Exit and Voice in American Health Care

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Until the 1960s, the main way for patients to affect health care institutions was by choosing their doctors or hospitals or leaving those with which they were dissatisfied. They had few avenues to exert their voice to bring about change through complaints, politics, or other means. The balance between exit and voice shifted in the 1960s, as the women's health and disability rights movements brought about change by increased use of political voice and, to a lesser degree, by exit. With the growth of managed care since the 1980s, enrolled individuals have had fewer opportunities for exit and greater potential to exercise voice to influence managed care organizations. However, that potential has not yet been adequately realized. Current debates about consumer rights focus on appeals of decisions by managed care organizations to deny services. They generally ignore the role of members in organizational policy or governance. This Article explores the relation between exit and voice in American health care and its prospects for the future.

INTRODUCTION

Until recently, the American health care system was characterized by fee-for-service practice, uncoordinated medical providers, and a system of halfway markets and regulation.[1] Most individuals were covered by indemnity insurance. Patients who were insured were free to switch doctors, hospitals, and other health care providers when they were dissatisfied; but exiting did not necessarily allow them meaningful choices, nor did it prompt organizations to change. There also were few institutionalized opportunities to exercise voice. Most recipients of health care did not view themselves as consumers, had few incentives to express their voice, and remained unsure about where they should express their concerns.[2]

1. *See* Stuart H. Altman & Marc A. Rodwin, *Halfway Competitive Markets and Ineffective Regulation: The American Health Care System*, 13 J. HEALTH POL. POL'Y & L. 323, 324 (1988).

2. This Article applies the concepts of *exit* and *voice* developed in ALBERT O. HIRSCHMAN, EXIT, VOICE AND LOYALTY: RESPONSES TO DECLINE IN FIRMS, ORGANIZATIONS

Two significant consumer movements—the women's health movement and the disability rights movement—changed health care by strategic use of voice (complaints, protest, concerted political activity) and exit (choosing alternative providers). Both movements included individuals with long-term health concerns— a status or illness that allowed them to self-identify and organize to collectively express their voice and seek alternative providers.

In the last thirty years, government health policy has encouraged two principal changes: 1) increased market competition (including encouraging consumer choice as a means to make health care providers responsive) and 2) the growth of managed health care. These changes have altered the problems consumers face and their opportunities to use exit or voice.

Health care market competition has created a more dynamic and turbulent health care delivery system. It also has expanded the range of providers, the methods of treating illnesses, and the choices available to consumers. At the same time, the growth of managed care has restricted consumers to a set panel of providers, thereby reducing exit options. Managed care has also created protocols which restrict the clinical choices available to physicians. The result: exiting from one managed care organization (MCO) to another offers consumers fewer clinical choices than in a fee-for-service indemnity health insurance system. By coordinating care the MCO becomes the responsible party, making it a natural and appropriate target for complaints. There is greater potential for activating consumer voice against the MCO than against a cluster of independent and loosely coordinated hospitals and doctors.

AND STATES (1970). Hirschman contrasts the use of *exit* (leaving a firm or choosing an alternative product, a traditional market oriented approach) with *voice*, complaining or engaging in concerted activity, a traditional political approach. His book shows how the two choices interact and can yield different responses depending upon the circumstances. Hirschman's book has spawned a significant literature in social policy. For a summary of recent use of these concepts, see ALBERT O. HIRSCHMAN, *Exit and Voice: An Expanding Sphere of Influence, in* RIVAL VIEWS OF MARKET SOCIETY AND OTHER RECENT ESSAYS 77–101 (1986); R.B. Freeman et al., *Political Economy: Some Uses of the Exit-Voice Approach,* AM. ECON. ASS'N, May 1976, at 361, 386–89; Albert O. Hirschman, *Exit, Voice, and Loyalty: Further Reflections and a Survey of Recent Contributions,* 13 SOC. SCI. INFO. 7, 7–26 (1974), *reprinted in* 58 MILBANK MEM'L FUND Q. HEALTH & SOC'Y 430, 430–56 (1980). For commentary on the implications of the exit-voice concept, see Brian Barry, *Review Article: "Exit, Voice, and Loyalty,"* 4 BRIT. J. POL. SCI. 79, 79– 107 (1974); A.H. Birch, *Economic Models in Political Science: The Case of "Exit, Voice, and Loyalty,"* 5 BRIT. J. POL. SCI. 69, 69–82 (1975). For other discussions of exit and voice in American health care, see Rudolf Klein, *Models of Man and Models of Policy: Reflections on Exit, Voice, and Loyalty Ten Years Later,* 58 MILBANK MEM'L FUND Q. HEALTH & SOC'Y 416, 419 (1980) [hereinafter Klein, *Models of Man*]; Paul Starr, *Changing the Balance of Power in American Medicine,* 58 MILBANK MEM'L FUND Q. HEALTH & SOC'Y 166, 166–72 (1980) [hereinafter Starr, *Changing the Balance of Power*]; Carl M. Stevens, *Voice in Medical-Care Markets: Consumer Participation,* 13 SOC. SCI. INFO. 33, 33–48 (1974).

Until recently, health policy focused on increasing exit options for consumers in managed care. It promoted choice among MCOs and the use of report cards to help consumers compare them. As of the summer of 1999, however, interest is shifting toward enabling the complaint and appeals process and providing opportunities for consumers to express themselves.[3] President Clinton's Advisory Commission on Consumer Protection and Quality in Health Care proposed a right for individuals to have their appeals reviewed by neutral parties outside of the MCO. Several bills in Congress and current state laws would accomplish the same end.[4] Some writers also are interested in expanding consumer voice in MCO governance and operations.[5]

I. EXIT AND VOICE IN INDEMNITY INSURANCE

A. Some Choice

In the past, most Americans who had private health insurance were covered by indemnity insurance, and most doctors and hospitals were paid a fee for each service rendered.[6] Insurers would reimburse the insured for the cost of medical services, minus copayments and deductibles paid by the individual.

Doctors and hospitals, loosely constrained by minimal regulation, medical norms, and potential liability for negligence, decided what therapies to use. Doctors enjoyed enormous clinical freedom.[7] Numerous studies of how physicians practiced indicate wide variation in the basic approaches doctors used for common

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3.   *See* H.R. 358, 106th Cong. (1999). *But cf.* Patients' Bill of Rights Act of 1999, S. 1344, 106th Cong. (1999) (providing less favorable treatment of appeals for denial of services and other consumer issues than the House version).

4.   *See* KAREN POLLITZ ET AL., THE HENRY J. KAISER FAMILY FOUNDATION, EXTERNAL REVIEW OF HEALTH PLAN DECISIONS: AN OVERVIEW OF KEY PROGRAM FEATURES IN THE STATES AND MEDICARE 1 (1998).

5.   *See* MARC A. RODWIN, CONSUMER VOICE, PARTICIPATION, AND REPRESENTATION IN MANAGED HEALTH CARE 1 (Consumer Federation of America White Paper, 1998) (available at <http://www.spea.indiana.edu/mrodwin>) (on file with the *University of Michigan Journal of Law Reform*) [hereinafter RODWIN, CONSUMER VOICE].

6.   *See* 42 U.S.C. § 1396 (1993) (enabling Medicare and Medicaid). The public sector covered those over 65 years under Medicare and the very poor were covered by Medicaid.

7.   Since the late 1960s, private and public insurers have used utilization review programs, with limited success, to ferret out and deny payment for unnecessary medical services. *See generally* CONTROLLING COSTS AND CHANGING PATIENT CARE: THE ROLE OF UTILIZATION MANAGEMENT (Bradford H. Gray & Marilyn J. Fields eds., 1989) (providing an historical account and descriptive overview of utilization review programs).

conditions.[8] Insured individuals could choose their doctors and hospitals, subject to the willingness of doctors to treat them, the limitations of the market, state licensing laws, and medical etiquette. There were few rules, yet few meaningful alternatives.

From the 1930s until the 1960s, medicine was a seller's market. A shortage of doctors made it possible to give short shrift to patients' wishes and still maintain a secure source of patient revenue.[9] Patients' choices were also limited by information deficits, particularly disparities in knowledge between doctors and patients.[10] Added artificial restraints exacerbated this restraint on choice. Medical codes of ethics prohibited advertising professional fees and facilitated other anti-competitive practices. Hospital rate setting similarly constrained market restructuring, limiting new ways of organizing and delivering health services.[11]

In addition, scant published information was available about the relative effectiveness of many therapies. Patients usually relied on doctors to tell them what they needed. Aside from bedside manner and reputation, patients had little basis for the choice of one doctor over another. If a patient-doctor relationship turned sour, exit might be a good move, but patients rarely had much information about a new doctor, except by word of mouth. Patients had some choice, but it was not well-informed as they had little information to guide them.

