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Regulation & Policy

The Patient As A Policy Factor: A Historical Case Study Of The Consumer/Survivor Movement In Mental Health

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Abstract

This paper analyzes the history of the modern consumer/survivor movement and its impact on the policy-making climate in the mental health field. The growing attentiveness to consumers' perspectives is presented largely as a consequence, not a cause, of radical restructurings of the mental health system. Consumers' perspectives have entered policy discourse in the wake of policy failures and have flourished in a climate of perpetual crisis and tight budgets. Precisely because it has been such a contested arena for so long, the mental health field has produced some innovative responses to demands for patient empowerment.

ONE OF THE MOST STRIKING CHANGES in health care policy making over the past forty years has been the growing attentiveness to the voices of patients. The concept that the end users of health care—variously conceived of as patients, consumers, or simply "the public"—should be actively involved in decision making, in both therapeutic and economic domains, has gained widespread acceptance.

The principle of "empowerment," defined as having the right to make one's own health care choices, is now frequently invoked as one of the fundamental measures of enlightened health care. Yet the project of empowering patients remains very much a work in progress. Older paternalistic models of physician-dominated decision making have eroded without clear agreement on what should take their place. Efforts to rethink the power dynamics between doctor and patient are occurring in the context of an often brutal economic restructuring of the health care system. Returning power to end users in a fragmented, politicized health care system remains a daunting prospect.

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Moreover, patient agency, as exercised in therapeutic or economic domains, does not easily fit into existing mod of health care policy making. Patients do not possess the kinds of social, economic, and political resources traditionally thought essential to wielding power in policy settings. Compared with that of other key players—the medical profession, the insurance industry, the pharmaceutical industry, and the hospital industry—their influence much harder to identify and measure. There is an urgent need, then, to think more critically and systematically at the "patient factor" in policy making.¹

To that end, this paper examines the growing influence that people who suffer from severe, persistent mental illnesses have had in mental health policy making since 1980. This group of patient actors would seem little likely qualify as a powerful interest group: They suffer from a highly stigmatizing disability, often criticize modern biomedicine, and frequently depend on a fragile network of social services to maintain their independence.

Yet despite these disadvantages, consumer/survivors have come to participate in a wide range of policy-relevant activities. The magnitude of change involved is illustrated by consumer/survivors' evolving role in writing major policy documents, from no part in the Mental Health Study Act of 1955 to a small but significant presence in the 1978 Carter Commission, to a highly visible role in the 1999 surgeon general's report on mental health. As that 1999 report acknowledged, "Through strong advocacy, consumer and family organizations have gained a voice in legislation and policy for mental health service delivery."² In short, consumer/survivor groups have played a vital role in drawing attention to the "quality chasm" in mental health care.³

Yet although barely begun, the idea of according consumer/survivors a privileged role in policy making has prompted expressions of concern: worries that the "wrong" consumer perspectives are being accorded too much policy weight; that their views are insufficiently evidence based; and that they are contributing to the fragmentation that besets mental health policy. In his 2005 presidential address to the American Psychiatric Association (APA), Steven Sharfstein observed that a "blizzard of policy proposals...sits unadopted, because nobody has the moral authority to pull together a winning political coalition," in part because psychiatry now competes with the "consumer movement," the pharmaceutical industry, and the insurance industry in its bid to exercise leadership in the mental health field.

In light of such concerns, it seems an opportune time for historical reflection on the "patient factor" in mental health policy making. To that end, I offer here a highly selective history of the consumer/survivor movement. My focus is primarily on groups having an advocacy or "social movement" agenda as opposed to a strictly self-help or therapeutic purpose. Although disliked by many, the term "consumer/survivor" has emerged as a commonly used label for patient advocates in the mental health field, so I use it here.⁵

A 'Selective' History Of The Consumer Movement In Mental Health

The consumer/survivor movement represents the extreme edge of a new kind of health consumerism that became widely accepted during the 1970s, as many Americans, especially the educated and affluent, embraced the idea that they should take an active role in their health care. Along with the women's health and disability rights' movements, ex-patient groups offered some of the earliest and most radical critiques of medical authority. That the mental health field would produce one of the earliest and most radical of angry patient movements comes as no surprise, given that psychiatry had a long history of patient resistance dating back to the nineteenth-century crusades of Elizabeth Packard.⁶

