Psychiatric Survivors and Nonsurvivors

In a recent workshop, Jay Mahler, representing the California Network of Mental Health Clients, introduced himself as a "consumer-survivor." Since the early 1980s a small number of consumers have identified themselves as "psychiatric survivors," but the term now appears to be becoming respectable, even politically correct. For example, the Center for Mental Health Services, a national model for political correctness, now uses the term "consumers/survivors" in some of its publications.

Let's be clear about what is meant by "psychiatric survivors." Deenron, a vituperative antispsychiatry newsletter, describes itself as for "psychiatric survivors and allies." The most radical organized antispsychiatry group named itself the National Association of Psychiatric Survivors. On the Internet, Shoshanna's Psychiatric Survivor's Guide opens with a quote from Dr. Peter Breggin: "Going to a psychiatrist has become one of the most dangerous things a person can do."

Thus the term "psychiatric survivor" is not being used like "cancer survivor," someone who has had cancer and survived it. Rather, it's being used like "Holocaust survivor," an individual who has been unjustly imprisoned and even tortured. As such, psychiatric survivors strongly oppose psychiatry in general and deny the need for involuntary hospitalization or involuntary medication, even for profoundly disabled individuals who have no insight into their illness or their need for treatment. Many psychiatric survivors also deny that schizophrenia and bipolar disorder are brain disorders, despite overwhelming scientific evidence. For example, psychiatric survivor Al Siebert claims that "what is called schizophrenia in young people appears to be a healthy transformational process that should be facilitated instead of treated."

At the workshop, Jay Mahler said he could not conceive of any circumstance in which he would support involuntary hospitalization or treatment. As he spoke, I calculated the number of people with severe psychiatric disorders who are no longer alive because "psychiatric survivors" like Mr. Mahler along with civil liberties lawyers have made it virtually impossible to treat such patients when they have no insight into their illness or their need for treatment. Given the suicide and accidental death rates for such individuals, including those who freeze to death in cardboard boxes on the streets, at least a half-million persons who were severely psychiatrically ill are now prematurely deceased.

The policies espoused by "psychiatric survivors" have thus led to a large number of nonsurvivors. Political correctness currently focuses on the "survivors." Humane considerations suggest that our focus should instead be on the growing number of nonsurvivors. — E. Fuller Torrey, M.D., National Institute of Mental Health Neuroscience Center: St. Elizabeth Hospital, Washington, D.C.
Taking Issue With Taking Issue: "Psychiatric Survivors" Reconsidered

Editor's note: We received more than 70 letters in response to the Taking Issue commentary by E. Fuller Torrey, M.D., in the February issue, an all-time record for a single article. Many of the letters were from persons who identified themselves as psychiatric survivors and wrote to protest our publication of the commentary after reading an alert on the Internet by Support Coalition International, the publisher of Dendron News. Others wrote in support of Dr. Torrey or of psychiatric treatment, and some went beyond the "survivor-nonsurvivor" question to address other issues. Excerpts from 20 of the letters are published here, along with a reply from Dr. Torrey.

To the Editor: In his Taking Issue commentary in the February issue, E. Fuller Torrey (1) defamed several membership-based advocacy organizations. We help lead these organizations. In some instances, we were among their founders. We are all psychiatric survivors. Let us introduce ourselves:

Jay Mahler: "I survived forced electroshock, along with weeks of solitary confinement and restraint. High dosages of forced neuroleptic 'drugs' gave me seizures. I was locked up for many months."

Rae Unzicker: "I survived not only the childhood abuse that initiated my involvement in the mental health system, but also the retraumatization that occurred as a patient in five hospitals. I survived solitary confinement for two weeks, without clothing and with only a rubber mattress and blanket. I survived four-point restraints, again without clothing, and the forced administration of devastating drugs."

Janet Foner: "I was dragged from the entrance of the hospital to the locked ward, forcibly injected, and put in solitary confinement. My nonviolent 'crime' was shouting, I was drugged insensible, and locked up for ten months."

David Oaks: "I survived five institutionalizations. Neuroleptics often felt like torture. For complaining about conditions, I was held down in solitary confinement and forcibly injected."

Judi Chamberlin: "As a voluntary patient, I was placed in solitary confinement. Once I was committed, it was worse. I was forcibly drugged, held in a dismal, prisonlike facility, and denied access to water and hygiene facilities."

