

# **Mental Health, United States, 2004**

**U.S. Department of Health and Human Services  
Substance Abuse and Mental Health Services Administration  
Center for Mental Health Services  
1 Choke Cherry Road  
Rockville, Maryland 20857**

**Edited by Ronald W. Manderscheid, Ph.D. and Joyce T. Berry, Ph.D., J.D.**

## **Chapter 4**

### **The Evolution from Advocacy to Self-Determination**

Ronald Bassman, Ph.D.  
*The Community Consortium Inc.*

#### **Introduction**

The 21st century promises new hope and opportunity for persons diagnosed with mental illness. The President's New Freedom Commission on Mental Health report, *Achieving the Promise: Transforming Mental Health Care in America* (2003), concluded that people are more likely to recover from a mental disorder when they are treated with fairness and respect. When their human rights are ignored or neglected, recovery is undermined. The power of this insight is validated by the profound changes in the supports and services available for people with mental illnesses. The person with mental illness, once having no choice but to be a passive recipient of services, now has the opportunity to be an active, decisionmaking participant in community life.

From antiquity to the present day, madness has stubbornly resisted numerous and varied attempts to unlock its unwelcome grip on human beings. Historically, people with mental illness have suffered not only from the effects of their extreme mental and emotional states, but also from harmful treatments. Too often, desperate, ill-conceived attempts to control, prevent, and eliminate this frightening and confounding human condition have resulted in severe and painful damage to the minds and bodies of people whose voices, rights, and feelings were sacrificed in the name of treatment.

Until the latter half of the 20th century, knowledge of mental illness was the exclusive domain of the professional observers and treaters of madness. By virtue of being mad, a person was deemed to be without credibility and not able to contribute any meaningful knowledge to help understand madness. But the compelling need to give testimony to what one has experienced and witnessed as a patient has defied all attempts at suppression. A vast body of rarely read, first-person stories bears witness to patients' need to reclaim their voices and find a way to speak their own truth (Frank, 1995).

Hornstein (2002) points to parallels between patients' autobiographical accounts of mental illness and slave narratives, in that both bear firsthand witness to oppressive treatment and injustice. The personal stories of abuses and the descriptions of self-initiated successful recoveries were not only dismissed, but were often actively silenced. Hornstein notes the silencing of patients reflected in the autobiography of the 19th century economist and feminist theorist, Charlotte Perkins Gilman; her doctor warns her "never [to] touch pen, brush, or pencil as long as you live."

Occasionally, one of these patient narratives breaks into public awareness and becomes a catalyst for change. *In A Mind That Found Itself* (1908), Clifford Beers vividly described the abuses he saw and experienced as a patient confined to an institution after a failed suicide attempt. He advocated for extending the rights of mental patients and for the reform of inhumane practices. Of note is the assistance he received from a prominent psychiatrist, Adolph Meyer, who helped edit this book, while also convincing Beers to tone down his criticism of asylums and psychiatry. Beers, Meyer, and other colleagues founded the National Mental Hygiene Committee (now the National Mental Health Association) in 1909. Without the backing of a prominent and credible person, Beers's story and the reforms it inspired might have languished in obscurity along with other silenced testimonies.

This chapter explores how consumer/survivors<sup>1</sup> have expanded our understanding of major mental illness and contributed to changes in attitudes and in the way mental health services are delivered. Before the rise of the consumer/survivor movement, it was almost unthinkable that a person diagnosed with mental illness would be regarded as a whole person who was entitled to dignity and respectful treatment. While many significant social, economic, political, and demographic forces were instrumental in changing the mental health system, the main focus of this chapter is on the changes wrought by the passionate, dedicated work of those whose label as mental patients once excluded them from any credibility. Today, consumer/survivors are exposed to concepts that were unheard of several decades ago: Recovery, resilience, empowerment, self-determination, informed choice, self-help, and peer support are now embedded in the language of mental health.