Beginnings. 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 psychotropic drug treatments, the widening legal conceptions of patients' rights, and the intellectual critiques associated with the antipsychiatry movement. Although those developments profoundly affected the status of people with serious me

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disorders, they were largely spearheaded by professionals—psychiatrists, lawyers, and academics—rather than ex-patients. The main advocacy organization in the field, the National Mental Health Association (NMHA), was founded by an ex-patient, Clifford Beers, but had long been dominated by its professional constituencies.⁷

Ex-patients' involvement. As of 1970, then, the claim to have special insight into mental disease by having actually experienced it was a novel assertion. It was on precisely these grounds that ex-patients, as individuals and in groups, began to assert a new entitlement to speak on their own behalf. This early survivor movement bore the imprint of 1960s radicalism. As Sally Clay, an early participant, recalled, its leaders "dressed like hippies and talk like militants." Movement historians usually cite the Oregon Insane Liberation Front, founded in late 1969 or early 1970, as the first consumer-run rights group for mental patients. Other groups soon followed in New York, Boston and San Francisco. With the founding in 1972 of the newsletter *Madness Network News*, the sense of a broader movement with common goals began to develop.⁸

Early counterculture ideology. The early survivor movement drew heavily from the intellectual traditions of the antipsychiatry movement, particularly the works of R.D. Laing and Thomas Szasz. In their speeches and writings patient activists portrayed madness not as an illness but as an alternative state of being, one that frightened and challenged the sane/straight community, much as feminism frightened male chauvinists and gay rights frightened homophobes. Inspired by other liberation movements of the 1960s and 1970s, including Black Power, women's liberation, and Gay Pride, they celebrated "mad pride," suggesting that the route to wholeness lay in accepting their uniqueness and changing society so that their differences could be accepted, rather than used as grounds for involuntary confinement and repressive "treatment" regimens.⁹

The 1970s survivor movement aimed not at influencing the mental health system but at developing a viable alternative. That spirit is illustrated in Judi Chamberlin's 1978 book, *On Our Own*, often referred to as the "bible" of the new empowerment philosophy. The key to improving the mental health system, Chamberlin argued in the book, was giving patients control over their own therapeutic fates. Unlike the orthodox mental health system, which fostered patients' compliance through taking medication and conforming to hospital regimens, consumer/survivor groups stressed measures designed to lead to recovery—that is, being able to live fully and independently. Participation was voluntary; service providers were chosen by clients and often included other ex-patients. Most important, clients helped determine all aspects of the organization's operation.¹⁰

Disagreements among activists. Chamberlin's book helped galvanize the creation of consumer/survivor groups both in the United States and elsewhere. By the late 1980s, sociologist Robert Emerick found more than a hundred such groups in existence. But although agreeing about the core principles of self-help and recovery, consumer/survivor groups immediately began to disagree over other issues. First, groups differed in their commitment to advocacy. Sixty percent of the groups Emerick surveyed took an outer-focused "social movement" approach, compared with 40 percent choosing a more inner-focused "individual therapy" approach. (Examples of the latter include Recovery, Inc. and Emotions, Anonymous.) Second, groups differed over the necessity to practice separatism—that is, to exclude mental health professionals and other non-consumer/survivors from their groups. Third, groups differed in the degree to which they rejected the medical model of mental disease and the value of therapeutic modalities. Finally, groups differed over whether consumers should be paid for their work with other consumers.¹¹

These differences were reflected in the national organizations created by consumer/survivor groups in the 1980s. The more radical National Association of Mental Patients (NAMP) preferred the term "survivor," with its overtones of the Holocaust, while the more moderate National Association of Mental Health Consumers (NAMHC) used the term "consumer," which suggested a greater willingness to work within the mainstream mental health system.¹²