Since Torrey mentioned the Holocaust, we need to respond that there are those who still deny the well-documented reality of that nightmare, just as Torrey denies the horror of psychiatric human rights' violations today. The Holocaust itself was partially fueled by psychiatrists' writings from the eugenics movement. Approximately 75,000 mental patients were killed by Nazi psychiatrists in the experimental prelude to the Holocaust, and eventually 250,000 to 300,000 patients were murdered (2).

Unfortunately, these deaths are still happening. We call ourselves psychiatric survivors to remember elders who die from electroshock, and to remember youth who—due to coerced psychiatric drugging—die from neuroleptic malignant syndrome, gagging, overheating, and so forth. We were told our 'genetically flawed brains' would require a lifetime of drugging. We thrive without drugs largely due to the eugenics movement; approximate 75,000 were murdered (2). To the Editor: E. Fuller Torrey says that I am denying that schizophrenia is a brain disorder with my assertion that schizophrenia in young people appears to be a healthy transformation process that should be facilitated instead of treated. "He has it backward. Mainstream psychiatry is in denial, not me. I know from personal experience that what was diagnosed as my schizophrenic breakdown in 1965 was not a brain disorder, it was a healthy, transformational breakthrough."

Karl Menninger (1) understood this phenomenon. He wrote, "Not infrequently we observe that a patient...

References

Ms. Chamberlin is an associate with the National Empowerment Center in Lawrence, Massachusetts. Ms. Foner is co-coordinator of Support Coalition International in New Cumberland, Pennsylvania. Mr. Mahler is a technical advisor with Mental Health Consumer Concerns in Martins, California. Mr. Oaks is editor of Dendron News and co-coordinator of Support Coalition International in Eugene, Oregon. Ms. Unzicker is president of the National Association for Rights Protection and Advocacy in Sioux Falls, South Dakota.

As managed care spreads, I fear that we are going to become increasingly dependent on short-term quick fixes such as overmedication, the indiscriminate use of electroshock, and such draconian measures as outpatient commitment. What we need is not to increase these measures of force and coercion. "Forced treatment" is an oxymoron; treatment that does not respect the recipient's rights is doomed to failure.

I can't join with Dr. Torrey in his demand for an increase in force, but I could join in his call for more resources to meet this national health crisis. We need a system of care that would address our basic needs, including physical and mental health treatment, housing, and employment. If such a system existed, force would not be necessary.

Joseph A. Rogers

Mr. Rogers is executive director of the National Mental Health Consumers' Self-Help Clearinghouse in Philadelphia.

To the Editor: Dr. Torrey correctly points out that the Center for Mental Health Services uses the term "consumer/survivor" in some of our publications. It does so for a number of reasons. As a measure of self-determination and empowerment, we should respect how people choose to identify themselves. "Consumer/survivor" is used by an increasing large number of groups and individuals. Some use "survivor" as a political statement, while others use the term to connote strength and the ability to overcome mental illness. Some survivors are critics of psychiatry, while others are ardent supporters of treatment.

Using "consumer/survivor" promotes inclusivity and the need for diversity. For too long, nomenclature has caused great schisms among the mental health community. At this critical juncture in mental health care, it behooves us to move beyond this semantic debate and focus on a shared mission of improving the quality of life for all people who use mental health services.

F. Paolo del Vecchio

Mr. del Vecchio is consumer affairs specialist for the Center for Mental Health Services in Rockville, Maryland.

To the Editor: It is especially unfortunate that a spokesperson for the family movement such as Dr. Torrey should launch such a frontal, public attack on the consumer-survivor movement at this time. With the dwindling of finances for mental health care in this age of managed care, we need to find a common ground so that we can stand together to ensure that there are adequate resources for quality care.

The National Empowerment Center and the Self-Help Clearinghouse have joined with the National Alliance for the Mentally Ill, the National Mental Health Association, and several other national groups in the National Managed Care Consortium to further a common goal: to ensure that the concerns of key constituencies are brought into the federal managed care deliberations. We have been able to agree on a set of core values and principles that emphasize respect, participation in planning, and voluntary services. The consumer-survivor movement and the family movement may agree to disagree on certain other topics.

Daniel B. Fisher, M.D., Ph.D.

Dr. Fisher is executive director of the National Empowerment Center in Lawrence, Massachusetts.

To the Editor: Torrey's claim that psychiatric survivors deny that schizophrenia and bipolar disorder are brain disorders "despite overwhelming scientific evidence" shows his closed-mindedness to the scientific debate and the available evidence. Many scientists outside the American Psychi-
Atric Association (and quite a few on the inside) point to the significant ambiguity in the empirical data regarding the "brain disorder" status of most mental and emotional problems. Even publications by the National Institute of Mental Health admit no clear and convincing evidence of the disease status of major mental disorders.

