Preface:
The Concept of Consumer Exit, Voice, and Representation

This report examines the potential role for the public in making MCOs respond to their wishes—by means other than choosing to enroll in one MCO rather than another, i.e., market exit. It describes various ways consumers can become involved in shaping the policies of MCOs and differing ideas about how the public's views can be represented. We begin here with a brief definition of key terms.

Market proponents believe 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 managed care organizations. For them, the engines driving change are financial incentives for individuals to shop for the health plan which offers the best value. If the performance of an organization declines, its customers or members will become dissatisfied, and their defections will signal the firm to clean up its act. In short consumers can express their dissatisfaction by *exiting,* purchasing their services elsewhere.

For Albert Hirschman, author of the classic, *Exit, Voice, and Loyalty: Responses to Decline in Firms, Organizations and States,* there are two choices: not just *exit* but *voice*—complaints, grievance, protests, and political pressures.[1] Consumers may express their voice horizontally, among themselves and potential consumers, or vertically to authorities. They may express themselves individually or collectively. Voice takes many forms. Individuals can state their views when asked, complain, file grievances, protest, bargain collectively, participate in organizational governance, appeal to higher authority, or become active in politics. They may express their concerns to physicians, managers, policymakers or influential outsiders—such as the press or activists—who may take up their cause. Voice can be exercised episodically as special circumstances arise, or continuously through established consultative mechanisms. Sometimes exit and voice reinforce each other, while at other times they may be at cross-purposes. Each has strengths and limitations. Exit, for example, sends a powerful signal that something is wrong, but reveals little or none of the information that voice can provide about the problem or possible remedies.[2]

Individuals can express their voice by participating in decision-making. At its fullest, participation can mean consumer or citizen control.[3] It may also be something less, such as delegated power in a specified area or a partnership between producers and consumers. Participation can also be merely a device for informing those who make decisions, a form of consultation. Organizations can also use token participation as a means of co-optation or manipulation.

Most individuals don't have the time to participate in decision-making or to express their voice on every issue that arises. However, their views or interests can be *represented* by an intermediary that speaks or acts for the groups they represent.[4] How the views of the consuming public are best represented is a major challenge in making voice effective.

One can distinguish three different kinds of representation: (1) *Formal Representation*, the institutional mechanisms by which representatives are selected and controlled[5]; (2) *Substantive Representation,* the process of acting in the interests of constituencies; and (3) *Descriptive Representation,* choosing representatives to mirror the represented group's ethnic or social makeup or other characteristics.

Consumer representatives can play various roles. These range from directing or controlling policy, exercising delegated power for defined tasks, being a partner with producers, providing advice, or participating without power as a token or symbolic gesture.[6]

Chapter I: The Interplay of Consumer Voice and Exit in Managed Care

I. How Consumer Voice Became an Issue

Once called "an alternative delivery system," and considered a means of reform, managed care has now become the predominant vehicle through which the public receives health care services. Yet the public now views managed care organizations (MCOs) as a source of problems to be addressed, and the issues surrounding MCOs figure prominently on the national political agenda. In the last five years there have been successive waves of state and federal legislation and regulation of managed care which aim to protect the public and bolster the authority of doctors and other providers in relation to MCOs.[7]

Take, for example, recent legislation for a "bill of rights" for managed care consumers.[8] These include several items: the right to appeal decisions not to provide services, the ability to sue MCOs for medical malpractice, easy access to specialists, coverage for emergency care, an accessible network of providers, access to out-of-network providers, and prohibitions on MCOs restricting communication between doctor and patient.

Step back from these issues. Underlying all these legislative provisions lies one question. Which issues should be left to the market and which should be decided by public policy through some kind of representative process? The spate of current regulation represents political backlash against the policies and practices of MCOs.[9] The public has used the political process to achieve what it could not through the market. This is in sharp contrast to conventional ideas about how consumers affect the behavior of firms: namely that consumer choice in the market will force health care providers to cater to their wishes. The fact that there is a political backlash suggests that at least in certain situations the market does not work on its own and that the public relies on an alternative—exercising its voice.[10]

Health care represents an unusual case for testing the efficacy of markets, government regulation, and democratic means of exercising public control over firms.[11] U.S. policy has shifted, sometimes intervening in health care markets, other times leaving them alone.