B. Little Voice

Professional norms discouraged patient participation in medical decision making and limited patients' access to information. As a result of training and tradition, many physicians were paternalistic. They gave patients minimal information about medical risks or alternative approaches. Jay Katz's history of informed

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8.   This literature was spawned by the work of Wennberg and Gittelshon. *See* John E. Wennberg & A. Gittelshon, *Small Area Variations in Health Care Delivery*, 183 SCIENCE 1102, 1107 (1973) (describing Vermont's variations in health care delivery).

9.   *See generally* RASHI FEIN, THE DOCTOR SHORTAGE: AN ECONOMIC DIAGNOSIS (1967); Uwe E. Reinhardt, *Health Manpower Forecasting: The Case of Physician Supply, in* HEALTH SERVICES RESEARCH: KEY TO HEALTH POLICY (Eli Ginzberg ed., 1991) (outlining a theoretical model for forecasting physician supply and offering comments on historical statistical beliefs).

10.   *See* Kenneth J. Arrow, *Uncertainty and the Welfare Economics of Medical Care*, 53 AM. ECON. REV. 941, 964–65 (1963).

11.   *See generally* Altman & Rodwin, *supra* note 1.

consent aptly described this situation as "the silent world of doctor and patient."[12]

Not only were doctors silent, but patients had few opportunities to express their voice. Medical and social norms encouraged patients to play a passive, sick role and to depend on doctors, not to challenge them and risk straining the relationship.[13] Patients likewise lacked incentive to complain—if they disliked the doctor, they could switch to another.

If patients could not ask their doctor to change his or her behavior, to whom could they voice their concerns? There was no governmental authority to oversee the health care system. Patients could complain of egregious conduct to state licensing boards, but these boards had limited powers. Typically, licensing boards exercised their power only to revoke or suspend the licenses of doctors who had been convicted of criminal offenses or were impaired by alcohol or drug use.[14] Courts provided a forum for patients injured by medical malpractice, but this was a very limited and costly form of consumer voice.[15]

The organization of medical care also impeded consumers from expressing their voice. There was no entity responsible for coordinating or overseeing health care to which consumers could complain. The health care delivery system was fragmented, and for most patients and doctors there were no organizations like HMOs to oversee doctors or coordinate medical care. Hospitals exercised only minimal control by granting doctors admitting privileges.

Patients also were not organized. They faced health care choices as individuals. There was little in the way of institutions to amplify their voice or purchasing power. Patients generally did not see common quality problems stemming from the way medicine was organized, nor did they typically view themselves as consumers. When patients were dissatisfied, they generally attributed the problem to their doctor.

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12. *See generally* JAY KATZ, THE SILENT WORLD OF DOCTOR AND PATIENT (1984).

13. *See* Talcott Parsons, *The Sick Role and the Role of the Physician Reconsidered*, 53 MILBANK MEM'L FUND Q. HEALTH & SOC'Y 257, 266–71 (1975).

14. *See* ROBERT C. DERBYSHIRE, MEDICAL LICENSURE AND DISCIPLINE IN THE UNITED STATES 77–85 (1969); RANDOLPH P. REAVES, THE LAW OF PROFESSIONAL LICENSING AND CERTIFICATION 208–14, 225–30 (1984).

15. *See generally* PETER A. BELL & JEFFREY O'CONNELL, ACCIDENTAL JUSTICE: THE DILEMMAS OF TORT LAW (1997) (providing an overview of tort and medical malpractice law and policy); *see also* SYLVIA A. LAW & STEVEN POLAN, PAIN AND PROFIT: THE POLITICS OF MALPRACTICE (1978); PAUL C. WEILER ET AL., A MEASURE OF MALPRACTICE: MEDICAL INJURY, MALPRACTICE LITIGATION, AND PATIENT COMPENSATION (1993).

II. THE SEEDS OF CHANGE: THE WOMEN'S HEALTH AND DISABILITY RIGHTS MOVEMENTS

Exit and voice in medicine were transformed in the 1960s. Change came from social and protest movements outside of health care.[16] The civil rights movement of the 1960s brought a distrust of the discretionary authority and paternalism of the medical establishment, as well as of such institutions as government, religion, prison, and social work.[17] Disaffected groups wanted to participate in decision making. Two social movements in particular—the women's and disability rights movements[18]—focused attention on health issues and sought changes in the way medical personnel and institutions treated their members. Both movements combined voice and exit to advance their goals. They engaged in protest, politics, and publication to change the way professionals and the public thought about issues and their standard practices. They also created self-help groups and alternative institutions as a way to spur change and seek control.

A. The Women's Health Movement

Women's groups felt that many of their problems were improperly medicalized—women were not allowed to control their bodies and were denied autonomy, notably in birthing and abortion.[19]

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16.   For example, the Johnson administration's War on Poverty promoted "maximum feasible participation" by citizens affected by federal programs in projects of the Office of Economic Opportunity, especially community health centers. The aim was to make community action programs responsive to residents. Statutes creating Health Systems Agencies for health planning also relied on citizen/consumer participation. *See* National Health Planning and Resources Development Act of 1974, Pub. L. No. 98-641, 88 Stat. 2225, 2232–41 (1974); *see also* JAMES A. MORONE, THE DEMOCRATIC WISH: POPULAR PARTICIPATION AND THE LIMITS OF AMERICAN GOVERNMENT 264–65 (1990) (discussing community health centers) [hereinafter MORONE, THE DEMOCRATIC WISH]; DANIEL P. MOYNIHAN, MAXIMUM FEASIBLE MISUNDERSTANDING 185 (1969) (discussing the Model Cities Program).

17.   *See* DAVID J. ROTHMAN, STRANGERS AT THE BEDSIDE: A HISTORY OF HOW LAW AND BIOETHICS TRANSFORMED MEDICAL DECISION MAKING 98–100 (1991).

18.   Other factors also prompted change. There was a movement for patients' rights, which used courts to change health care law and policy, and the growth of medical consumerism. *See, e.g.,* Canterbury v. Spence, 464 F.2d 772 (D.C. Cir. 1972); Superintendent of Belchertown State Sch. v. Saikewicz, 370 N.E.2d 417 (Mass. 1977); *In re* Karen Quinlan, 355 A.2d 647 (N.J. 1976). For a review of patients' rights abuses, see George J. Annas, *The Hospital: A Human Rights Wasteland,* CIVIL LIBERTIES REV., Fall 1974, at 9–29.

19.   *See* THE BOSTON WOMEN'S HEALTH BOOK COLLECTIVE, OUR BODIES, OURSELVES 138, 157 (1973).

Women's health groups complained that physicians spoke conde-scendingly to women and treated them as incapable of understanding information or participating in medical care deci-sions.[20] The result, they said, was poor care provided in a demeaning manner, which often reduced rather than improved the quality of women's lives.

Women's groups wanted to change medical practice.[21] In articles and books they showed that medicalization forced women into a "sick" role, with many unnecessary or even harmful medical proce-dures performed routinely.[22] Critiques of medical textbooks blasted sexist images and statements.[23] Women's groups used the media to criticize standard practices and clinical choices, and to suggest al-ternative treatments.[24] One of the most influential books was *Our Bodies, Ourselves,* published by the Boston Women's Health Collec-tive, a focal point for women's health organizing. An alternative guide to health care and a critique of medical practice, the book offered information on medical issues as an alternative and sup-plement to that of traditional medical care. Eventually the views of protesters became part of the discourse in such mainstream publi-cations as *McCall's.*[25]

The critique of medicine by the women's health movement changed popular perceptions and even the standard practices of medicine. For example, the Boston Women's Health Collective worked with medical schools to change gynecological training and to show medical students how to perform pelvic exams in a sensi-tive manner.[26] Women's groups' use of voice was complemented by

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20.   *See* Mary Lynn M. Luy, *What's Behind Women's Wrath Toward Gynecologists,* 42 MOD. MED. 17, 18–19 (1974).

21.   *See generally* Catherine Kohler Riessman, *Women and Medicalization: A New Perspective,* SOC. POL'Y, Summer 1983, at 3.