Organization of families. The consumer movement became even more diverse in the late 1970s, as the families of people with mental disorders began to organize. In 1979, they formed the first branch of what would become the National Alliance on Mental Illness (NAMI), in Madison, Wisconsin. In the 1980s, NAMI grew quickly as an advocacy organization devoted to securing more funds for research into the biological origins of mental illness. Thus, the concept of "family" developed within the consumer movement over the legitimacy of families, as opposed to patients' perspectives.

treatment. These tensions carried over into the older mental health associations, which struggled to respond to b new strands of activism.¹³

Activists' Influence On Policy: Drivers Of Change

Until the late 1970s, activists had little direct impact on mental health policy deliberations, regardless of whether they called themselves consumers or survivors. Aside from a small number of "radical therapists," mental health professionals did not see the consumer/survivor movement as having a legitimate voice in policy making. Their encounters were usually hostile and confrontational, as symbolized by the picket lines organized by survivor groups at the APA's annual meetings starting in the early 19

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Deinstitutionalization and welfare policy. Yet larger changes were at work that gradually created more recepti to consumer/survivors' perspectives. The continued trend toward deinstitutionalization created pressing needs fo new forms of community-based support systems for people with severe and persistent mental disorders. The 197 expansion of welfare programs, including Social Security disability payments, provided them more such support t in the past. But lack of funding for and coordination between medical and social services left many consumer/survivors to fend for themselves. In this climate, self-help emerged as a strategy that was critical to consumer survival.¹⁴

Community support programs. As disillusionment with the latest round of reforms increased in the 1970s, consumer/survivor perspectives began to attract more policy interest. One of the first signs of this receptivity was inclusion of a consumer-survivor, Priscilla Allen, in the 1978 Carter Commission. An active, effective participant, Allen persisted in bringing the group's focus back to the needs of people with severe and persistent mental disabilities.¹⁵

An even more significant change came when the newly formed Community Support Program (CSP) of the Nation Institute of Mental Health (NIMH), charged with addressing the problems of deinstitutionalization, began in 1978 t invite patient activists to participate in its annual "Learning Conferences." Impressed by the ideas shared at these meetings, by 1984 the CSP had adopted "self-determination" and "consumer empowerment" as part of its missio addition to funding consumer-run programs, the CSP began to fund an annual "Alternatives Conference" to conv consumer/survivors to share ideas.¹⁶

Other advocacy groups. This greater receptivity paralleled the growing visibility of patient and consumer advoc groups more generally. Women's health, disability rights, and AIDS activists stressed common themes of questio medical authority, promoting self-determination, and resisting stereotypes. Thus, by the mid-1980s the consumer/survivor movement had peer groups in other areas of health care making arguments similar to their ov As the overall concept of patient responsibility expanded in this era, it became all the more difficult to deny the sa rights to those whose disabilities were mental, not physical. Moreover, the self-help approach championed by the consumer/survivor movement proved surprisingly compatible with the increasingly conservative political climate c the 1980s.¹⁷

Cost control and managed care. In more indirect ways, the growing debate about cost control and managed ca also stimulated greater attention to users' perspectives on health care. The need to control health care costs encouraged new kinds of cost-benefit analysis, in which spending was calibrated against effectiveness, in turn fostering closer scrutiny of the benefits that users derived from specific services.¹⁸

Signs Of Growing Influence

Planning councils. For all of these reasons, the idea of involving

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consumer/survivors in mental health policy making has steadily gained credibility over the past decade. One sign of their growing influence has been the expanding inclusion of consumer representation on the planning councils required by federal and state mental health laws. As Athena McLean has noted, a major accomplishment of patient activists was convincing policymakers that such planning bodies needed to have equal numbers of patient/consumers as well as family members. Thus, the 1986 State Comprehensive Mental Health Plan Act and the 1992 restructuring that created the Substance Abuse and Mental Health Services Administration (SAMHSA) made consumer parity a requirement for federal funding.¹⁹