From World War II until the mid-1970s, medical care was viewed as different from most other goods and services. The federal government subsidized the growth of medical schools and in 1965 created Medicare and Medicaid, publicly financed insurance programs for the elderly and the poor. Most people did not believe that the market alone could perform these functions. The government also subsidized health insurance for the middle class through tax subsidies for employer-provided health insurance and health insurance provided by nonprofit insurers and hospitals.[12] Even economists, led by Nobel laureate Kenneth Arrow, believed that markets could not work in health care as in other sectors of the economy because of imbalances of information between providers and patients.[13] This skepticism regarding health care markets was used to justify professional licensure, regulation of hospital construction using certificate-of-need, and community health planning. It is also supported by an ideal of professionalism which ceded authority to doctors to regulate themselves and act in the interest of patients, and which provided little external oversight.

Health planning in the U.S. was bolstered by the passage of the Comprehensive Health Planning Act in 1966, which required localities to survey and produce health plans.[14] The trend was continued by 1972 legislation creating Professional Standard Review Organizations, which were charged with assessing the appropriateness of hospital care that patients received under Medicare.[15] Hospital expansion was regulated by legislation in 1972.[16] The trend was solidified by enactment in 1974 of the Health Planning and Resources Development Act, which created Health Systems Agencies with consumer representation to implement health planning.[17]

Yet while health care regulation grew in the 1970s, at the same time other trends emerged that promoted a market-oriented approach to health care. The tide shifted in the late 1970s and early 1980s, and for the next 25 years many restrictions on markets were chipped away. Courts, economists, and critics suggested that regulation of health care was fueling health care spending and stifling innovation. There was a steady flow of proposals to promote health care markets followed by changes which treated medical care services more like other goods and services. The professional exemptions from anti-

trust laws were removed by lawsuits in 1975[18] and 1982.[19] Federal certificate-of-need regulation of the growth of medical facilities was dismantled in the 1980s. Starting in 1978, Alain Enthoven proposed managed competition to control health care spending and improve quality.[20] The 1980s and 1990s were also characterized by the rapid growth of the investor-owned for-profit health care sector and conversion of not-for-profit providers and insurers to for-profit status.[21] In 1997 62% of MCOs were for-profit, up from only 12% in 1981.[22]

The 1960s skepticism about markets in health care gave way to celebration of markets in later years. The language of markets, management, and money became integral to discussions of health care.[23] Health care institutions also changed. The most prominent development was the rise of MCOs, which combined prepaid health care insurance with the delivery of health care services, frequently with financial and managerial controls over the provision of health care services. These organizations had their origins in the 1930s as experiments to deliver health care through nonprofit prepaid group practice that increased access to services and lowered costs. Initially viewed as something of a "socialistic" experiment, medical societies fought them. Yet a few such prepaid group practices thrived, including Kaiser Permanent in California and Group Health Cooperative of Puget Sound in Washington state, Group Health Association in Washington, DC, Harvard Community Health Plan in Boston.[24] They served as a model for President Nixon's Health Maintenance Organization (HMO) Act of 1973. And since the 1980s it has been for-profit variations of such prepaid group practice that have grown most rapidly. As they grew, so did the ways in which insurance and health care services could be organized, financed, and marketed. Somewhere around the late 1970s, the term "managed care organization" was coined to describe a wide variety of such organizations that were not organized as the original HMOs were, i.e., as individual organizations integrating both the insurance and delivery of medical services, and with physicians as salaried employees.