22.   *See* BEATRICE S. LEVIN, WOMEN & MEDICINE 1–2 (1980) (noting how prescribing estrogen and D.E.S. to women caused serious problems with little or no medical benefits, and how prescription of those drugs continues); Mary Ann Elston, *Medicine as 'Old Husbands' Tales': The Impact of Feminism, in* MEN'S STUDIES MODIFIED: THE IMPACT OF FEMINISM ON THE ACADEMIC DISCIPLINES 192, 195 (Dale Spender ed., 1981) (describing why the health movement was important to women in the United Kingdom and citing as an analogous analysis of the women's health movement in the United States BARBARA EHRENREICH & DEIRDRE ENGLISH, COMPLAINTS AND DISORDERS: THE SEXUAL POLITICS OF SICKNESS (1973)).

23.   *See* THE BOSTON WOMEN'S HEALTH COLLECTIVE, *supra* note 19, at 22–23.

24.   *See generally* SHERYL B. RUZEK, THE WOMEN'S HEALTH MOVEMENT: FEMINIST AL-TERNATIVES TO MEDICAL CONTROL (1978).

25.   *See* Judy Klemesrud, *Why Women Are Losing Faith in Their Doctors,* McCALL'S, June 1973, at 76 *passim* (detailing the condescending attitudes of the gynecological profession and observing changing attitudes in and outside the profession).

26.   *See* Susan Bell, *Political Gynecology: Gynecological Imperialism and the Politics of Self-Help,* SCI. FOR PEOPLE, Sept.–Oct. 1979, at 8.

the creation of alternatives and the possibility of exit, as Women's groups offered competing services and institutions. For example, the Los Angeles Feminist Women's Health Center started as a self-help group and became a significant alternative care institution.[27] Some women's groups also evaluated doctors and hospitals, circulating lists of those to avoid and those they recommended. Other groups created networks of alternative providers. In Chicago, a group called "Jane" organized an underground network that provided access to abortion before the procedure became a constitutional right in 1973.[28] By 1981 there were approximately 100 women's health centers in the United States.[29] Women's groups created classes and services on alternative approaches to birth, including home birth and midwifery.

Some groups argued that women themselves, with the support of nurses, midwives, and lay personnel, could address many health care concerns. Catherine Kohler Reissman suggested increasing lay women's control over their health outside of traditional medical care institutions.[30] Many women's groups advocated the use of midwives. Women's groups preferred this alternative to hospital birthing, where they saw women placed in a passive role by doctors who controlled timing and process and frequently performed inappropriate cesarean section deliveries.[31]

In the wake of the women's health movement, medical providers catered more to women. Some hospitals sought to capture part of the alternative market by changing their standard practices. They offered home-like birthing rooms and a birthing process more responsive to women's concerns.[32] HMOs began marketing birthing centers, albeit in hospitals. For example, the Marketing Women's

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27.   *See* RUZEK, *supra* note 24, at 169–72.

28.   *See id.* at 25; "Jane," *Just Call "Jane", in* FROM ABORTION TO REPRODUCTIVE FREEDOM: TRANSFORMING A MOVEMENT 93, 93–94 (Marlene G. Fried ed., 1990); Lindsy Van Gelder, *The Jane Collective: Seizing Control,* Ms., Sept.–Oct. 1991, at 83.

29.   *See* Mary K. Zimmerman, *The Woman's Health Movement: A Critique of Medical Enterprise and the Position of Women, in* ANALYZING GENDER: A HANDBOOK OF SOCIAL SCIENCE RESEARCH 442, 460 (Myra Marx Ferree & Bess B. Hess eds., 1983).

30.   *See* Riessman, *supra* note 21, at 16–17.

31.   *See generally* THE AMERICAN WAY OF BIRTH (Pamela S. Eakins ed., 1980); Carol Sakala, *Medically Unnecessary Cesarean Section Births: Introduction to a Symposium,* 37 SOC. SCI. & MED. 1177, 1177, 1180–81, 1183 (1993).

32.   *See* RUTHIE H. DEARLING ET AL., MARKETING WOMEN'S HEALTH CARE 58 (1987) (examining established marketing theories and modifying them to provide guidelines for specifically marketing women's health care programs); Nancy Worcester & Mariamne H. Whatley, *The Response of the Health Care System to the Women's Health Movement: The Selling of Women's Health Centers, in* FEMINISM WITHIN THE SCIENCE AND HEALTH CARE PROFESSIONS: OVERCOMING RESISTANCE (Sue V. Rosser ed., 1988) (analyzing the increased marketing of women's health care centers and elaborating on the necessity for centers meeting the needs of all women).

Health Care report stated that "catering to the maternity market segment is critical to patient acquisition, not only for the maternity department, but for other health services as well."[33]

B. The Disability Rights Movement

Society has long stigmatized people with disabilities, warehoused them in institutions, made them dependent upon service providers, discriminated against them in employment, and hampered their access to public buildings and other facilities.[34] People with disabilities felt marginalized and treated as second class citizens. Starting in the 1960s, they protested, organized politically, and sought civil rights.

People with disabilities objected to the way medical and other professionals treated them. Professionals and custodians, they felt, neglected their interests and concerns, particularly those involving quality of life.[35] Disabled individuals confined to institutions were restricted from living independent lives because of both their immobility and their dependence on the schedules and goodwill of professionals. Even when they lived outside of institutions, professionals still exercised control over important aspects of their

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33.   DEARLING ET AL., *supra* note 32, at 58.

34.   For a review of disability policy in the United States, see EDWARD D. BERKOWITZ, DISABLED POLICY: AMERICA'S PROGRAMS FOR THE HANDICAPPED (1987) (proposing that disability policy move away from income maintenance and toward societal integration to end the disabled's stigmatization as helpless); DEBORAH A. STONE, THE DISABLED STATE (1984) (adhering to the view that disability is a socially recognized category, rather than an attribute of individuals, that carries with it social stigma and political privilege). *See generally* MILBANK Q. (Supp. 2 1989) (containing a variety of articles discussing disability policy intended to restore socioeconomic independence).

For a history of the disability rights movement, see generally GARY L. ALBRECHT, THE DISABILITY BUSINESS: REHABILITATION IN AMERICA (1992) (relating how the development of social legislation and advanced capitalism jointly address concerns of persons with disabilities); RICHARD K. SCOTCH, FROM GOOD WILL TO CIVIL RIGHTS: TRANSFORMING FEDERAL DISABILITY POLICY (1984) [hereinafter SCOTCH, TRANSFORMING DISABILITY POLICY] (discussing how section 504 of the Rehabilitation Act of 1973 transformed federal policy for individuals with disabilities by extending them civil rights, beginning with guaranteed access to federally-funded programs and facilities); JOSEPH P. SHAPIRO, NO PITY: PEOPLE WITH DISABILITIES FORGING A NEW CIVIL RIGHTS MOVEMENT (1993) (describing how the myths, fears, and stereotypes of society make having a disability more difficult, and that the new thinking of those with disabilities is that there is no pity or tragedy in their disability); Richard K. Scotch, *Disability as the Basis for a Social Movement: Advocacy and the Politics of Definition*, 44 J. SOC. ISSUES 159, 159–72 (1988) [hereinafter Scotch, *Disability as the Basis for a Social Movement*].

35.   *See* Telephone Interview with Victor Willi, Executive Director, Center for Independent Living of Toronto (Mar. 22, 1994) (on file with author).

clients' lives.[36] Specifically, medical professionals assumed that they should decide what services people with disabilities needed and the best way in which to provide them.[37]

Not surprisingly, people with disabilities sought more control over their lives, their medical treatments, and their service providers. They challenged the presumptions that they were sick or infantile, and that they were incapable of making choices themselves.[38] Disability rights advocates argued that it was important to treat people with disabilities as normal, to let them make their own decisions, and to give them the dignity of risk.[39] They maintained that professionals, like personal care attendants, should work under the direction of disabled people and allow them to set their own goals and agenda.

To address these problems, disability rights activists used voice and sought exit options. Some activists engaged in publicized political protests, such as staging sit-ins at the Department of Health and Human Services.[40] Others lobbied for legislation that would make public facilities accessible. Still others used lawsuits to enforce anti-discrimination statutes.[41] A theme of these protests was that people with disabilities should be able to leave medical and other institutions that provide services. However, there were no satisfactory alternatives available. It took voice to create exit options.