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State mental health agencies. State and local mental health agencies have begun to solicit consumers' input in other ways. Faced with a continual struggle to cut costs while improving services, agencies have seen the value working with consumer advocates to make the most of their scarce dollars. By 1998, twenty-seven states had positions for consumers on their staffs. In addition, some public agencies have begun to hire consumers to be providers themselves, to run groups and assist with case management—a strategy that both provides supported employment for a person in recovery and is cost-effective, since consumers usually work for lower salaries than professional staff require.²⁰

Research initiatives. Consumer/survivors have also become involved in research initiatives, particularly those designed to evaluate treatment outcomes. Here again, pressure to rethink investments in specific treatment modalities has resulted in opportunities for consumers' input. The expansion of health systems research, quality assurance programs, and evidence-based medicine all focused greater attention on outcome measurement in health care in the 1990s. Initially, these initiatives were expert-driven and did not allow for the possibility that patients might define outcomes differently than health care professionals did. But consumer/survivors soon began to demand a greater role in developing the measures used to compare treatments, to ensure that outcomes they particularly valued, such as the ability to live independently or to hold a job, were included. Studies showing that inclusion of measures important to patients increased a program's likelihood of therapeutic success increased their leverage in this regard.²¹

Other signs of change. The past decade has seen a growing effort on the part of mental health professionals to understand consumer/survivors' perspectives on contentious issues such as involuntary commitment and medication side effects. To cite just a few signs of change: In 1994 *Psychiatric Services* began to publish a regular column featuring the perspectives of consumers and family members, and in 1997 SAMHSA sponsored a dialogue between psychiatrists and consumers that focused on the barriers to trust and communication that existed between them.

Educating providers. Focusing consumers' efforts on educating providers has emerged as one of the most promising avenues for development. As Alexander Young and colleagues noted in a 2005 study, a serious barrier to the use of available support services lies in mental health professionals' "negative attitudes toward rehabilitation mutual support" and tendency to "underestimate consumers' interest in collaborative treatment." In a study conducted in five large provider organizations, these researchers found that a consumer-led program, featuring educational outreach, technical assistance, and clinician-client dialogues, greatly improved the likelihood that patients received a wide range of supportive services.²³

Consumers' Current Networks Of Influence

Consumer/survivors' involvement in policy making has increased greatly over the past two decades. Yet to return to the questions posed earlier, it would seem that their networks of influence bear little resemblance to the institutional resources and influence commanded by the pharmaceutical or insurance industries. In the mental health field, as in other arenas of health care, consumers' interests tend to be the least

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well organized and most underfunded. Their input has been welcomed and acted on only to the extent that it serves the purposes of other, better-organized stakeholders.

Areas of conflict. Perhaps inevitably, the growing prominence of consumers in positions of influence has increased the amount of consumer-versus-consumer conflict. Nowadays it is possible to find self-identified consumer/survivor on every side of current debates in the mental health field. Asserting a position based on personal experience also has become less and less compelling, as illustrated in a 2002 exchange in *Psychiatric Services* in which both parties to an argument cited their own experiences in recovering from schizophrenia.²⁴

This diversity is complicated by consumer advocates' relationships to other stakeholders in the field. A case in point is the funding of consumer groups by drug companies. As such funding has increased in recent years, it has prompted growing ethical and political controversy throughout health care. Its impact on the mental health field is especially unsettling, given the field's long history of contentious debates about the role of medication in treatment. Arguments about the authenticity of consumers' perspectives are now complicated by accusations and counteraccusations about undue corporate influence.²⁵

Perhaps the sharpest point of controversy remains involuntary treatment. Some critics argue that the survivor wing of the movement has created such hostility to both medication and involuntary treatment that many people who might benefit from new drug regimens are left to suffer with devastating mental disorders. Their opponents respond by suggesting that an overemphasis on compulsory medication programs diverts funding away from more integrated approaches to recovery that require investment in housing, employment, and other social services.²⁶