I am currently studying 1,046 articles on the causes of schizophrenia published between 1991 and 1995. Anyone who looks at this body of literature quickly becomes convinced that Torrey is wrong—there is no clear and convincing evidence that schizophrenia is a brain disorder. When one leading textbook on mental disorders points out that "there is yet no conclusive explanation of the causes of mental disorder nor an established cure," it is not surprising that psychiatric survivors might have the same reservations about jumping on the "Decade of the Blain" bandwagon with Dr. Torrey.

Robert E. Emerick, Ph.D.
Dr. Emerick is professor of sociology in the College of Arts and Letters at San Diego State University.

Reference

To the Editor: I am a survivor of mental illness who happens to agree with Dr. Torrey. Although I believe that there may be some cases where psychiatric treatment has been abused by doctors or staff, I personally don't see myself as the survivor of a Holocaust from psychiatry, and I am getting tired of Support Coalition International's politicizing the term.

Bernard A. Zuber

Mr. Zuber lives in Pasadena, California.

To the Editor: Psychiatric survivors' groups offer psychiatry a golden opportunity to build credibility and trust with the public, even if said survivors might never regain their sense of trust. How? By supporting wide-open inquiries by impartial boards into survivors' complaints, and by using the results of such inquiries to alter, limit, discard, and/or denounce any practices, techniques, or principles shown to need adjustment or reform. Calling for such inquiries and making changes if needed would show an attitude of confidence and fairness every American would have to applaud.

Jeff Levinger

Mr. Levinger is president of Levinger Associates, Inc., in San Francisco.

To the Editor: As someone who long ago was diagnosed with bipolar disorder, I think E. Fuller Torrey's article questioning the concept of "psychiatric survivors" makes sense. I too suffered at the hands first of an incompetent psychiatrist and then of one whose motives for keeping patients ill seem deeply suspect.

It is quite unfortunate that we have human beings in the medical profession, and often enough they either make bad decisions or don't have anything better to work with. Nevertheless, I know I would have been long dead if not for lithium and the fine doctor I have worked with for many years. It is very foolish to reject these benefits of modern life.

Jeanne Desy

Ms. Desy lives in Columbus, Ohio.

To the Editor: By citing views that are so vividly anti-disease and anti-involuntary treatment, Torrey invites us to overlook a far larger middle group that consists of most individuals with psychiatric conditions. The experiences of these individuals with treatment and involuntary confinement deserve to be recognized and learned from. They write and speak eloquently of surviving both their symptoms and their treatment, seeking to inform us of how our intentions to treat can also damage and wound. Efforts to squelch or trivialize these expressions impoverish our understanding of the nature of psychiatric disorders and the unintended consequences of treatment.

Sue E. Estroff, Ph.D.
Dr. Estroff is professor of social medicine, psychiatry, and anthropology at the University of North Carolina at Chapel Hill.

To the Editor: Torrey's commentary evokes images of hundreds of thousands of mentally ill persons wandering the streets without any insight into the reality of their situation. The facts are otherwise. The overwhelming incidence of mental illness is episodic; for most people the times of serious functional impairment come and go. These periodic impairments still leave them unable to pursue careers in mainstream society and lead them into poverty and, at worst, homelessness. Psychiatric drugs help some people escape this cycle, but they have damaging effects on others and may leave them even worse off than before.

Many homeless mentally ill persons avoid treatment not because they think there is nothing wrong with their lives, but because they know that something is very wrong with the way they are treated. Many who have been involved with the mental health system and have emerged from it have had such bad experiences that they want to stay as far away as possible from psychiatric treatment. Society's challenge is to offer alternatives that give people a chance to meet their own needs, not to treat them in a manner that alienates them even further.

Dennis Budd

Mr. Budd is president of Project Acceptance, Inc., an organization run by mental health consumers in Lawrence, Kansas.

To the Editor: Congratulations for printing the article by E. Fuller Torrey demonstrating the case of a new ruling class: professional survivors. Professional survivors are easy to identify. They receive grants from, or are paid directly by, the Center for Mental Health Services and almost all state departments of mental health. They claim to have never had a neurobiological disorder, while at the same time claiming to be spokespersons for those who do.

Under the guise of empowerment, professional survivors work in concert with government agencies to move funding from services for people with neurobiological disorders to their own organizations. Their success is reflected in the fact that 15,000 people with mood disorders kill themselves every...
year, 3,000 individuals with schizophrenia kill themselves every year, more than 30,700 individuals with serious neurological disorders serve time in our jails every year, and 150,000 individuals with serious neurological disorders live on the streets or in shelters.