People with disabilities formed self-help groups and independent living centers.[42] These centers provided social support, helped

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36.   *See* ALBRECHT, *supra* note 34, at 128; SCOTCH, TRANSFORMING DISABILITY POLICY, *supra* note 34, at 28.

37.   *See* Interview with Victor Willi, *supra* note 35.

38.   For a discussion of how people with disabilities were segregated and warehoused, see *City of Cleburne v. Cleburne Living Center, Inc.*, 473 U.S. 432 (1985).

39.   *See* Irving K. Zola, *Toward the Necessary Universalizing of a Disability Policy*, 67 MILBANK Q. 401 *passim* (1989).

40.   *See generally* RICHARD BRYANT TREANOR, WE OVERCAME: THE STORY OF CIVIL RIGHTS FOR DISABLED PEOPLE (1993).

41.   *See, e.g.*, Olmsted v. L.C. *ex rel.* Zimring, 527 U.S. 581 (1999) (mentally disabled patients brought action against state challenging confinement in a segregated environment); Albertson, Inc. v. Kirkingburg, 527 U.S. 555 (1999) (former employee, fired from his job as a truck driver after failing to meet the Department of Transportation's basic vision standards and not rehired even after obtaining a waiver of the same standards, brought action against employer); Bragdon v. Abbott, 524 U.S. 624 (1998) (HIV-positive patient sued her dentist under the Americans with Disabilities Act (ADA) for refusing to treat her); Pennsylvania Dept. of Corrections v. Yeskey, 524 U.S. 206 (1998) (state prison inmate sued the Department of Corrections under the ADA for denying him admission to a prison boot camp program due to a history of hypertension).

42.   *See* Scotch, *Disability as the Basis for a Social Movement*, *supra* note 34, at 169. Independent living allows people with disabilities to control their lives rather than rely on professionals to provide services and supervision. It breaks relations of dependency and facilitates living outside of institutions: in communities, in families, or as individuals.

political organization, and created a community.[43] They varied in style and approach, but typically people with disabilities provided the organizational leadership and performed many of the services.[44] The centers offered counseling, informal networks and information, and various forms of social support.[45]

Attitudinal change also fostered voice. Rather than apologize for being different and trying to conform, many disabled people began to celebrate their differences and wanted society to change its attitudes and responses.[46] This new voice was exercised in the health care arena as people with disabilities sought to explain their lives, aspirations, and problems, rather than have professionals speak for them. This expressive aspect was partly geared toward political change, and partly toward an effort to assert humanity, individuality, and community that had long been dormant. This new attitude also manifested itself in people who demanded that employers and institutions make accommodations to meet their needs instead of trying to adapt on their own to institutions.

C. *The Two Movements in Perspective*

The women's health and the disability rights movements were social movements with easily identified and organized constituencies. Women were united by their gender. People with disabilities had long-term health care concerns but did not want to be treated as patients or to have their problems reduced to medicine. Each movement had political organizations in place to promote its health care agenda.

Neither women's groups nor disabilities rights activists viewed themselves primarily as patients or consumers, yet both used consumer-oriented strategies to complement their political organizing. The women's health movement was effective in part because doctors and hospitals responded to its concerns in an

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43.   *See* NANCY CREWE & IRVING K. ZOLA, INDEPENDENT LIVING FOR PHYSICALLY DIS-
ABLED PEOPLE 43–44 (1983); Irving K. Zola, *The Politicization of the Self-Help Movement,* SOC.
POL'Y, Fall 1987, at 32, 32–33.

44.   *See generally* Irving K. Zola, *The Evolution of the Boston Self-Help Center, in* A WAY OF
LIFE FOR THE HANDICAPPED 143 (Glenys Jones & Norman Tutt eds., 1987).

45.   *See id.*

46.   Many of the deaf, for example, speak of a deaf community and culture and rejoice
in their own language. *See* OLIVER W. SACHS, SEEING VOICES: A JOURNEY INTO THE WORLD
OF THE DEAF 122–23 (1989). Some have resisted efforts to have deaf people speak or lip
read and favor American Sign Language over Sign English, which follows the syntax of Eng-
lish.

effort to compete and increase their business. Women's groups used markets by providing medical care information to women, by rating and referring to selected doctors, and by providing alternatives to traditional medical care. The disabilities rights movement promoted the idea that people with disabilities should not have to rely on the judgment and choices of professionals but instead should make decisions on their own. This approach often drew on market and consumer approaches.

Both the women's and disability rights movements played a central role in fostering medical consumerism. They championed the idea that individuals seeking medical care were not always passive patients but could make choices if given information. They also claimed that medical consumers had the right to make demands and set their own standards. They served as a model for a wide array of consumer health groups. Activists thought that if consumers had a greater say in medical care, the health care system would function better.

Although many of their concerns were focused on issues unique to their own situations, both groups pressed for reforms that affected all medical consumers. They sought to wrest decision making authority from medical professionals and medical organizations. They demonstrated that groups receiving services could be a force for change if they were able to challenge authority collectively and use exit options. Their strengths also illustrated the difficulties most medical consumers faced. Most consumers are less able to predict their illnesses and have less need of medical services. They have difficulty identifying key concerns and little reason to become interested in medical issues. They thus lack a rallying point to exercise effective voice or organized exit.

The concern with increasing the voice of medical consumers, in part, prompted the idea in the late 1960s that consumers should be represented in local health planning agencies, whose purpose was to ration the use of regional resources and to control health care spending. Federal legislation mandated consumer representation on health system agencies, a major governmental effort to promote consumer voice.[47] However, the health planning process proved only partially effective in restraining health spending for several reasons.[48] First, local health planning boards did not control

47. *See* VICTOR G. RODWIN, THE HEALTH PLANNING PREDICAMENT: FRANCE, QUEBEC, ENGLAND, AND THE UNITED STATES 190–91 (1984) (discussing the 1974 Health Planning and Resources Act).

48. *See id.* at 192 (arguing that U.S. health planners and policymakers were unable to control the costs of health programs and services during the 20-year growth period from the mid-1960s to the mid-1980s).

funds.[49] Also, it proved easy for hospitals or groups wanting to build facilities to mobilize opposition that overrode the health planning agencies.[50] Finally, consumers were not as effectively organized as provider groups.

By the end of the 1970s, many questioned the effectiveness of health planning agencies, and the idea that consumer voice would be a force for positive change in health policy. The Reagan administration finally pulled the plug on federal health planning in favor of encouraging markets in health care. However, consumer voice in planning had enduring contributions. It helped change the political agenda and wrested authority from medical professionals. Ironically, it also shifted authority from the medical profession to bureaucracies and organizations.[51] The stage was set for changes in the way our health care system operated.

III. EXIT, VOICE, AND MANAGED CARE

Fast forward to the late 1990s. The American health care system has changed and so has the use of exit and voice. Managed health care, once labeled an alternative delivery system, has become the norm: it has largely replaced indemnity insurance and fee-for-service practice. While indemnity insurance still exists, it is usually as managed indemnity insurance, a variation of managed care.

Managed care health plans receive a fixed premium and are responsible for providing all necessary medical services.[52] Unlike indemnity insurers of the past, MCOs have tools to control medical expenditures and incentives to use them. The control occurs in several ways. Often a primary care physician must authorize referrals to specialists or hospitals and has financial incentives to keep costs down because he shares part of the cost of referrals. MCOs also review and can veto elective surgery, expensive medical procedures, and referrals to specialists (so-called utilization review). Most MCOs restrict patients to a closed panel of doctors and hospitals or make patients pay higher co-payments if they use medical

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49.   *See id.* at 194.

50.   *See id.*

51.   *See generally* MORONE, THE DEMOCRATIC WISH, *supra* note 16 (studying attempts to foster participatory democracy in American history).

52.   These changes have altered financing outside of MCOs as well. For example, hospitals are now paid prospectively by Medicare, rather than per diem or fee-for-service, a change that turned hospitals, once profit-centers, into cost-centers. *See generally* Bruce C. Vladeck, *Medicare Hospital Payments by Diagnosis-Related Groups*, 100 ANNALS INTERNAL MED. 576 (1984) (describing the Medicare payment system).

services outside the network. MCOs also use selective contracting to obtain lower rates from hospitals and doctors and typically share with them the financial risk of providing the services.