Areas of agreement. For all these arguments, equally striking are the areas of agreement that have emerged in the mental health field. Working papers posted on Web sites of state mental health agencies and patient advocacy groups suggest substantial consensus around key ideas: that self-determination is a core principle of treatment; that treatment plans must be individualized to reflect patients' different states of "readiness" to pursue treatment; that integrated programs of community support, including housing, employment, and supportive peer groups, as well as medication, are essential to long-term recovery; and that cutbacks in public funding threaten disaster for the most vulnerable.²⁷

AS THIS HISTORY SUGGESTS, the growing influence of consumer/survivor perspectives has largely been a consequence, not a cause, of radical restructurings of the mental health field. One can easily imagine that the complicated array of economic and treatment issues surveyed in this volume of *Health Affairs* would have come about if no such movement had ever developed. Consumer/survivor perspectives entered policy discourse in the wake of policy failures and have flourished in a climate of perpetual crisis and tight budgets. Patient advocates have proved more effective in reshaping the criteria for what constitutes effective treatment: an integrated program of health and social services aimed at recovery and rehabilitation. They have had far less success in addressing the systemic problems in health care and welfare policies that stand in the way of such an integrated approach. In that failure, they are in good company, for no stakeholder group has been able effectively to address those problems.

Yet the more hopeful aspects of these debates need also to be acknowledged. Precisely because it has been a contested area for so long, the field of mental health has produced some refreshingly honest, insightful discussions of the problems inherent in patient empowerment. That initiative has had to contend with the jagged edges of change: a long tradition of mistrust between physicians and patients; a plethora of advocacy groups with very different philosophies and priorities; intense disagreements over treatment modalities; fiscal limitations on available resources; and the entrenched stigma that surrounds mental disease.

This process might best be described as policy innovation on the edge of desperation, by imperfect actors facing intensely frustrating circumstances. Out of these struggles have emerged some thoughtful and creative experiments in "patient-centered medicine" and "consumer-driven health care" that deserve wider notice within the health care field. In spite of being underfunded, divided among themselves, and subject to intense hostility and suspicion from other stakeholders, consumer/survivors have nonetheless succeeded in turning mental health care in more patient-centered directions.