The integration of health care and behavioral health care principles are fast finding acceptance as the preferred practice for sustaining a healthy population (Institute of Medicine, 2001). Consumer-centered care for mental illness is following closely behind the ideal for general health care—encouraging physicians and patients to engage in collaborative relationships in which transparency of information is a prominent feature. The chapter concludes by projecting the theme of consumer-centered services 25 years into the future. It speculates about what newer forms of mental health services might look like, and how changes in attitudes about mental illness and mental health services can result in more inclusive communities for everyone.

### **Historical Roots of the Consumer/Survivor Movement in Mental Health**

Historical precedent for today's consumer/survivor activism may go back to *The Petition of the Poor Distracted People in the House of Bedlam*, a pamphlet published in 1620 (Brandon, 1991). However, the prototype of today's consumer/survivor self-help groups was the Alleged Lunatics' Friend Society, which was begun in England in 1845. For John Perceval,<sup>2</sup> the most famous of the founders, obtaining the cure for oneself was an act of resistance to the system.

The criticism of the Alleged Lunatics' Friend Society, appearing in the British newspaper, *The Times*, on March 27, 1846, is ironic:

Some of the names we have seen announced suggest to us the possibility that the promoters of this scheme are not altogether free from motives of self-preservation . . . we think they should be satisfied to take care of themselves, without tendering their services to all who happen to be in the same position (Hervey, 1986, p. 245).

In 1838, Richard Paternoster was released from the "madhouse" after being confined there for 41 days. After he was discharged, he advertised in a newspaper for fellow sufferers to join him in a campaign to redress abuses suffered by mental patients. Initially, he was joined by four men, the most influential being John Perceval, son of the assassinated prime minister. Perceval was in the asylum administered by Edward Long Fox, which was known then as the foremost institution of its kind. Such was Dr. Fox's reputation that he had been invited to treat the madness of King George III. Yet, reputation notwithstanding, Perceval said that his care in the asylum was barbarous. Paternoster and Perceval were joined by William Bailey, an inventor who had spent 5 years in madhouses, and Dr. John Parkin, another ex-patient. The four men named their self-help group The Alleged Lunatics' Friend Society. The objectives of the society were to reduce the likelihood of illegal incarceration and improve the condition of asylums, to offer help to discharged patients, and to convert the public to an enlarged view of Christian duties and sympathies (Hervey, 1986).

In the 20th century, the 1960s served as the incubator for groups of people who banded together to focus on making major societal changes. The civil rights movement, the women's movement, gay pride, the anti-Vietnam War movement, and people with disabilities, including disabled veterans, were challenging attitudes, legal barriers, and institutional practices. These social action groups had several common themes centered around a critical attitude toward authority and the bureaucratic organizations that controlled policies and services (Borkman, 1997).

### **The History of the Consumer/Survivor Movement in the United States**

In the United States during the 1960s and 1970s, the organizing efforts of former psychiatric patients laid the groundwork for the current consumer/survivor movement. The early participants were angry at being treated as if they were less than human in institutions where they were seen as so hopeless that any treatment could be tried on them. They found their experiences validated only by others who shared similar experiences of abuse within institutions. After they were forced to suppress their feelings and denied credibility both within institutions and in the outside community, their meetings helped them realize that they were capable human beings with unique abilities who were deserving of dignity and respect.

During much of the 20th century, one could be judged psychotic and confined to a psychiatric facility for disorders prompted by poverty, race, culture, sexual orientation, or the failure to meet gender expectations in one's marriage. Services were guided by "our willingness to incarcerate them in hospitals and our unwillingness to have them in our communities . . . an 'out of mind, out of sight' attitude" (Mosher & Burti, 1994, p. 20). Persons who fit into the broad category of mental illness were, with few exceptions, thought to be in need of special care,

monitoring, and controls. Beginning in the early 1970s, consumer/survivors challenged the existing attitudes and treatments.

For the first time in American history, formerly hospitalized mental patients created and ran their own organizations. The earliest groups formed spontaneously in Oregon, California, New York, Massachusetts, Pennsylvania, and Kansas. The first organized group was the Insane Liberation Front founded in Portland, Oregon, in 1970. A year later, the Mental Patients' Liberation Project was founded in New York, and the Mental Patients' Liberation Front was organized in Boston. In 1972, the Network Against Psychiatric Assault was established in San Francisco. Other groups formed in the early 1970s included Project Release in New York and The Alliance for the Liberation of Mental Patients in Philadelphia (Beard, 2000; Chamberlin, 1990).