It is hoped that after reading Dr. Torrey’s commentary, the leadership of the Center for Mental Health Services and state departments of mental health will focus their efforts on those who need treatment, rather than those who need to prevent it.

D. J. Jaffe

Mr. Jaffe is a spokesperson for the Alliance for the Mentally Ill/Friends and Advocates of the Mentally Ill in New York City.

To the Editor: The testimony of psychiatric “survivors” reaffirms the disappointing limitations of our current science: our diagnostic categories are imperfect, our treatments are not always effective, and powerful treatments always carry some risk of adverse effects. Clinical practice is a lesson in humility. Scientific medicine progresses by examining averages—the experience of large numbers of patients. Over the last 30 years, we have accumulated overwhelming evidence that modern psychiatric treatments, are, on average, remarkably effective. Clinical practice, however, teaches us that averages do not always apply to individuals. No responsible clinician would claim that any treatment is always safe or never harmful.

While we are cautious not to mechanically apply averages to the individual, the “survivors” make an even more dangerous leap: applying the experiences of individuals to the entire population. It is certainly true that some individuals have fared better after rejecting conventional psychiatric treatment. Their experience, however, does not negate the experience of a much larger number who have obtained dramatic and enduring benefit.

Gregory Simon, M.D., M.P.H.

Dr. Simon is associated with the Center for Health Studies/Mental Health Services of the Group Health Cooperative in Seattle.

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To the Editor: To hold Jay Mahler and civil liberties lawyers responsible for making it “virtually impossible to treat [people] with no insight into their illness or their need for treatment” is to truly miss the point of the last 30 years of experience with deinstitutionalization. The real culprit is the unwillingness of society to support adequate care for the mentally ill, or perhaps the failure of mental health advocates to justify such care to legislators and their constituents.

While I personally support civil commitment in the circumstances described by Torrey and know consumer-survivors who do also, that is not the issue. There are currently few viable treatment options other than involuntary commitment. Many involuntary detentions could be avoided with adequate alternatives. But because of the lack of alternatives, people are often forced to trade their liberty for care. In fact, many persons come to psychiatric emergency services today begging for civil commitment because that is the only way to get any help. Although civil commitment saves lives, for many it results in a learned helplessness that ensures their revolving-door participation in the system. Some patients avoid all treatment because of fear of civil commitment.

The lack of alternatives to hospitalization remains a key issue in psychiatric care, and the problem will only be exacerbated with the coming of managed care.

Steven P. Segal, Ph.D.

Dr. Segal is professor and director of the Mental Health and Social Welfare Research Group in the School of Social Welfare at the University of California, Berkeley.

To the Editor: Like the thousands of nonsurvivors Dr. Torrey identified, my brother died last year because of his schizophrenia, perhaps because it was so difficult for us to get him treatment. For nine torturous years my parents and I were forced into inaction due to the current laws, and all the while the delusions and voices overwhelmed my brother’s life. It was only after his condition degenerated to the point where he was destroying the house that we could finally get him to the hospital.

Then, as so often the case, catching a person during that very small window of time when he or she is “a danger to himself or others”—and before he or she are dead—is an overwhelming task with a disease that can fluctuate dramatically in a matter of hours. In our case, my parents were taking their first real vacation in years, and we just couldn’t respond to my brother quickly enough. How many people can be prepared for their worst nightmare 100 percent of the time?

Sadly, because the many who don’t get treatment are usually outside the system, they rarely get counted in unnatural death statistics. I applaud Dr. Torrey for his efforts in helping the mentally ill. Finally, someone is counting, and speaking out for the people who no longer have a voice—the huge population of nonsurvivors.

Brian Chiko

Mr. Chiko is webmaster at www.schizophrenia.com in San Jose, California.

To the Editor: I’ve benefited immensely from psychiatric care over the years. The label I use for myself in relation to psychiatric care is “consumer” or “client.” I find the labels “psychiatric survivor” and “patient” to be inaccurate and undesirable.

Larry McCleery

Mr. McCleery lives in Salt Lake City, Utah.

To the Editor: The consumer-survivors who are the subjects of Dr. Torrey’s commentary appear to have adopted the philosophy of Dr. Thomas Szasz (1), who has written that the concept of mental illness is erroneous, and that practices based on the concept are an “immoral ideology of intolerance.”