Editor's Notes

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NOTES

1. For example, the "patient factor" is largely absent from the standard text on mental health policy, D. Mechanic, *Mental Health and Social Policy: The Emergence of Managed Care*, 4th ed. (Boston: Allyn and Bacon, 1999). Note: Because of space limitations, an extended bibliography is available online at <http://content.healthaffairs.org/cgi/content/full/25/3/720/DC1>.
2. U.S. Department of Health and Human Services, *Mental Health: A Report of the Surgeon General* (Washington: U.S. Government Printing Office, 1999), 92.
3. Institute of Medicine, *Crossing the Quality Chasm: A New Health System for the Twenty-first Century* (Washington: National Academies Press, 2001); and IOM, *Improving the Quality of Health Care for Mental and Substance-Use Conditions*, Quality Chasm Series (Washington: National Academies Press, 2006).
4. S.S. Sharfstein, "Response to the Presidential Address: Advocacy for Our Patients and Our Profession," *American Journal of Psychiatry* 162, no. 11 (2005): 2045–2047 (quotes on pp. 2045 and 2046). [Free Full Text] See also S. Satel, *PC, M.D.: How Political Correctness Is Corrupting Medicine* (New York: Basic Books, 2001), esp. chap. 2.
5. The distinction between "social movement" and "individual therapy" groups is developed by R. Emerick, "Self-Help Groups for Former Patients," *Hospital and Community Psychiatry* 41, no. 4 (1990): 401–407. [ISI] [Medline]
6. On the new health consumerism, see N. Tomes, "Patients or Health Care Consumers?" in *Public Health and Public Policy*, ed. R. Stevens, C. Rosenberg, and C. Burns (New Brunswick, N.J.: Rutgers University Press forthcoming), 83–110. On rights movements in health, see S.A. Halpern, "Medical Authority and the Cultural Rights," *Journal of Health Politics, Policy and Law* 29, nos. 4–5 (2004): 835–852. [Free Full Text] On Packard see B. Sapinsley, *The Private War of Mrs. Packard* (New York: Paragon House, 1991). On psychiatry's peculiar vulnerabilities to social criticism, see E. Brody, "Patients' Rights: A Cultural Challenge to Western Psychiatry," *American Journal of Psychiatry* 142, no. 1 (1985), 58–62. [Abstract]
7. See G.N. Grob, *From Asylum to Community* (Princeton, N.J.: Princeton University Press, 1991); and N. D. "Psychiatry and Anti-Psychiatry in the United States," in *Discovering the History of Psychiatry*, ed. M. Micale and R. Porter (New York: Oxford University Press, 1994), 415–444. On Beers and the NMHA, see N. Dair *Clifford W. Beers* (Pittsburgh: University of Pittsburgh Press, 1980).
8. S. Clay, "A Personal History of the Consumer Movement," 2002, <http://www.sallyclay.net/Z.text/history.htm> (accessed 14 February 2006). There is as yet no comprehensive history of the modern consumer/survivor movement. Useful short accounts include J. Chamberlin, "The Ex-Patients' Movement: Where We've Been and Where We're Going," *Journal of Mind and Behavior* 11, no. 3 (1990): 323–336 [ISI]; A.H. McLean, "From Ex-Patient Alternatives to Consumer Options: Consequences of Consumerism for Psychiatric Consumers and the Ex-Patient Movement," *International Journal of Health Services* 30, no. 4 (2000): 821–847 [CrossRef] [ISI] [Medline]; D. Moxley and C.T. Mowbray, "Consumers as Providers," in *Consumers as Providers in Psychiatric Rehabilitation*, ed. C.T. Mowbray et al. (Columbia, Md.: International Association of Psychosocial Rehabilitation, 1997), 2–34; and "Overview of Consumer and Family Movements," in DHHS, *Mental Health 92–97*. For parallel developments in Canada, see B. Everett, *A Fragile Revolution* (Waterloo, Ont.: Wilfrid Laurier University Press, 2000).
9. See S. Hirsch, ed., *The Madness Network News Reader* (San Francisco: Glide Publications, 1974).
10. J. Chamberlin, *On Our Own: Patient-Controlled Alternatives to the Mental Health System* (New York: Hawthorn Books, 1978).
11. These differences are enumerated in Emerick, "Self-Help Groups"; and M. O'Hagan, *Stopovers on My Way Home from Mars* (London: Survivors Speak Out, 1993), 31, 76.