While patients are vulnerable to poor care in any setting, MCOs pose two new problems. Their fixed premium per patient and control over what health services are offered create an incentive to reduce services, an incentive they frequently pass along to physicians. MCOs exercise control over physicians' clinical choices through medical protocols and utilization review, reducing the choices available to doctors and patients. When the organization performs well, this control can improve the health care of patients. However, the opposite also can occur.[53]

Public policy has also changed. Health policy now might be characterized as halfway managed competition. It relies on exit as a way to control costs and hold MCOs accountable, although it does not go as far as proponents of managed competition would like.[54] Alain Enthoven and others introduced their theory of managed competition over twenty years ago.[55] Enthoven's key idea is that the best way to control health care spending and increase the availability and quality of services is to give consumers a choice among competing MCOs. He acknowledges a need for oversight by purchasers, government, or quasi-public "sponsors" to encourage competition over price, quality, and service. And he would limit consumer choice to standardized benefit packages to allow for easier price and service comparisons. But, for Enthoven, the engines driving change are financial incentives for individuals to shop for a health plan that offers the best value. If the performance of an organization declines, its customers or members will become

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53.   *See* MARC A. RODWIN, MEDICINE, MONEY AND MORALS: PHYSICIANS' CONFLICTS OF INTEREST 215 (1993).

54.   *See* Alain C. Enthoven, *The History and Principles of Managed Competition,* HEALTH AFF., Supp. 1993, at 24, 27–32 [hereinafter Enthoven, *History and Principles*] (arguing that true managed competition occurs where a sponsor offers a menu of many health plans, not at the individual provider level, because among other things, sponsors can manage enrollment and create price-elastic demand).

55.   *See* ALAIN C. ENTHOVEN, HEALTH PLAN: THE ONLY PRACTICAL SOLUTION TO THE SOARING COST OF MEDICAL CARE (1980); Alain C. Enthoven, *Consumer-Choice Health Plan: A National-Health-Insurance Proposal Based on Regulated Competition in the Private Sector,* 298 NEW ENG. J. MED. 650, 653 (1978); Alain C. Enthoven, *History and Principles, supra* note 54, at 28; Alain C. Enthoven, *Managed Competition in Health Care and the Unfinished Agenda,* HEALTH CARE FINANCING REV., Supp. 1986, at 105; Alain C. Enthoven & Richard Kronick, *A Consumer-Choice Health Plan for the 1990s: Universal Health Insurance in a System Designed to Promote Quality and Economy* (pts. 1 & 2), 320 NEW ENG. J. MED. 29, 29–37 (1989); Alain C. Enthoven & Sara J. Singer, *Markets and Collective Action in Regulating Managed Care,* HEALTH AFF., Nov.–Dec. 1997, at 26.

dissatisfied, and their defections to competitors will signal the firm to clean up its act.

The Health Maintenance Organization (HMO) Act of 1973[56] requires an annual period of HMO open enrollment to allow consumers to change providers, although it does not require consumer voice. Federal antitrust law promotes consumer opportunities for switching providers as a desirable goal. Health care researchers focus on how consumers choose among competing MCOs and what kinds of information consumers want and need to make effective choices.[57] Consumer groups and others rate MCOs and issue report cards to facilitate consumer choices.[58] What does such choice entail? Exiting from one managed care organization to another.

Private employers typically allow employees to switch health care insurance plans on an annual basis. The Federal Employees Health Benefits Program (FEHBP) also allows employees to switch, by permitting them to choose among more than 400 health insurance plans meeting minimum standards.[59] The new MCOs also foster more choice. The fastest growing types of managed care—independent practice associations, preferred provider plans, and point-of-service plans—allow consumers to opt out of the preferred list of providers if they shoulder greater co-payments. These models represent a change from the traditional HMOs that limit services to their own staff physicians.

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56.   42 U.S.C. § 300e (1994).

57.   *See* Kyle L. Grazier et al., *Factors Affecting Choice of Health Care Plans*, 20 HEALTH SERV. RES. 659, 662 (1986); Michael S. Klinkman, *The Process of Choice of Health Care Plan and Provider: Development of an Integrated Analytic Framework*, 48 MED. CARE REV. 295, 295 (1991); David Mechanic, *Consumer Choice Among Health Insurance Options*, HEALTH AFF., Spring 1989, at 138, 139–40; David Mechanic et al., *Choosing Among Health Insurance Options: A Study of New Employees*, 27 INQUIRY 14, 14 (1990); Shoshanna Sofaer & Margo-Lea Hurwicz, *When Medical Group and HMO Part Company: Disenrollment Decisions in Medicare HMOs*, 31 MED. CARE 808, 820 (1993). For a summary of law promoting disclosure of information to facilitate consumer choice, see William M. Sage & David Anderson, *Health Care Disclosure Requirements, in* HEALTH LAW HANDBOOK 185, 185–205 (Alice Gosfield ed., 1997).

58.   *See* Arnold Epstein, *Performance Reports on Quality—Prototypes, Problems, and Prospects*, 333 NEW ENG. J. MED. 57, 57–58 (1995); Rita Rubin, *Rating the HMOs*, U.S. NEWS & WORLD REP., Sept. 2, 1996, at 52, 52–63.

59.   *See* WALTON FRANCIS, CHECKBOOK'S GUIDE TO 1995 HEALTH INSURANCE PLANS FOR FEDERAL EMPLOYEES 4 (1994).

A. The Limits of Exit

Policy favoring exit is one thing; market reality is another. Will consumers switch to a competing health plan they prefer? Will they have genuine alternatives? Most firms—particularly small and mid-sized ones—offer little choice. In 1996, fifty-two percent of mid-sized firms offered workers only one plan and only twenty-four percent offered three or more.[60] Also, most employer-sponsored insurance plans only allow employees to switch once a year. The poor have few exit options.[61] Some state Medicaid programs lock beneficiaries into a managed care plan, generally the one with the lowest premium. Current law allows Medicare beneficiaries to leave HMOs with thirty days notice, but proposed legislation would limit changing plans to once a year.[62]

Clearly a powerful tool for change, exit is limited as an option or in its effect because of unusual features of medical markets. Ownership of MCOs and hospitals is becoming concentrated. If, as some analysts predict, a few oligopolies soon dominate the market, they may become complacent about the risk of losing market share and less responsive to consumer switching.[63] Albert Hirschman also warns about what he calls "lazy monopoly" or collusive behavior.[64] A firm in a restricted market may choose to be rid of its difficult customers rather than change its behavior. Dissatisfied customers will only be able to switch to an equally unresponsive competitor if a problem is endemic among all rival health plans. Most perverse of all, MCOs may prefer to lose subscribers with high-cost illnesses because, due to fixed premiums, their exit is the organization's gain. Under these circumstances, the threat of exit will not encourage improved performance.

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60.   *See* Telephone Interview with John Gable, Co-Director of Health Care National Consulting, Center for Survey Research (Apr. 19, 1998) (describing the KPMG Peat Marwick publication of *Health Benefits in 1996*) (on file with author).

61.   *See* Shelley I. White-Means, *Consumer Information, Insurance, and Doctor Shopping: The Elderly Consumer's Perspective*, 23 J. CONSUMER AFF. 45, 45 (1989).

62.   *See* H.R. 2491, 103d Cong., ch. 1, § 8001, pt. C, § 1851(e)(3) (1993). There are sound reasons for this policy. If people can switch between plans at will, they may first opt for a low-cost plan with limited benefits until they need a service and then jump to a high-cost plan that provides it. But if the premium rates of different plans reflect the health of their subscribers, the market will reward plans that are good at avoiding sick people, rather than plans that are good at treating them.

63.   *See* PAUL STARR, THE SOCIAL TRANSFORMATION OF AMERICAN MEDICINE 429, 442 (1982); Richard Kronick et al., *The Marketplace in Health Care Reform: The Demographic Limitations of Managed Competition*, 328 NEW ENG. J. MED. 148, 149 (1993).

64.   *See* ALBERT O. HIRSCHMAN, EXIT, VOICE, AND LOYALTY 57–60 (1970).

MCOs intentionally give consumers fewer exit options than traditional insurance.[65] They restrict patient choice of doctors and other providers to a closed network or offer patients significant financial incentives to use preferred providers. Even when available, exit often has limited value. Switching physicians within a plan may amount to no choice among clinical alternatives because MCOs regulate the clinical decisions of all their physicians through financial incentives and organizational rules.