During this time, there was also a shift in how the public viewed the users of medical services. Traditionally, they were called patients and were usually treated paternalistically by doctors. But patients' rights, women's health, and disability rights movements helped change the way patients were viewed. Patients' rights advocates argued that doctors should respect the autonomy of patients, obtain their informed consent before providing medical treatment, and allow patients to participate in medical decision-making.[25] Their intent was to foster the autonomy and rights of women and people with disabilities and patients in general. They engaged in concerted political activity to change our health care system.[26] However, in the process, they encouraged market trends. If people that were ill could make more decisions themselves than doctors had traditionally accorded, then it was easy to conceive of them as medical "consumers" rather than patients.[27] And indeed, that is what happened. Soon the focus shifted from patients' rights and informed consent to consumer choice and consumer rights.[28] While these changes eliminated a great deal of physician paternalism, individuals were left to the vagaries of the market with the assumption that they could be better off with unrestricted consumer choice.

The Flaw in Current Policy

For the past two decades public policy treated MCOs as if they were providers of most other consumer services, and that with the right market conditions, they would cater to consumer preferences. Major efforts were channeled into providing consumers with information and eliminating other obstacles to health care markets functioning well.[29] Employers and other purchasers also began to use their purchasing power to obtain better value for their money. While admitting that MCOs were not perfect, many people saw increased market competition as the main way to improve managed care.

This conception of managed care is flawed. Managed care is not a traditional service, and individual patients and MCO members—what I will call *consumers* for short—are very different from purchasers or users of most other services. These differences, often ignored by those who advocate consumer choice among alternative MCOs, limit the effectiveness of market approaches as a means to promote accountability of MCOs to the public.

MCOs, unlike providers of most private services, exercise authority over those who receive their services, much the way that governmental institutions exercise authority over citizens who are beneficiaries of their social programs and policies. There are four key reasons.

First, participation in MCOs is often *not voluntary*. For many privately insured individuals, being a managed care subscriber is not their own choice. Most employers do not give employees a choice of more than one health plan. Thirty-five percent of covered employees were offered only one plan and only half of employees were offered three or more plans.[30] In 1998, 54% of Medicaid recipients were enrolled in managed care plans.[31] And, once an individual is enrolled in an MCO, their choice is more restricted than otherwise.

Second, a major distinction between managed care and indemnity insurance is that indemnity insurers don't judge the necessity for medical care or control its use of services while MCOs do. MCOs mediate what services to provide members and decide what services are medically necessary and how to provide them. MCOs make these choices subject to a limited budget and so effectively *ration* resources.[32]

Third, MCOs also collect approximately equal funds from a large number of individuals and provide differing levels of benefits based on their criteria of need, thereby *redistributing* resources among individuals.

Moreover, the funding for MCO services is *publicly subsidized* and the services they provide are *imbued with a public purpose*. Rather than being merely private purchases, many health care services have a public aspect and affect the community as well.

These features make consumer choice in the health care market less viable as a way to promote organizational accountability. Traditional government regulation of industry is one way to address this problem but there is also another: giving the public greater say in the operation of MCOs. Since MCOs exercise authority over their members, individuals subject to MCO authority should receive an accounting for their performance and main policy choices they make. The public should also have some voice in key policies and decisions that MCOs make, just as is the case for governmental agencies. Yet MCOs today perform their work using criteria that are not generally known let alone subject to public debate, representation, or approval.[33]

II. Managed Care as a System of Authority

Not Voluntary

Most individuals enrolled in MCOs don't choose them from alternatives such as indemnity insurance, nor do most people even have a choice among competing MCOs. Indemnity insurance, once the norm, is now available mainly for the well-to-do, only approximately 11% of the American public in 1998.[34] Even choosing among managed care plans is limited. Most employers do not give employees a choice of more than one health plan. In 1999, 35% of employees were offered only one plan and only half of employees were offered three or more plans.[35] The poor, in particular, have few exit options.[36] Some state Medicaid programs lock beneficiaries into a managed care plan, generally the one with the lowest premium.