The strongest critics of mental health treatments have always been former mental hospital patients. They expressed their pain and outrage and insisted that the therapies forced upon them were not effective. Members of these groups asserted that they were best qualified to judge how they needed to be treated. Some of the groups sought to establish their own programs as alternatives to hospitals. Activities of the movement pioneers included organizing support groups, advocating for patient rights, lobbying for changes in laws, identifying themselves as former mental patients when speaking out in public, and publishing articles and books about their experiences. The experiences they shared with other consumer/survivors had taught them that the treatments of people diagnosed with mental illness were rife with physical and emotional abuses, and that the blatant insults to their dignity and integrity as individuals hindered their recovery. The consumer/survivors adopted the consciousness-raising methods of the women's movement and challenged the oppression of what they came to call "mentalism" (Chamberlin, 1990). The names that they called themselves, like "psychiatric survivors" and "psychiatric inmates" and group names like the Insane Liberation Front were designed to call attention to the humiliating language others thoughtlessly used to describe them. By communicating through newsletters like the *Madness Network News*, organizing meetings with other groups, and staging protests, they began to convey their messages to a larger constituency.

Carole Hayes-Collier (2004), an early participant in the consumer/survivor movement, proudly describes her introduction to the movement as a turning point in her life. She had been working part time for a small human service agency when a student brought her a copy of an article about a group of mental patients meeting together to work on rights issues. Hayes-Collier had earned a bachelor's degree in sociology at Le Moyne College, but before that time had been in four mental hospitals. Since she was open about being a mental patient and often spoke up about related issues, she was intrigued. She and a few other consumer/survivors decided to work together to create a local chapter of New York City's Mental Patients' Liberation Project. The first meeting was modeled after an article in *Parade* magazine, which described that New York City group. At meetings held in a free clinic space and in a church basement, they held discussions about abuses and oppression in mental hospitals. Working together, they organized demonstrations and public education initiatives.

The significance of the consumer/survivor movement and self-help groups is demonstrated in Hayes-Collier's description of the meetings. She recalls,

Gatherings were very much energized by the motivation to create social change and join with other movements in asserting and assuring our rights. By joining together, we gained a sense of empowerment and the initiative to reclaim not only our rights, but also our lives. We were excited about meeting others who shared similar experiences and who understood our points of view. We wanted to eliminate coercion and promote alternatives (Hayes-Collier, 2004).

### **The Consumer/Survivor Movement Enters the Mental Health Arena**

The political and socioeconomic climate of the second half of the 20th century provided fertile ground for the growth of the consumer/survivor movement. Changes in government policy, funding, and responsibilities toward people with mental illness gave consumer/survivors new opportunities. Yet, despite the push for reform beginning in the mid-1950s, State institutions were essentially custodial facilities: Treatment programs were limited, wards were overcrowded, few recreational and social activities were available to patients, individual privacy was lacking, and recovery was not an expectation. The introduction of Thorazine into treatment protocols in the 1950s stimulated thinking about changes in the institutional environment. However, the provision of mental health treatment in the community did not become a national goal until 1963 when President John F. Kennedy proposed—and Congress enacted—the Community Mental Health Construction Act. Kennedy sought to change the locus of services by promoting the development of a range of community-based services. The goal was to enable people with the most serious mental disabilities to remain in, or return to, their communities and to live as independently as possible.

During the 1960s and into the 1970s, other State and Federal initiatives continued to nudge the mental health system away from its reliance on institutional care. Title XIX of the Social Security Act, enacted in 1965, established the Medicare and Medicaid program, which funded outpatient mental health services as well as general medical care for low-income citizens. The Federal Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI) programs provided people with psychiatric disabilities a subsistence income, which for the first time supplied the financial means for many people to leave institutions. But the income was not sufficient for most people to live on their own; many people leaving institutions at this time ended up in congregate living facilities or single-room occupancy housing. They were out of the hospital, but not really part of their communities.