Switching to another provider, in or out of a plan, may also mean severing an established patient-physician relationship. Exit is especially difficult for patients with chronic or complex conditions that require coordination among medical personnel or particular knowledge of the case. Especially for the sick and the frail, shopping for medical care may be physically and emotionally difficult.[66] Exit in medical care is most useful as a last resort. If a managed care organization's performance is mediocre but not bad enough to make consumers willing to leave, patients may simply endure lower quality.

Exit is a crude tool because managed care is a bundle of varied medical services, medical providers, and health insurance. Consider a family of three, each with different medical problems: the father with a cardiac problem, the mother with breast cancer, and the child with asthma. Suppose that the family must choose among three MCOs, each of which is strong in only one area of medical care that the family needs.[67] Which MCO should the family choose?

B. Consumer Voice as External Influences on Managed Care Organizations

After some health maintenance organizations cut hospital maternity stays to a maximum of twenty-four hours as a cost saving measure, the caption of one editorial cartoon read "HMOs: Heaving Mom Out" with an image of a mother in a catapult hospital bed.[68] Then the press learned that MCOs had contract clauses,

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65.   *See* Marc. A. Rodwin, *Conflicts in Managed Care,* 332 NEW ENG. J. MED. 604, 605 (1995).
66.   *See* Judith H. Hibbard & Edward C. Weeks, *Consumerism in Health Care: Prevalence and Predictors,* 25 MED. CARE 1019, 1028 (1987).
67.   *See* Klein, *Models of Man, supra* note 2, at 416–29 (1980).
68.   *See* Dan Wasserman, THE BOSTON GLOBE, Oct. 26, 1995 (on file with author). For an analysis and data on why shorter maternity stays save very little money, see Ming Tai-Seale et al., *Drive-Through Delivery: Where Are the "Savings"?,* 56 MED. CARE RES. & REV. 30, 30–46 (1999).

dubbed "gag rules," that barred doctors from making critical comments about the organization to their patients, discussing un-authorized treatment options, or disclosing how they were paid. On its cover *Time* magazine pictured a doctor gagged with a surgical mask.[69]

Market theory suggests that if enough consumers had wanted longer maternity stays than were standard, at least some MCOs would have catered to their wishes to lure them away from competitors. That did not happen. However, federal and state legislators, Republicans as well as Democrats, fell over each other to deliver what the market did not.[70] As of 1995, sixteen states established standards for maternity length of hospital.[71] Similarly, by 1995 fifteen states had prohibited gag clauses[72] and in 1996 Congress considered legislation that would have outlawed them entirely.[73]

However, legislatures do not always respond to consumers. Producers are generally better organized and have concentrated interests and resources, and legislatures respond to them more frequently. Much recent consumer protection legislation regulating managed care has been successful because consumer groups

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69.   *See* TIME, Jan. 22, 1996, at cover. There is controversy over what constitutes a "gag clause" or whether they exist. A General Accounting Office report found no gag clauses in contracts it reviewed. *See* GENERAL ACCOUNTING OFFICE, PUB. No. HEHS-97-175, MANAGED CARE: EXPLICIT GAG CLAUSES NOT FOUND IN HMO CONTRACTS, BUT PHYSICIAN CONCERNS (1997). However, there were many other clauses that may chill voice, and much turns on how one defines a gag clause. HMO industry leaders cite the GAO report as evidence that the press made up the controversy about gag clauses without any evidence. *See also* Karen M. Ignagni, *Covering a Breaking Revolution: The Media and Managed Care*, HEALTH AFF., Jan.–Feb. 1998, at 26, 28–29. Prior to the controversy, however, several MCOs told doctors not to tell patients about treatment options before the utilization review committee authorized them, *see* MOLINA MEDICAL CARE CENTER PROVIDER CARE MANUAL, KNOX-KEENE LICENSE APPLI-CATION exhibit I-6P:0284-7, Department of Corporations, Sacramento, California (1993) (on file with author), or that they should not disclose their contractual risk-sharing financial arrangements, *see* Steffie Woolhandler & David U. Himmelstein, *Extreme Risk—The New Corporate Proposition for Physicians*, 333 NEW ENG. J. MED. 1706, 1706–08 (1995) [hereinafter Woolhandler & Himmelstein, *Extreme Risk*].

70.   *See generally* Marc A. Rodwin, *Backlash as Prelude to Managing Managed Care*, 24 J. HEALTH POL. POL'Y & L. 1115 (1999) [hereinafter Rodwin, *Backlash*].

71.   *See* George J. Annas, *Women and Children First*, 333 NEW ENG. J. MED. 1647, 1648–49 (1995); FAMILIES USA FOUNDATION, HMO CONSUMERS AT RISK: STATES TO THE RESCUE 2 (1996) [hereinafter FAMILIES USA, STATES TO THE RESCUE] (finding that 25 states had set such standards by mid-1996).

72.   *See* FAMILIES USA, STATES TO THE RESCUE, *supra* note 71, at 2.

73.   For example, Representative Greg Ganske (R-IA) introduced to the 104th Congress H.R. 2976, The Patient Right to Know Act, which would have prohibited MCOs from interfering in doctor-patient communications.

formed coalitions between physicians and other health care providers.[74]

Consumers cannot depend solely on legislation when markets fail. Enacting legislation is costly and insensitive to individual circumstances—not a desirable or feasible means for consumers to express their everyday wishes. Special circumstances made it easier to enact limits on drive-through deliveries than to get action on other consumer issues. Maternity is, well, a motherhood issue. Gag rules, too, threatened to deny all consumers enrolled in managed care the opportunity to hear information about alternative treatments. In both cases, the problem was visible and easily understood, and the number of potential beneficiaries was large and easily organized.

Gag rules highlight the limited options for consumer voice.[75] Managed care plans wrote such clauses to restrict the flow of negative information about their policies from physicians to patients in the hope of decreasing consumer exit to competitors.[76] They sought to chill physician speech and thereby repress potential consumer complaints. Because the clauses may never have been legally enforceable, their prohibition may do little to allay the underlying public concern. When the contracts of troublesome physicians expire, managers of health plans can simply refuse to renew them, rendering anti-gag clause legislation ineffective.[77] Legislation prohibiting MCOs from suppressing physician and consumer voice will not be sufficient.

Consumer voice must be expressed in other public forms which affect MCOs.[78] There are several possibilities. Employers often pool their purchasing power and form cooperatives that contract with MCOs. Rather than simply negotiate over price, the cooperatives have formed long-term working relationships with MCOs. The cooperatives gather information on what they want and on how MCOs work. The purchasers then tell MCOs what they want the MCOs to provide, discuss details of how the MCOs might operate differently, and ultimately put their wishes in a contract with performance measures and incentives to encourage the services

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74.   *See generally* Rodwin, *Backlash, supra* note 70. For an analysis of consumer protection and managed care, see Marc A. Rodwin, *Consumer Protection and Managed Care: Issues, Reform Proposals, and Trade-offs*, 32 HOUS. L. REV. 1319, 1381 (1986).

75.   *See* Wendy K. Mariner, *Managed-Care Gag Cheats the Patients*, NAT'L L.J., Feb. 5, 1996, at A19.

76.   *See generally* Jagdip Singh, *Voice, Exit, and Negative Word-of-Mouth Behaviors: An Investigation Across Three Service Categories*, 18 J. ACAD. MARKETING SCI. 1 (1990) [hereinafter, Singh, *Voice, Exit*].

77.   *See* Woolhandler & Himmelstein, *Extreme Risk, supra* note 69, at 1706–08.

78.   *See* RODWIN, CONSUMER VOICE, *supra* note 5, at 4–6, 16–23.

purchasers seek.[79] Such voice, combined with purchasing power, has become a major force in changing how MCOs operate. However, the concerns of consumers/employees are not formally represented in purchasing cooperatives, because the cooperatives represent employers. Employees could be heard, however, if they worked through unions or were represented in other ways in purchasing cooperatives.

There are other institutions that influence or oversee MCOs, and these too could be leveraged to bolster consumer voice. For example, voluntary accrediting organizations, such as the National Committee on Quality Assurance, set standards for MCOs.[80] Similarly, the National Association of Insurance Commissioners drafts model state laws, which often influence state policy. These organizations now have enormous influence on how MCOs operate. A greater consumer presence in these organizations would affect standard practices of MCOs across the country. Most accrediting organizations have consumer representatives on advisory committees. Generally, however, provider groups greatly outnumber consumers. There is, also, very little in the way of funding to support consumer advocates or institutional means to hold the representatives accountable to consumers.