Moreover, many individuals who would like to be insured by managed care or other health insurance, can't. Approximately 18% of Americans lacked health insurance in 1997 and 32% did not have health insurance some time over the previous two years.[37] MCOs and other insurers refuse to enroll many individuals because they are already sick or have a higher than average risk of becoming ill. Still other people lack funds to purchase the most basic insurance. And after Congress passed the Balanced Budget Act, which created new options for managed care in the Medicare program, most MCOs decided not to participate in the program, effectively denying this as a market option for most seniors. As of January 1999 10.4 million Medicare beneficiaries had no choice of managed care plans, 4.7 million had only one plan and 23.8 million had more than one plan to choose from.[38] And between 1998 and 2000, 198 HMOs dropped out of the Medicare program, forcing 750,000 people to find a new Medicare plan.[39] Thus managed care is imposed on many who would like an alternative. It is not an option for others who would choose it if they could.

Rationing and Redistribution

MCOs not only provide services but also ration medical care for their members. MCOs receive fixed premiums and are responsible for providing all necessary medical services for their subscribers (subject to exclusions specified in their policies). To stay solvent MCOs must manage their costs and spending and develop ways to deliver their services efficiently. However, there is also a trade-off between the money spent on patient care and the profit or surplus the MCO receives.[40] In short, a main way MCOs control spending is by limiting the volume and cost of services they provide to subscribers.

To limit their costs, most MCOs create procedures and rules which control access to specialists, hospital care, pharmaceutical products, and other services.[41] They set guidelines for treating different medical conditions and the length of hospitalization. MCOs also typically review the necessity of medical services that doctors recommend and can veto or modify choices that doctors make. In so doing, MCOs limit the discretion of the individual clinician as an agent for patients. In making such decisions, MCOs assess the value of reducing different categories of medical risk, in effect balancing claims to services from competing groups. Such choices are not merely technical or reducible to medical knowledge, science, or an economic calculus. They require judgments about values that are essentially political. In effect, health policy is delegated to MCOs and their agents.

Of course, MCOs tend not to override or ignore most physician decisions about what care is medically necessary. So MCOs enlist the aid of doctors in rationing medical care. MCOs attempt to change the standard of care and the individual decisions of doctors. They harness physician self-interest as a tool to control resource use. They pay doctors in ways that give them financial incentives to be frugal in using or recommending services or referring patients to specialists or hospitals. Doctors in most MCOs bear part of the cost for the resources the MCO uses, a powerful incentive to make clinical choices in ways that reduce resource use. The fewer costs incurred for patient care, the greater the income physicians will receive. Doctors are now partners with MCOs in controlling costs through rationing.[42]

Health insurance by its nature redistributes resources from the healthy to the sick. People pay for health insurance because they want to be able to tap medical benefits should they need them but do not know whether they will. They pay premiums regardless of their health but don't reap the benefits unless they need medical services. This redistributive function makes enrolling in an MCO or other health insurance more like funding a governmental program than purchasing an individual product. The insurance plan, like a government social program, provides economic security for all those who are eligible to receive benefits, and the individuals who don't need the service in effect subsidize the program for those who do. Willingly (or reluctantly), we pay taxes to fund a government program

because we feel obligated to help those the program supports and also because the program might help us. Yet in the case of governmental programs the public can use the political process to determine how the program works. There is little public input into the operations of managed care.

Public Subsidy

Our private health insurance system and infrastructure are publicly subsidized. In 1998 approximately 46% of U.S. health care spending was paid for directly with public funds through programs such as Medicare, Medicaid, and CHAMPUS (Civilian Health and Medical Program of the Uniformed Services).[43]

Even private payments are subsidized by tax-expenditures. Employers' payments for health insurance premiums are tax deductible business expenses. Employees, too, often pay their share of premiums with pre-tax earnings through workplace tax benefit plans, which have the same effect as a tax deduction. Individuals who purchase health insurance on their own also can deduct their premiums. The loss of tax revenue from such subsidies, the so-called "tax expenditure" was $111 billion in 1998.[44] Our medical infrastructure is subsidized as well. Government funds have contributed to construction of nearly all U.S. hospitals through the Hill-Burton Act. Graduate medical education and biomedical research are heavily subsidized by the National Institutes of Health. MCOs share in this subsidy.