These new Federal entitlements coincided with the rise of mental health legal advocacy initiatives inspired by the civil rights movement. Congress passed the Protection and Advocacy for Individuals with Mental Illness Act (PAIMI) in 1986. The purpose of PAIMI was to protect and advocate for the rights of persons with mental illness. With the formation of federally funded Protection and Advocacy agencies, consumer/survivors were able to become involved in the investigation of abuse and to advocate for patient rights legislation. The judiciary began to heed the arguments of patients' rights attorneys who challenged the way States treated citizens diagnosed with mental illness. Across the country, advocates challenged the civil commitment process. Court decisions created the constitutionally based doctrines of the right to treatment (as opposed to custodial care) and the right to be treated in the least restrictive environment. In many States, the use of involuntary treatment was limited through court decisions and statutory change, thus becoming another

factor driving down the census of State hospitals. Still, the forces that resulted in what came to be known as “deinstitutionalization”—psychotropic drugs, community mental health centers (CMHCs), Federal entitlement programs, civil rights advocacy, and court decisions outlawing unpaid labor—were not sufficient in themselves to ensure that people with long institutional histories could successfully re-integrate into their communities. The income support, mental health treatment, and housing arrangements were insufficient for people who had been completely dependent on psychiatric institutions to meet all their needs. The learned helplessness that served as a survival skill within psychiatric institutions conflicted with the skills required for community living. These factors combined to make deinstitutionalization an apparent failure in the view of many (Scull, 1990).

In response, the National Institute of Mental Health (NIMH) created the Community Support Program (CSP) in 1977. CSP was built on the recognition that people with long-term psychiatric disabilities needed access to a wide variety of support services, not just mental health treatment, to live successfully in the community. CSP encouraged the development of networks providing access to a range of services, including health care, social services, housing, and transportation, which were to be coordinated on the individual level by case managers.

At the beginning, CSP invited input and participation first from families and later from consumer/survivors. Consumer/survivors insisted that the interests of families were not the same as their own, because many consumer/survivors objected to forced treatment and involuntary commitment, while many families favored both. These differences in ideology between families and consumer/survivors sharpened after families organized the National Alliance for the Mentally Ill (NAMI) in 1979 and fashioned it into a powerful advocacy organization (McClean, 2003). Although polarized stances on forced treatment and self-determination continue to be divisive issues for the consumer/survivors who support key principles (self-determination, speaking for themselves) of the movement founders, NAMI has expanded its base by reaching out to consumers for participation and membership.

The consumer/survivor movement received a large boost when consumer/survivors gathered at the first Conference on Human Rights and Against Psychiatric Oppression in 1973. Continuing until 1984, these annual conferences became a means of support, raising consciousness, discovering identity, and developing a sense of pride. At first, consumer/survivors found rapport with critical anti-psychiatry theorists who challenged mainstream conceptions of mental illness. Radical practitioners and academics found commonality and shared change agendas with consumers/survivors. These collaborative relationships with nonconsumer/survivors ended in the early 1980s when consumer/survivors decided to exclude mental health professionals from their movement. Much like the leadership of Alcoholics Anonymous, they believed that it was necessary to exclude those who lacked the lived experience in order to preserve consumer/survivor leadership and independence.

The structure and composition of the annual meetings shifted when the conferences received financial support from the Federal Government. In 1985, On Our Own of Maryland was awarded CSP funds to hold the first Alternatives Conference at the College of Notre Dame in Baltimore. It was a national meeting at which consumer/survivors offered workshops on how to start self-help groups, how to raise funds, and other topics relevant to self-help. These conferences brought in new

people, consumers who were less rejecting of mental health services than the early movement participants who identified themselves more as psychiatric survivors. The consumer/survivor movement of the late 1960s began as a human rights movement by ex-patients and psychiatric survivors who objected to institutionalization and treatments that deprived them of hope, independence, and control over their lives. With government support, the first Alternatives conference expanded, validated, and gave notice of the importance of the consumer/survivor movement. However, it also strayed from its 1960s origins. The pioneering anti-psychiatry "survivors and ex-patients" were joined by "consumers," who accepted the medical model of mental illness while still advocating for changes in services, including self-help and consumer-run services. This first Alternatives conference splintered the movement into polarized groups. Acceptance of the medical model and the overriding value of psychiatric drugs and the opposition to forced treatment became contentious issues. Although they were unable to reach agreement on such issues, participation in national conferences gave consumer/survivors an opportunity to exchange and refine their ideas (McClellan, 2003). The National Alternatives conferences continue to meet annually and receive funding from the Center for Mental Health Services (CMHS).