Psychiatrists as ethical physicians have practiced their profession in keeping with the science and social standards of the time. Thirty years ago, Dr. David Vail (2), among others, pointed out the need for humanistic practices in caring for people with mental illness. Psychiatrists have made huge advances in their understanding of mental illness and in the nature of treatment to try to alleviate suffering and prevent danger to those afflicted.
and to others. To negate the concept of illness affecting emotions and behavior flies in the face of reality.

Lucy Ozarín, M.D., M.P.H.

Dr. Ozarín, now retired, was a medical director with the U.S. Public Health Service in Bethesda, Maryland.

References

To the Editor: Dr. Torrey reacts angrily to the "psychiatric survivor" movement rather than asking why these "survivors" are so negative about psychiatry. I am sad that he didn't see in their anger reactions to the real barriers to access to care. Although it is unpleasant to be berated by angry former patients, it is still of interest to know why they are so angry. Sadly, those of us who work in public mental health systems (and, recently, those who work in private managed care systems) have some idea. So many psychiatric patients have encountered faceless and hurried staff in hospitals, have no relationship with their psychiatrists, and are subject to confusing and uncomfortable treatments. Many of those with serious mental illness who have needed involuntary care have been placed in welfarly inadequate facilities, poorly staffed and devoid of any of the attributes of human care.

Some former patients may make the mistake of blaming our profession for the inadequacies of the system. They assume that a bad system is synonymous with bad practitioners. In truth, psychiatrists suffer from inadequate systems as well. We should listen to the message behind the anger and ally ourselves with the majority of consumers and advocates for improving care.

Charles Hufnagel, M.D.

Dr. Hufnagel is president of the American Association for Community Psychiatrists.

In Reply: Thanks to all who took the time to respond and to Ms. Desy, Mr. Chiko, Mr. Jaffe, and Mr. Zuber for their kind words. I did not, as some writers suggest, criticize the psychiatric consumers' movement but rather the small but noisy subset who call themselves "survivors." These are individuals who compare American psychiatry to the Holocaust (Ms. Chamberlin et al.), who claim that schizophrenia is a "healthy, transformational breakdown," and who promote themselves as being "weller than well" (Dr. Siebert), whatever that means.

Psychiatric consumers, whom Dr. Estroff correctly notes are a "far larger middle group," are already making major contributions to American mental illness services as mental illness professionals and consumer case managers, and in day programs, clubhouses, and drop-in centers. As I have noted elsewhere (1,2), the potential for consumers to improve mental illness services is enormous. The small subset of survivors impedes this potential by discrediting the entire consumer movement.

As Mr. del Vecchio notes, I also criticized the federal Center for Mental Health Services, which has been the major funding source for the survivors movement. In an agency known for its political correctness, the survivors have acquired a psychiatric radical chic, a badge of misplaced liberalism. In addition, the logic of having one federal agency (the Center for Mental Health Services) support a group that denies the existence of serious mental illness, while another federal agency (the National Institute of Mental Health) supports research on these diseases, completely escapes me.

Dr. Emerick, a sociologist, claims there is no convincing evidence that schizophrenia is a brain disorder and cites a sociology book to prove it. What can one say? Dr. Emerick joins other sociologists who have made simplistic contributions to psychiatry, such as Thomas Scheff, who claimed that psychotic behavior was merely a problem in labeling or Erving Goffman, who said that most psychiatric inpatients are really sane. In the halcyon halls of academia, such ideas appear interesting. At ground level, where 28 percent of homeless mentally ill persons are obtaining food from garbage cans, such ideas appear preposterous.

Dr. Simon and Segal and others are correct that public services for individuals with serious mental illnesses are insufficient on the best of days and abysmal on most, as I have documented (2-5). And I agree with Ms. Chamberlin et al. that psychiatry has at least its share of incompetent practitioners. But just because some diabetics have been treated incompetently, one does not argue that internal medicine should be abolished.

Finally, it is significant that none of the writers who criticized my commentary addressed its main point—the need to involuntarily hospitalize and treat hundreds of thousands of seriously psychiatrically ill individuals who have no insight into their illness or their need for treatment. The survivors claim involuntary treatment should never be allowed. I believe this policy has led to at least a half million premature and unnecessary deaths.

Fifteen years ago, when I was a psychiatrist in a public psychiatric hospital, I sought to extend an involuntary commitment for a severely psychotic and disabled young man who had no insight into his illness. Before the court proceedings I asked the patient's public defender what she thought would happen to him if she was successful in obtaining his release. She replied that getting him released from the hospital was her concern, but what happened afterward was not her concern. We have seen the consequences, and the answer is no longer acceptable.

E. Fuller Torrey, M.D.

References:

LETTERS