In sum, MCOs make public policy on medical matters, have significant control over the lives of their members, and use public funds to perform their work. This itself is reason for giving the public voice into MCO policies and requiring MCOs to account for their decisions to the public. Yet many people shy away from public solutions. They prefer to let individual choice in the market be the means to make private firms responsive to consumers. They say that individuals can leave one MCO for another. However, such an approach is sorely inadequate for managed care.

III. Why Market Choice Alone Can't Make MCOs Respond to Consumers

Typically, private firms have good reasons to cater to consumer wishes. If they provide poor services, they risk losing consumers to competing firms. Providing good service is in the firm's interest especially where a business relies on repeat customers and long-term relationships for its reputation. This need to attract and keep customers helps restrain the interest of a firm in maximizing its short-run profit by skimping on quality. In principle MCOs should behave in the same way as other firms and thus resist temptations to provide too few or poor quality services. These general incentives, however, don't work as well for MCOs for several reasons.

MCOs have no financial incentives to cater to the needs of members who can use medical care the most, those with chronic, high-cost illnesses. Such individuals represent a loss to MCOs because they cost much more to treat than the premiums they pay. MCOs are better off deterring such individuals from joining rather than attracting them. The threat of leaving is not an effective means for such individuals to make their MCO respond to their needs.

Moreover, typically employers, not employees, decide which MCOs or other health insurance plan to offer to employees. This reduces the responsiveness of MCOs to individual members because employers are imperfect agents for their employees. While employers and employees have common concerns, their interests are not always the same, a fact evident from management-labor disputes. Certainly, employers need to treat employees well enough to retain a ready supply of labor and therefore will try to maintain a minimum level of satisfaction. However, a firm's loyalty and obligations are primarily to shareholders or other owners, not employees.

Ownership of MCOs is also becoming concentrated, and this limits available choice. Some analysts believe that a few oligopolies will soon dominate the market. If this occurs these MCOs may become complacent about the risk of losing market share and therefore less responsive to consumer switching.[45] Albert Hirschman calls attention to what he calls lazy monopoly or collusive behavior.[46] In a restricted market, a firm may choose to be rid of its difficult customers rather than change its behavior to please them. If a problem is endemic among all rival plans, dissatisfied customers will only be able to switch to an equally unresponsive competitor.

However, choice within an MCO or physician network might render unnecessary choice among competing MCOs. Is this so? Will MCOs respond to consumers if they can choose among several physician groups, or go outside the preferred provider network? Such choice won't produce options for consumers that make the most significant difference. MCOs restrict the clinical decisions of all physicians through organizational rules and influence physician discretion through financial incentives.[47] Thus when consumers switch doctors, they are subject to the same organizational constraints that significantly affect the care they receive. Moreover, many consumers in preferred provider organizations can't afford to pay the extra fees required to seek care outside the list of preferred providers.

Unlike many other services, there are high costs for most people to switch MCOs. For one, patients are often loyal to their doctors. Switching doctors 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. And especially for the sick and the frail, shopping for medical care may be physically and

emotionally difficult.[48] If the MCO's performance is mediocre but not terrible, they may simply suffer poor quality and the market will not do its work.

The fact that managed care provides a bundle of varied medical services, medical providers, and health insurance also makes exit a crude tool. 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 can choose among three managed care organizations, each of which is strong in only one area of medical care that the family needs.[49] Which should the family choose?

Rational Consumer Choice and Report Cards

Individuals are also not in a good position to evaluate MCOs. For most purchases consumers make—food, clothing, home products, restaurants, and rental housing—the stakes are low and the variables that differentiate the product or service relatively few. People make these purchases frequently and when they make a bad choice they learn quickly, without much cost, and are better informed the next time.

Choosing an MCO is a different matter. The consequences can be great, the number of factors that differentiate MCOs are many and often not apparent to the layperson. People make such choices infrequently. Experience is also an inadequate guide. Since most people are healthy, they won't encounter the effect of their MCO policies or learn how well it performs until they are ill—which is when they will need it most. Even then, their experience probably won't be a good guide for the future. Unless consumers have a chronic condition, they probably won't need the care of the same doctors and other providers again. Other medical personnel may perform very differently, and so might the MCO for different kinds of medical problems.