Consumer/survivor influence was ensured when, in 1989, a new Federal law mandated new State mental health planning processes that included consumer/survivors and other stakeholders. Involving consumer/survivors in the process of constructing their State's mental health policy assured them of a seat at the policy table. Consumer/survivor visibility and credibility were heightened by a series of CSP-sponsored dialogs on recovery between consumer/survivors and policy-making administrators and mental health professionals representing different disciplines. These meetings facilitated communication between groups with diverse views and enhanced their ability to work together.

In 1988, CSP began funding consumer/survivor-run demonstration services projects that were developed in collaboration with State mental health program staff. These collaborations allowed consumer/survivors to share their ideas about service needs and their empowerment philosophy. The meetings and discussions gave evidence of the contributions that consumer/survivors could make and stimulated thinking about how to best utilize their lived expertise. The National Association of State Mental Health Program Directors (NASMHPD), composed of all of the directors of their respective State mental health agencies, unanimously signed the Position Paper on Consumer Contributions to Mental Health Service Delivery, which affirmed the value of consumer/survivor perspectives (NASMHPD, 1989).

The 1990s saw the creation of offices of consumer affairs in more than 50 percent of the Nation's State mental health agencies. The ideas behind these offices, which were headed and staffed by people with psychiatric histories, were to ensure that consumer/survivors were involved in all aspects of planning, policy development, program development, and other agency operations and to promote a recovery-oriented reform agenda.

In the early 1990s, Federal funds were made available for the formation of a Consumer/Survivor Research and Policy Workgroup to help develop a consumer/survivor-driven research and policy agenda. In 1993, consumer/survivors were included in the development of the Mental Health Statistics Improvement

Program (MHSIP) Consumer-Oriented Mental Health Report Card, a SAMHSA/CMHS project.

By the end of the 20th century, consumer/survivors were pushing the envelope on many fronts. They were recognized as being able to bring a unique and valuable perspective to the understanding and treatment of people with mental illness. Emerging from their beginnings in protest, consumer/survivor activists found themselves considering the gains they had made, and what would be the next steps.

### **The Consumer/Survivor Movement at the Beginning of the 21st Century**

The impact of consumer/survivor organizations and individual consumer/survivors on mental health services, legislation, and research is undeniable. The U.S. Surgeon General's report on mental health (U.S. Department of Health and Human Services, 1999) states, "One of their greatest contributions has been the organization and proliferation of self-help groups and their impact on the lives of thousands of consumer/survivors of mental health services. The opportunity to participate in self-help has provided hope and stability where there was none, and empowered the once hidden to become participating worthwhile members of society."

President Bush's New Freedom Commission on Mental Health report (2003) recommends that mental health service systems move beyond merely managing symptoms toward a consumer-centered, recovery-oriented system. The report states, "Because recovery will be the common, recognized outcome of mental health services, the stigma surrounding mental illnesses will be reduced, reinforcing the hope of recovery for every individual with a mental illness" (p. 4). The report further states that consumers should be significantly involved in everything from planning to choosing providers to delivering services.

Not very long ago, if you were a consumer/survivor and were seeking a job in the community or attempting to return to college, you had to be very creative in explaining the gap in your resume. Revealing your psychiatric history was almost certain to block entry into your chosen field. Being open about your background was an invitation to discrimination. With the passage of the Americans with Disabilities Act of 1990 (ADA), consumer/survivors had new protection against discrimination, along with the right to reasonable accommodations, but the ADA was only one step in alleviating the stigma associated with mental disability. The most meaningful challenge to stigma has to come from consumer/survivors themselves, and the first priority has to be changing the way "mental patients" tend to denigrate their own abilities and prospects. This internalized stigma, whereby one passively accepts the "good patient" role with its requirement of compliance and the need for lifelong care, is disempowering. Sensitizing more consumers to the meaning and value of the popular movement sayings, *I am more than my diagnosis, I speak for myself*, can be a powerful weapon against stigma.

