it is a commonly and heavily used word in daily practice that lacks a clear meaning. Its connotation, however, is less clouded: the patient is judged negatively because he or she is far from an ideal patient.

By reviewing the literature on “difficult patients,” we tried to shed light on unspoken judgments that are so prominent among mental health professionals. In doing so, we highlighted different points of view, and individual characteristics of the patient were the basis of only one viewpoint. Interpersonal and systemic explanations for labeling patients as difficult were reviewed in at least as much detail. Moreover, in our discussion we stated that a “difficult” patient easily becomes a “bad” patient in the minds of mental health professionals, which often worsens the care or treatment offered. Here we also agree with Dr. Corrigan in that this name calling leads to further stigmatization of patients, who are solely blamed for a difficult relationship between them and mental health care.

Yet we believe that frankly speaking about “difficult patients” does more good than keeping quiet about them. By carefully investigating the meaning of “difficult,” we hope to have contributed to the discussion about patients who are not perceived positively by professionals. More sophisticated and accurate descriptions of the difficulties may then be incorporated, which we hope will result in acknowledging problems instead of denying them for fear of stigmatizing these patients.

Bauke Koekkoek, R.N., C.N.S., Berno van Meijel, R.N., Ph.D. Giel Hutschemaekers, Ph.D.