The lack of knowledge that most people have about medicine has always been an obstacle for their making choices.[50] However, it's much harder to compare two MCOs than two physicians practicing the same specialty because the number of variables is much greater and there is much less reliable information.[51] In choosing among MCOs, consumers compare two networks of physicians, hospitals, and other medical personnel. In addition, one must compare systems of quality assurance, methods of administration, including systems for resolving complaints, handling appeals, and organizing personnel and services. Each is difficult to assess. Consumers would like to know whether the MCO would provide good care for them when they need it. But since most people don't know what illness they will have and thus, what medical personnel will provide the service, it's hard to compare two different MCOs. Moreover, most MCOs can contract with different providers yearly and so even a careful assessment of which MCO has the best provider network is constantly in flux.

There is now a movement to create report cards that rank MCO performance along several dimensions to help consumers choose among them.[52] Still in their infancy, most report cards have focused on consumer satisfaction and medical outcomes for a few medical conditions. They measure quality based on proxies such as the rate of childhood immunizations or the success rate in coronary artery bypass surgery.

Typically designed to be understandable by the layperson, report cards focus on a few key measures and in doing so simplify and screen out a great deal of pertinent information. For example, there is very little public information on the internal operations of MCOs, their management practices, the criteria they use for utilization review and the process used to conduct it, and the incentives paid to physicians for cost containment. There is also little data available on the performance of physician groups, which are now assuming functions that were traditionally the province of MCOs, including bearing financial risk, overseeing quality assurance and utilization review, and monitoring consumer complaints. Furthermore, much of the data is not collected using uniform standards and is not subject to audit.

Report cards also infrequently provide data related to MCO performance in addressing particular medical conditions, which would help people who are most apt to make comparisons: those with chronic illnesses. And most report card measures of outcome are based on averages of all physicians in the MCO rather than the much smaller physician groups that will serve a particular member. The measures of outcome therefore don't accurately reflect the experience of the doctors consumers will use.

Report cards aimed at individual consumers simplify greatly and therefore lack detail that would allow a robust and sophisticated assessment of MCOs. Information about MCOs that is not included in report cards could reveal a great deal about an MCO's values, particularly on how and where to ration and what groups gain and lose by the way the MCO manages costs. However, providing a great deal of detailed and complex information about MCOs probably would overwhelm most laypeople.[53] This problem could be overcome if instead a great deal of information was made available to expert intermediaries. They could use such information to make informed judgements and advise consumers on which MCOs to avoid or to seek out.[54] That is the model and lesson of the information disclosure in the securities market.[55]

Nevertheless, it will be hard for anyone to perform this expert-intermediary role because much of the kind of data that would allow a thoughtful assessment of the performance of MCOs and providers is not publicly available. MCOs have or could produce most of this information but are unlikely to do so voluntarily. They consider this information their private property, and making it public is costly and offers MCOs few benefits. Rather, it raises potential dangers, for example, that

outsiders will raise questions about their performance or that other firms will use the information to compete with them. Most HMOs also are worried that releasing information could yield increased regulatory oversight or could help lawyers bring lawsuits against them.

As we have seen, consumers' relation to MCOs is very different from their relation to providers of other services, and is more like that of a citizen to a governmental program providing benefits. Moreover, choice of MCOs is less effective as a tool to make MCOs responsive to consumers than is the case for many other services. Small wonder then, that as managed care became the predominant means by which the public received health care and problems with managed care came to light, there was a public backlash.

IV. Why Current Proposals for a Patients' Bill of Rights Are an Important but Insufficient Remedy

Current public debate over how to reform managed care ignores key issues. Some proposals would provide consumers with more information so that the market can work better. Thus, bills introduced in numerous state legislatures required that MCOs disclose to their subscribers the financial incentives that doctors receive to be frugal in providing services and a good deal of other information about how MCOs work.[56] The assumption behind such disclosure is that informed consumers can make better choices among competing MCOs and thereby force MCOs to cater to their preferences or lose business.