Stigma and discrimination were greatly diminished when consumer/survivors became open about their experiences, when they became coworkers on the job and fellow students in the classroom, and when they lived next door and socialized with their neighbors. When your friend is a consumer/survivor, the fear and mystery surrounding mental illness begins to dissolve. Inspiring others by telling their stories, sharing their successes on the job and in the community made recovery real for consumer/survivors. It was self-help in action. Refusing to be silent,

consumer/survivors wrote and told their stories. Consumer/survivors returned to colleges, attained their degrees, became mental health professionals (psychologists, social workers, psychiatrists, lawyers), administrators, and researchers and proved the value of their experience. What was once a liability became a credential signifying a special, lived expertise.

Today, consumer/survivors are ubiquitous in the field of mental health. They direct their own organizations. Clubhouses, drop-in centers, crisis respite, warm lines, peer advocates, peer specialists, peer educators, peer counselors, and peer benefits specialists are the places and people through which consumer/survivors are working to empower themselves and other consumer/survivors. Consumer/survivors sit on local, State, and Federal boards and advisory councils. They review mental health grants and participate in funding and policy decisions. Several States have recognized the important contributions of consumer/survivors by creating career paths for Peer Specialists with certification, credentialing, and civil service status attached to the jobs.

In 1992, the first national Technical Assistance Center (TAC), directed by and for consumer/survivors, was funded by CMHS to assist in the transformation of the mental health system by providing consumer/survivors with skills to develop and sustain peer-run programs. Recognizing the value of self-help, these programs were created to maximize consumer/survivor self-determination and recovery. An important feature of the TAC programs is promotion of infrastructure development of self-help groups at the State and local levels. Following the initial grant to the National Mental Health Consumers' Self-Help Clearinghouse, the National Empowerment Center (NEC) and the Consumer Organization and Networking Technical Assistance Center (CONTAC) were awarded similar grants. Joining the three TACs, two Consumer-Supporter Technical Assistance Centers received TAC grants, the Support Technical Assistance Resource Center (STAR) and the National Consumer-Supporter Technical Assistance Center (NCSTAC). STAR, a program of the National Alliance for the Mentally Ill, and NCSTAC, a program of the National Mental Health Association, were created to provide support, technical assistance, and resources to help improve and increase the capacity of consumer/survivor operated programs and self-help.

The anti-elitist attitude of the 1960s, with its emphasis on self-determination and self-reliance, was a driving force for the early consumer/survivor groups (Dain, 1989). Changes in Federal laws, policy, and funding encouraged and empowered consumer/survivor groups. How would the movement remain true to the fight for rights and social justice when funding and support came from government sources? Just as consumer/survivors were making sure that leadership arose from among their own ranks, difficult decisions had to be made about how accepting government funding would affect the ideals emerging from the organizations' origins as a human rights movement. Managed care presented another challenge to the consumer/survivor movement. Private sector behavioral health care companies embraced the efficacy and cost savings of peer support services. As more consumer/survivors became paid mental health workers, they faced the challenge of maintaining their special perspective while adapting to the credentialing and reporting requirements of more traditional service providers. Consumer/survivors who did not accept the medical model were in danger of losing their funding. Would they be able to maintain their identities as peers, or would they be absorbed into the larger mental health provider community as quasi-professionals?