C. Consumer Voice Within Managed Care Organizations

Voice within MCOs has advantages that voice external to MCOs lacks. Voice can focus on problems of the individual MCO and facilitate experimentation. Consumers might be more willing to get involved in local MCOs and institutions than in regional or national organizations. Yet, today, consumers have very few opportunities to express voice within MCOs. Public policy could promote the use of voice to change this situation. State or federal government should focus on creating incentives for MCOs to

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79.   *See* Marc A. Rodwin, *Consumer Protection and Managed Care: The Need for Organized Consumers*, HEALTH AFF., Fall 1996, at 110, 119–20.

80.   *See* National Committee for Quality Assurance, *NCQA HEDIS 2000 Data Submission* (last modified Dec. 23, 1999) <http://www.ncqa.org/pages/policy/hedis/00sub.html> (on file with the *University of Michigan Journal of Law Reform*); National Committee for Quality Assurance, *Accreditation* (last modified Dec. 23, 1999) <http://www.ncqa.org/pages/policy/accredidation/mco/acred497.htm> (on file with the *University of Michigan Journal of Law Reform*).

develop mechanisms that would make it easier for consumers to exercise their voice.[81]

Well-run MCOs make an effort to find out what their consumers want. Consumer satisfaction surveys are a form of voice. Like polls in electoral politics, they shape how leadership responds to the public, and perhaps even displace traditional forms of voice such as protest and complaint. Consumer satisfaction surveys have led MCOs to increase the hours for appointments with physicians, to train medical personnel in communicating and empathizing with patients, and to create new ways of compensating physicians to reward their contribution to consumer satisfaction.

Not surprisingly, however, managers typically undertake consumer surveys more for internal use or public relations than for addressing consumer concerns.[82] The information can bolster the MCOs' control by helping them to respond preemptively to problems. Managers can disclose results that show the organization in a good light and keep other data confidential. In short, consumer satisfaction surveys are not the instruments of consumers; consumers have no role in developing or analyzing the surveys or in disseminating the results.

Albert Hirschman distinguishes between vertical voice (individuals privately and separately expressing themselves to the organization's management) and horizontal voice (organized discussions and activities of consumers or employees).[83] Each kind requires different channels. Many people become concerned with policy only when it affects them directly. These people often respond initially through grievance. Grievance is direct, tied to individual concerns, and often produces results quickly. By and large, consumers in managed care have options to exercise vertical voice by filing complaints or by appealing denials of services. Some problems, however, require changes in policy or even a consumer role in governance. Consumers have little leverage through horizontal voice, which might affect organizational governance.

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81.   *See* Lena Kolarska & Howard Aldrich, *Exit, Voice, and Silence: Consumers' and Managers' Responses to Organizational Decline,* 1 ORG. STUD. 41, 57 (1980) [hereinafter Kolarska & Aldrich, *Exit, Voice, and Silence*].

82.   *See id.*

83.   *See* ALBERT O. HIRSCHMAN, *Exit, Voice, and Loyalty: Further Reflections and a Survey of Recent Contributions, in* RIVAL VIEWS OF MARKET SOCIETY 77, 82–83 (1986).

D. Grievances

Most managed care plans have grievance procedures.[84] Except for Medicare HMOs, however, there are no uniform standards in force and consumer groups have found existing procedures deficient.[85] Most complaints today are reviewed solely by the MCOs. In effect, the consumer seeks redress from an interested source that creates its own policies about what services should be provided.

Many consumer groups and legislative proposals, therefore, would allow a patient to appeal to a neutral, independent party when his or her doctor or MCO decides that a medical service is unnecessary or inappropriate.[86] The President's Advisory Commission on Consumer Protection and Quality in Health Care has recommended that consumers have a right to have their appeals reviewed by an external source.[87] By executive order President Clinton has mandated that all federal programs comply with these recommendations.[88] This is already the practice for appeals in the Medicare program, where an independent group, the Center for Health Care Dispute Resolution, reviews all appeals under a contract with the Health Care Financing Administration.[89] The American Association for Health Plans, the managed care trade association, publicly recommended that its member plans adopt binding independent review of patient appeals.[90] Many MCOs already have an independent organization choose neutral

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84.   *See Proposed ERISA Claims Procedures Regulation Before the Department of Labor* (Feb. 18, 1999) (testimony of the Special Comm. on Health Ins. of the Nat'l Ass'n of Ins. Comm'rs) (last modified Nov. 15, 1999) <http://www.naic.org/1news/testimonies/990218test.htm> (on file with the *University of Michigan Journal of Law Reform*) (describing extant and proposed grievance regulations and noting that all 50 states require at least a one-step review).

85.   *See* Susan J. Stayn, Note, *Securing Access to Care in Health Maintenance Organizations: Toward a Uniform Model of Grievance and Appeal Procedures*, 94 COLUM. L. REV. 1674, 1708 (1994) [hereinafter Stayn, *Securing Access*].

86.   *See, e.g.*, The Patient Access to Responsible Care Act of 1997, H.R. 1415, 105th Cong. § 2 (1997).

87.   *See* ADVISORY COMM. ON CONSUMER PROTECTION AND QUALITY IN THE HEALTH CARE INDUS., CONSUMER BILL OF RIGHTS AND RESPONSIBILITIES: REPORT TO THE PRESIDENT OF THE UNITED STATES 57 (1997).

88.   *See* Memorandum on Federal Agency Compliance with the Patient Bill of Rights, 34 WKLY. COMP. PRES. DOC. 298, 298–99 (Feb. 20, 1998).

89.   *See Center for Health Dispute Resolution: Medicare Reconsideration Review Program* (last modified Aug. 28, 1999) <http://www.healthappeal.com/medicare.htm> (on file with the *University of Michigan Journal of Law Reform*).

90.   *See Role of Government in Regulating Health Insurance Plans Before the United States Health, Education, Labor and Pensions Committee* (Mar. 11, 1999) (statement of Karen M. Ignagni, President and CEO, American Association of Health Plans) (visited Oct. 23, 1999) <http://www.aahp.org/services/government&advocacy/policy/testimony/REG99WND.htm> (on file with the *University of Michigan Journal of Law Reform*).

experts outside the organization to review appeals from denial of experimental therapy or organ transplants.[91]

Review of appeals by neutral decision makers is necessary, but not sufficient, to give consumers a fair hearing. There should also be some kind of institutionalized advocacy. Organizations have resources and expertise on how to handle grievances. Individuals lack such expertise and resources and go through a grievance procedure infrequently; all of this places them at a disadvantage.[92] Experienced specialized advocates can address the disparity, but not fully.[93]

Grievance procedures, in most contexts, are not widely used by patients with problems. Consumers are often reluctant to complain or file grievances,[94] especially for medical care.[95] One study found that only one-third of consumers with complaints voiced them, complaints were resolved to the patient's satisfaction only a third of the time, and consumers' complaints in medicine were resolved less satisfactorily than seven other service categories surveyed.[96]

To help alleviate this problem, there should be protection for individuals who initiate a grievance and prompt, visible penalties against the organization if it retaliates. It would also be helpful for independent parties or an ombuds to conduct surveys of health care consumers and find out what problems they have. Independent parties are more apt than MCOs to design their

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91.   *See* Sharon Bernstein & Alissa J. Rubin, *State HMOs Will Allow Independent Appeals*, L.A. TIMES, Dec. 3, 1998, at A1 (describing how HMO members of the California Association of Health Plans adopted use of independent panels); Milt Freudenheim, *Aetna to Allow Outside Review of Care Denials*, N.Y. TIMES, Jan. 13, 1999, at C3.

92.   *See* Engalla v. Permanente Med. Group, 938 P.2d 903, 925 (Cal. 1997); Lisa Bingham, *Employment Arbitration: The Repeat Player Effect*, 1 EMPLOYEE RTS. & EMPLOYMENT POL'Y J. 189, 190–97 (1997).

93.   *See* Marc Galanter, *Why the 'Haves' Come Out Ahead: Speculations on the Limits of Legal Change*, 9 L. & SOC'Y REV. 95, 118 (1974).