Other groups champion a "patient bill of rights" which will allow lawsuits against MCOs, as well as appeals, from their decisions not to provide a service, and various minimum standards. These reform proposals seek legislative fixes to particular problems and provide important new remedies. Once in place, such standards, appeals, and the right to sue can improve performance, deter negligence, and provide important feedback to MCOs, advocacy groups, and oversight agencies. However, legislation creating due process rights does not change what caused the problems that give rise to grievances, nor create a mechanism to incorporate citizen voice into future policies or decisions of MCOs short of another round of legislation. Such legislation, although an important reform, leaves control over the policies and rationing priorities in the hands of MCO managers, not in those of the people who may use the services and ultimately pay for them.

The notion that consumers should have a right to appeal decisions to deny services to a neutral party is based on ideas about fair judicial process that every American takes for granted. The constitution requires that government agencies provide due process when important individual rights or benefits are at stake. Government agencies may not deprive citizens of property or important interests unless they do so using fair procedures and allow the individual to challenge the state action before a neutral party.[57] Constitutional requirements for due process, however, apply only when there is state action and so do not pertain to the action of firms acting in a private capacity.[58] Currently, Medicaid patients are entitled to constitutional due process and fair hearing requirements and Medicaid MCOs are legally obliged to provide such hearing.[59] Medicare patients are entitled to appeals by federal regulation.[60] It is therefore significant that legislation has now been passed by both houses of Congress to create due process rights for MCOs serving all patients.[61] Such legislation, if signed into law, will be an important step in protecting consumers and making their grievances heard.

Appeals of MCO decisions not to provide service give consumers the opportunity to be heard by a neutral party, which can require the MCO to provide the service. However, this kind of consumer voice does not address many problems. Such appeals can only change what services are provided in individual cases. They don't create precedents that bind the MCO (or other MCOs) to provide the same services to other individuals in similar circumstances. They can't change the MCO's general policies or the criteria it uses to decide what services are medically necessary. Nor do independent reviewers have authority to change rules and incentives that give rise to inappropriate denials. Typically, the substance of decisions of independent reviewers and the reason for their decisions are not published. There is, therefore, little opportunity for the public to learn what problems they have in common and to seek changes in organization policy.

Relying on individuals to file appeals is also inadequate as a remedy for mistakes. The evidence from studies of consumer complaints shows that the overwhelming majority of individuals with problems don't bother to make complaints.[62] Doing so is time-consuming and costly. Most individuals also lack confidence that speaking out will help them or they lack the ability to do so. The evidence of this is striking for medical malpractice. A study that independently measured the rates of injury to patients due to negligent conduct in hospitals showed few people brought claims. There were seven times as many negligent injuries as claims. Since some claims occurred when there was no negligence, the number of people who suffer malpractice that bring claims is even less, between 15 and 30 cases of malpractice injury for every claim made.[63]

V. What Consumer Voice Can Contribute

Today the priorities, standards, and processes MCOs use to limit services are not transparent, subject to public scrutiny or public approval. This should not be the case. Consumers can insist that managers publicly account for their rationing and management strategies and should have means to ensure that MCO policies meet their approval. The use of consumer voice can help in four ways: (1) it can set standards and priorities for benefit coverage decisions, (2) it can open to public scrutiny the process by which MCOs make key

decisions about rationing health care, (3) it can provide feedback about local problems, and (4) it can spur organizational change.

HMOs necessarily make many health policy choices for their members. Market exit is often a crude tool for gauging consumer satisfaction on such matters since the choice of whether or not to leave reflects the consumer views on a bundle of issues. Yet with a voice in MCO policy, consumers could steer the organization in the direction they wanted. The affected public could help reorient priorities and values when MCOs veered away from the sentiments of its members. Consumers could exercise choices about the scope of benefits as well as the direction, priorities, and standards of MCOs.