Opportunities for consumer/survivor empowerment were occurring on several fronts as the 21st century began:

1. The *Olmstead* Supreme Court decision mandated States to plan for community placement of all individuals residing in inappropriate institutional settings. *Olmstead* would provide a lever for various disability groups advocating against unnecessarily restrictive and costly congregate housing arrangements. Full community integration is the goal.
2. In 2001, the U.S. Department of Health and Human Services proposed privacy regulations for all medical records under the Health Insurance and Portability and Accountability Act of 1996 (HIPAA). These regulations, which went into effect in 2003, became an important foundation for protecting the privacy of patients. The privacy standards empower consumer/survivors to be more involved in determining their care and treatment by exercising access to and control of their patient records as well as providing a check on their accuracy.
3. In 2001, the Institute of Medicine issued *Crossing the Quality Chasm*, a report that promotes patient control as a core attribute of re-invented health care systems. The challenge for consumer/survivors is in making sure that mental health receives a similar push to move the person to the center of services, with all the comparable transparency and decisionmaking rights.
4. In 2002, President Bush created the New Freedom Commission on Mental Health and selected a consumer/survivor member to serve on it. Consumer/survivors testified, and their stories and insights provided valuable input to the deliberations. The recommendations of the final report were a clear endorsement of a recovery-oriented system with individualized treatment planning and a heightened role for active consumer participation.

It is not a coincidence that the road to recovery for a person diagnosed with mental illness is far more accessible today than in the early 1970s when the consumer/survivor movement began. Yet, the consumer/survivor movement is fraught with challenges that must be addressed. The diversity of perspectives—the differing views on the medical model, on psychiatric medications, on forced treatment, and even on what name to use to identify oneself—prevents the formation of an effective, unified national consumer/survivor organization.

Examples of serious challenges that face mental health consumer/survivors are as follows:

- Self-determination is losing ground to a highly organized campaign to create forced outpatient commitment laws.
- Advanced mental health care directives as an affirmation of one's personal choices are underutilized and have not been consistently upheld in the courtroom.
- The use of physical and pharmaceutical restraints to control patient behavior remains problematic.

Consumer/survivors must still strive to attain equal participation in their care. Although consumer/survivors are now represented on most mental health committees and workgroups, they are rarely represented equally, with tokenism being more the rule than the exception. Too few organizations truly understand what

it means to cultivate and support full consumer/survivor participation. However, consumer/survivors are encouraged by the Federal Government's efforts to move from tokenism to parity in representation on national workgroups involving mental health issues.

The consumer/survivor movement, despite its achievements, faces its greatest challenge from outspoken nonconsumer/survivor leaders representing well-financed special interest groups. Those powerful spokespersons have used their strong political bases to advance their views about the basis of mental illness and the role of psychiatric drugs, forced treatment, and behavior control. They have changed funding priorities to the detriment of consumer/survivor programs.

Other problems stifling the growth of the consumer/survivor movement are the following:

1. The underrepresentation of people of color
2. The difficulty engaging youth and mentoring new leadership
3. The compromises required to attain funding

Consumer/survivors who have struggled to be respected, who have recovered their dignity, and who have found paid jobs that have enabled them to start families are less able to be outspoken critics of those who pay their salaries. Perhaps it is only natural that when fewer egregious abuses are occurring, the uncompromising commitment and righteous anger of the early pioneers is less available to fuel activism.

Whereas once mental patient advocacy and reform was driven by the energy of a few creative and passionate reformers, only to fade when they passed away, today's critical mass of informed and active consumer/survivors may ensure that the movement continues to be influential. The consumer/survivor movement deserves to savor and relish its hard-fought gains, but a new momentum must be created to continue work that is far from finished.

### **Projecting the Hopes of the Consumer/Survivor Movement 25 Years into the Future**

When the conflict surrounding the need and justification for forced treatment is resolved, progress will rapidly accelerate. The increase in complex questions emerging from the field of bioethics will create better strategies for resolving the dispute over self-determination in mental health.

Based on the National Council on Disability's recommendation, involuntary treatment will no longer be considered a viable mental health treatment service.

Laws that allow the use of involuntary treatments such as forced drugging and inpatient and outpatient commitment should be viewed as inherently suspect, because they are incompatible with the principle of self-determination. Public policy needs to move in the direction of a totally voluntary community-based mental health system that safeguards human dignity and respects individual autonomy (National Council on Disability, 2000, p. 6).