94.   *See* ARTHUR BEST, WHEN CONSUMERS COMPLAIN 4 (1981); Alan R. Andreasen, *Consumer Complaints and Redress: What We Know and What We Don't Know, in* THE FRONTIER OF RESEARCH IN THE CONSUMER INTEREST 675, 675 (E. Scott Maynes & ACCI Research Committee eds., 1988); Arthur Best & Alan R. Andreasen, *Consumer Response to Unsatisfactory Purchases: A Survey of Perceiving Defects, Voicing Complaints, and Obtaining Redress*, 11 L. & SOC'Y REV. 701, 701 (1977); Jane Kolodinsky, *Complaints, Redress, and Subsequent Purchases of Medical Services by Dissatisfied Consumers*, 16 J. CONSUMER POL'Y 193, 195 (1993); Jagdip Singh, *Industry Characteristics and Consumer Dissatisfaction*, 25 J. CONSUMER AFF. 19, 23–25 (1991); Rex H. Warland et al., *Dissatisfied Consumers: Who Gets Upset and Who Takes Action*, 9 J. CONSUMER AFF. 148, 151 (1975).

95.   *See* Alan R. Andreasen, *Consumer Satisfaction in Loose Monopolies: The Case of Medical Care*, 2 J. PUB. POL'Y & MARKETING 122, 131 (1983); Jagdip Singh, *Determinants of Consumers' Decisions to Seek Third Party Redress: An Empirical Study of Dissatisfied Patients*, 23 J. CONSUMER AFF. 329, 329 (1989).

96.   *See* Alan R. Andreasen, *Consumer Responses to Dissatisfaction in Loose Monopolies*, 12 J. CONSUMER RES. 135, 138 (1985).

surveys in ways that will reveal critical comments. Their surveys also are more likely to reveal unsuspected problems, allow comparison across health plans, and identify flaws undetected by a formal grievance process.[97]

Grievance mechanisms are usually designed to resolve individual complaints. Managers often placate individuals who voice complaints—making exceptions to policy or working out some special accommodation—rather than deal with the source of the problems that affect the complainers and the silent alike.[98] Indeed, firms may use grievance mechanisms as an escape valve for angry consumers who might otherwise complain to public authorities or other consumers.[99]

Although complaints can be harbingers of systematic organizational problems, MCOs rarely analyze complaints to identify problems and even less frequently inform the public about them.[100] Publicizing the kind and number of complaints and appeals for services denied and how they were resolved would spur organizational change. Funding an ombuds or independent groups to prepare summaries and analyses of complaints and to disseminate the information would help spotlight problems and focus the attention of management.

Facilitating consumer voice through complaints is important. Yet many problems are systemic or are not well addressed by individual complaints. The consumer voice in management and daily operations must be strengthened. Employees should be able to collectively voice and represent their views in organizational policy and governance. One way to do this is to ensure that information from consumer complaints affects organizational policy, not just the resolution of individual cases. A second way is to provide for consumer representation at appropriate levels in MCOs and in groups that contract with MCOs or that oversee their performance. A third way is to ensure that information from consumer complaints reaches the press, policymakers, and consumer groups.

Dissemination of information about complaints to shareholders, prospective members, and the press would create public pressure on MCOs to respond to consumers and would prevent complaints

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97.   *Cf.* Lena Kolarska & Howard Aldrich, *Exit, Voice, and Silence, supra* note 81, at 54 (describing the effect of independent Polish media in causing managers of Polish organizations to create more efficient behavior).

98.   *See* Singh, *Voice, Exit, supra* note 76, at 3.

99.   *Cf.* RUDOLF KLEIN, COMPLAINTS AGAINST DOCTORS 121–34 (1973) (describing Britain's system of dealing with complaints).

100.   *See* Telephone Interview with Membership Services Department, Group Health Cooperative of Puget Sound (Mar. 1997) (on file with author).

from being buried in files. Exit and voice then would complement each other. Prospective enrollees might choose MCOs based on how they addressed complaints, which in turn would encourage management to resolve problems. Members might publish summaries of complaints in a newsletter, informing individuals with similar problems and facilitating the formation of groups to address common concerns. State insurance departments could then provide more intelligent oversight of MCOs.

E. Governance

Not-for-profit health care organizations are governed by boards that broadly represent the community, including consumers. To be sure, trustees in not-for-profits are usually nominated and chosen by management, which makes them less than ideal representatives of consumers. Although many not-for-profits behave like for-profits, others have pursued community missions and interests that a profit-oriented organization would probably not undertake. With for-profit MCOs growing in number and size, even this indirect form of consumer participation in governance is fading.

In light of problems with current health care markets and the disillusionment with traditional governmental regulation, consumer participation in governance ought to get another look. Because owners can govern, consumers might form cooperatives to own MCOs (or jointly own them with other groups) and elect their own trustees and management. Co-ops could require consumer approval for key management choices and strategic planning. The Group Health Cooperative of Puget Sound is an example. Operating since 1947 as a cooperative jointly owned by physicians and consumers, it now serves more than half a million members and is considered an exemplary consumer-oriented HMO.[101]

Nevertheless, maintaining consumer involvement is difficult, even in cooperatives. Today, about six percent of individuals insured by Group Health are co-op members with voting rights. Voting in elections has been around five percent for most of the last decade, but because of controversial issues in the last two years, turnout has been around fifteen percent. Since 1989, less than one percent have attended the annual meetings that determine what

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101. *See* WALT CROWLEY, TO SERVE THE GREATEST NUMBER: A HISTORY OF GROUP HEALTH COOPERATIVE OF PUGET SOUND, at ix, 16–18, 222 (1996).

goes on the ballot.[102] Most consumers simply do not have the time
or inclination to become involved in governance.[103] Consumers at-
tempting to start a cooperative HMO today would face immense
hurdles, particularly in raising capital and obtaining contracts with
large firms. Even Group Health has had to form an alliance with
Kaiser Permanente in order to compete for contracts with multi-
state employers.

There are, nonetheless, possibilities for injecting consumer voice
even in for-profit MCOs. For-profit MCOs could create advisory
boards for specific issues as they arose, or consumer councils for
ongoing and long-term advice and feedback.[104] Councils could ex-
press their views on issues that affect members and work with
management to improve the organization's performance.[105]

Both for-profit and nonprofit MCOs could also include con-
sumer representatives on boards that performed important
functions, or have boards report to consumer representatives. For
example, MCOs could create oversight boards operating in a man-
ner similar to independent auditors for financial institutions or
inspector generals for government agencies. Other boards could
address issues of management operations.

CONCLUSION

Today, the main problems MCOs face are the absence of effec-
tive consumer voice and over-reliance on exit. This may change if
consumer voice is increased. Too much consumer voice may create
other problems in managed care. Consumers might demand too
many services or slight budget requirements. They might also poli-
ticize and polarize issues and impede efficiency. Consumers may be
uninformed about medical, administrative, or policy issues. Efforts
to cater to them may introduce irrationalities into organizational
planning. MCOs' efforts to meet the demands of multiple con-
sumer groups might mean that their main objectives lose

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102. *See* James A. Morone & Theodore R. Marmor, *Representing Consumer Interests: The Case of American Health Planning*, 91 ETHICS 431, 448–49 (1981).

103. *See* Starr, *Changing the Balance of Power, supra* note 2, at 168.

104. *See* RICHARD B. FREEMAN & JAMES L. MEDOFF, WHAT DO UNIONS DO? 103–06 (1984); Richard B. Freeman, *The Exit-Voice Tradeoff in the Labor Market: Unionism, Job Tenure, Quits, and Separations*, 94 Q.J. ECON. 643, 645–46 (1980) (finding that when a grievance sys-
tem is in place in the union environment, workers are likely to seek a solution through the
procedure before quitting).

105. *See* Sidney Verba, *Democratic Participation*, 373 ANNALS AM. ACAD. POL. & SOC. SCI. 53, 57–58 (1967).

coherence. If there are significant efforts to increase consumer voice these problems will have to be faced.

Increasing consumer voice in our health care system would, to be sure, often be cumbersome and annoying to managers and medical personnel. However, consumer voice could help build stronger organizations by putting managers in touch with the experiences and desires of their customers, the patients. If those customers become sufficiently discontented, they will eventually call on legislatures to act on their behalf. The spate of consumer protection legislation regulating managed care suggests that the industry will face increasing constraints, that voice suppressed or ignored within MCOs will merely shift the forum in which voice is expressed. Those who claim that increased consumer voice within MCOs is impractical should contemplate the alternatives.