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12. DHHS, *Mental Health*, 94.
13. For an overview of NAMI's history, see *ibid.*, 96. On the NMHA and its state affiliates, see McLean, "From Patient Alternatives," 831–832.
14. On the expansion of Great Society entitlement programs and their consequences, see G.N. Grob, "Public Policy and Mental Illnesses: Jimmy Carter's Presidential Commission on Mental Health," *Milbank Quarterly* 83, no. 3 (2005): 425–456[CrossRef][ISI][Medline]; H.H. Goldman and A.A. Gattozzi, "Balance of Powers: Social Security and the Mentally Disabled, 1980–1985," *Milbank Quarterly* 66, no. 3 (1988): 531–551[ISI][Medline]; and H. Goldman, "How Do You Pay Your Rent?" Social Policies and the President's Mental Health Commission," *Health Affairs* 22, no. 5 (2003): 65–72.[Abstract/Free Full Text]
15. On Allen's role in the 1978 commission, see G.N. Grob and H.H. Goldman, *The Dilemma of Federal Mental Health Policy: Radical Reform or Incremental Change* (New Brunswick: Rutgers University Press, forthcoming); and Grob, "Public Policy," 428. Chamberlin, "The Ex-Patients' Movement," 329, notes that activists "packed" the public hearings held by the commission panels.
16. See McLean, "From Ex-Patient Alternatives," 826–827, 832–834.
17. See C. Weisman, *Women's Health Care: Activist Traditions and Institutional Change* (Baltimore: Johns Hopkins University Press, 1998); S. Epstein, *Impure Science: AIDS, Activism, and the Politics of Knowledge* (Berkeley: University of California Press, 1998); and J.P. Shapiro, *No Pity: People with Disabilities Forging a New Civil Rights Movement* (New York: Times Books, 1993). On the consumer health movement generally see Tomes, "From Patient to Consumer"; and Halpern, "Medical Authority."
18. On the field's economic challenges, see Mechanic, *Mental Health and Social Policy*; and D. Mechanic and D.D. McAlpine, "Mission Unfulfilled: Potholes on the Road to Mental Health Parity," *Health Affairs* 18, no. 1 (1999): 7–21.[Abstract/Free Full Text]On the accountability movement more generally, see M. Millenson, *Demanding Medical Excellence* (Chicago: University of Chicago Press, 1997).
19. McLean, "From Ex-Patient Alternatives," 835. Like other Great Society legislation, the 1963 CMC Act had provision for citizen participation, which some family members used to participate in their deliberations. *Ibid.* 826.
20. J.L. Geller et al., "A National Survey of 'Consumer Empowerment' at the State Level," *Psychiatric Services* 49, no. 4 (1998): 498–503.[Abstract/Free Full Text]For an overview of consumer/provider issues, see Mox et al., eds., *Consumers as Providers*.
21. See DHHS, *Mental Health*, 95; J. Campbell, "How Consumers/Survivors Are Evaluating the Quality of Psychiatric Care," *Evaluation Review* 21, no. 3 (1997): 357–363[ISI][Medline]; and New York State Office of Mental Health, "Infusing Recovery-based Principles into Mental Health Services," September 2004, <http://www.omh.state.ny.us/omhweb/statewideplan/2005/appendix4.htm> (accessed 14 February 2006). Also see J.Z. Sadler and B. Fulford, "Should Patients and Their Families Contribute to the DSM-V Process?" *Psychiatric Services* 55, no. 2 (2004): 133–138[Abstract/Free Full Text]; and R.L. Spitzer, "Good Idea or Politically Correct Nonsense?" *Psychiatric Services* 55, no. 2 (2004): 113.[Free Full Text]
22. J.L. Geller, "First-Person Accounts in the Journal's Second Twenty-five Years," *Psychiatric Services* 51, no. 2 (2000): 713–716[Free Full Text]; and SAMHSA, "Consumers and Psychiatrists in Dialogue," proceedings conference held 24–25 July 1997, Crystal City, Virginia, <http://www.mentalhealth.samhsa.gov/publications/allpubs/OEL00-0009/default.asp> (accessed 14 February 2006).
23. A.S. Young et al., "Use of a Consumer-Led Intervention to Improve Provider Competencies," *Psychiatric Services* 56, no. 8 (2005): 967–975.[Abstract/Free Full Text]
24. D.B. Fisher and L. Ahern, "Evidence-based Practices and Recovery," *Psychiatric Services* 53, no. 5 (2002): 632–633.[Free Full Text]Also, see M. Gibson-Leek, "Client versus Client," *Psychiatric Services* 54, no. 8 (2003): 1101–1102.[Free Full Text]
25. A. Herxheimer, "Relationships between the Pharmaceutical Industry and Patients' Organisations," *British Medical Journal* 326, no. 7400 (2003): 1208–1210[Free Full Text]; "Industry Role in Medical Meeting Decried," *Washington Post*, 26 May 2002; and J. Drinkard, "Drugmakers Go Furthest to Sway Congress," *USA Today*, 4 April 2005.
26. See, for example, Fisher and Ahern, "Evidence-based Practices and Recovery"; E.F. Torrey, "Psychiatric Survivors or Non-Survivors," *Psychiatric Services* 48, no. 2 (1997): 143; and the letters in response, *Psychiatric Services* 48, no. 5 (1997): 601–605.[ISI][Medline]
27. See, for example, Michigan Department of Community Health, "Dialogue on Self-Determination and the Children's Waiver/Choice Voucher," 5 March 2003, http://www.michigan.gov/documents/PathwaysDialogue_70246_7.pdf (accessed 14 February 2006); and New York State Office of Mental Health, "Infusing Recovery-based Principles into Mental Health Services."

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