With the conflict over forced treatment resolved, a national consumer/survivor membership organization will be created. Based on a vote of the membership, a newly agreed-upon name will replace consumer/survivor. This new group is now able to form an alliance with the National Alliance for the Mentally Ill, which has also changed its name. Joining to form coalitions with other disability groups, the multiple disability groups and their families have become a formidable advocacy force. All the disability organizations begin sharing mutually integrated advisory councils that promote communication and understanding of each other's issues.

Since consumer/survivors are no longer subject to de facto segregation, stigma and discrimination are weakened by their ubiquitous presence throughout the community. With this added exposure, there is a greater appreciation of the value of diversity and less fear of people who may look or act differently.

Knowledge of madness and other extreme states of emotion and consciousness expands exponentially when university programs integrate consumer/survivors into educational programs for mental health professionals. With regular exposure and new opportunities for dialog, creativity flourishes.

Consumer/survivors are offered an array of services with alternatives that enable them to make informed decisions on how to reduce their emotional distress and pain without sacrificing their long-term health and goals.

Recognizing the long-range benefits and cost savings, the U.S. Government creates a program to provide safe, affordable housing where people can have the supports they need to live with dignity and to develop their strengths and abilities. New funding strategies enable consumer/survivors to choose the supports and services they find helpful and hire and fire those who provide them with services. Consumer/survivors have the opportunity to be fully integrated members of the community.

## References

Bateson, G., ed. (1974). *Perceval's narrative: A patient's account of his psychosis, 1830–1832*. New York: William Morrow and Company.

Beard, P. (2000). The consumer movement. In Menniger & Nemiah (Eds.), *American psychiatry after World War II (1944–1994)*. Washington, DC: American Psychiatric Press, Inc.

Beers, C. W. (1908). *A mind that found itself*. New York: Doubleday.

Borkman, T. (1997). A selective look at self-help groups in the United States. *Health and Social Care in the Community*, 5(6), 357–364.

Brandon, D. (1991). *Innovation without change*. Basingstroke Hampshire, England: Macmillan.

Chamberlin, J. (1990). The ex-patients' movement: Where we've been and where we're going. *Journal of Mind and Behavior*. 11(3–4), 323–336.

Dain, N. (1989). Critics and dissenters: Reflections on 'anti-psychiatry' in the United States. *Journal of the History of the Behavioral Sciences*, 25, 3–25.

Frank, A. (1995). *The wounded storyteller: Body, illness and ethics*. Chicago: The University of Chicago Press.

Hayes-Collier, C. (2004). Personal communication.

Hervey, N. (1986). Advocacy or folly: The Alleged Lunatics' Friend Society 1845–1863. *Medical History*, 30, 245–275.

Hornstein, G. (2002, January 25). Narratives of madness, as told from within. *The Chronicle of Higher Education*, B7.

Institute of Medicine. (2001). *Crossing the quality chasm: A new health system for the 21st century*. Washington, DC: National Academy Press.

McClellan, A. (2003). Recovering consumers and a broken mental health system in the United States: Ongoing challenges for consumers/survivors and the New Freedom Commission on Mental Health. *International Journal of Psychosocial Rehabilitation*, 8, 47–68.

Mosher, L., & Burti, L. (1994). *Community mental health: A practical guide*. New York and London: W.W. Norton & Company.

National Association of State Mental Health Program Directors. (1989). *Position paper on consumer contributions to mental health service delivery systems*. Alexandria, VA: Author.

National Council on Disability. (2000). *From privileges to rights: People labeled with psychiatric disabilities speak for themselves*. Washington, DC: Author.

The President's New Freedom Commission on Mental Health. (2003). *Achieving the promise: Transforming mental health care in America. Final report*. (DHHS Pub. No. SMA-03-3832). Rockville, MD: U.S. Department of Health and Human Services.

Scull, A. (1990). Deinstitutionalization: Cycles of despair. *The Journal of Mind and Behavior*, 11(3), 301–311.

U.S. Department of Health and Human Services. (1999). *Mental health: A Report of the Surgeon General*. Rockville, MD: Department of Health and Human Services: U.S. Public Health Service.