Of course, affected members are unlikely to become involved in the details of organizational policy choices. It is not practical to involve MCOs members on most detailed issues. But consumers could have a say in the major decisions the organization makes and their approval could be required for strategic plans. There are likely to be periods when only a few members are interested in becoming involved. But if MCOs lose touch with their members, consumers are likely to become dissatisfied and more members will assert their views.

Consumer involvement opens up decision-making to public scrutiny. When key choices are presented to MCO members, the public can analyze them and subject MCO choices to criticism. Such a process can generate ideas that would not have been considered if a few managers made decisions privately, without a thorough discussion of the issues. The process of having to present and defend organizational choices to the public forces managers to think through options carefully thereby promoting better decision-making. Potential problems, will become known and managers can plan accordingly.

Consumer criticism can be a valuable source of information for MCOs. Often, however, the criticism is ignored by organizations. Yet when complaints are publicly available, they cannot be buried in files and managers are more likely to respond to them. Complaints may include the potential for embarrassing disclosures that could cause some members to leave, other potential members not to join, regulators to conduct an investigation, or the press to highlight the MCO in an unfavorable way. Consumer complaints, either through public forms or private correspondence, provide feedback to an organization. The disclosure of complaints may prompt the further monitoring of the MCO by consumer groups and public and private officials.

Consumer involvement in MCOs may decrease organizational efficiency because it can slow decision-making or call into question standard practices. Yet, that is also its virtue. By shifting some authority from other groups with power, consumer voice can be an engine of change. Organizational and professional routines are often conservative. If unquestioned, the status quo may continue even when new circumstances make change preferable.

Chapter II: Challenges to Effective Consumer Representation

I. A History of Consumer Involvement in American Health Care

Consumer representation and citizen participation blossomed in the Johnson administration's War on Poverty.[64] Several statutes imposed citizen participation requirements on Community Health Centers, Community Action Programs, and other recipients of federal funds. This trend continued until the 1980s.[65]

The Community Action Programs, created by the Office of Economic Opportunity (OEO), received a legislative mandate for "maximum feasible participation" of the poor.[66] It was a prominent experiment. The key idea was that institutions governed by community representatives could set priorities, manage a budget, and produce better programs than a governmental agency without roots in the community.[67]

There was little direction and a constant struggle over how to implement the participation requirements. Those speaking for the poor wanted both employment in the programs and a role in policy making. There was controversy, too, about how many poor people should serve on a community board,[68] whether citizens should give advice or make policy, and the jurisdiction of the board.[69]

The Office of Economic Opportunity Neighborhood Health Centers encouraged consumer participation and the formation of citizen advisory councils for several purposes: to shape health center policy, to implement the program, and to evaluate the center's service.[70] Neighborhood Health Centers had a majority of consumers on their boards, as did City Poverty Councils.[71] The ambulatory services advisory committee of the Ghetto Medicine Program of New York also required citizen participation.[72] Medicare was required to have consumer representation on the Health Insurance Benefits Advisory Committee, while Medicaid law mandated consumer representatives on state Medical Care Advisory Committees.[73]

The idea of citizen participation was later applied to local health planning agencies.[74] These local agencies were created to plan the use of regional resources and to control health care spending. Federal legislation mandated consumer representation on health system agencies as part of an implicit program of representing interest groups.[75] The health planning process proved only partially effective in restraining health spending for several reasons.[76] Local health planning boards did not control funds. Hospitals or groups wanting to build facilities mobilized opposition that often overrode the health planning agencies. Individuals chosen to represent consumers typically lacked the clout, resources, and institutional support that providers had. Consumer groups were not as easily or effectively organized as providers.[77]

Similar interest in consumer participation led to the requirements in the HMO Act of 1973 for consumer representation. Under the statute, federally qualified HMOs had to have at least one-third of their policymaking bodies drawn from their members. The representatives had to include medically under-served populations. This requirement was often ignored, and there is little evidence of significant consumer participation in federally qualified HMOs. The requirement was eliminated from the statute in 1988.[78]

There were important exceptions, however. A few HMOs started as cooperatives in the 1940s, and had a long tradition of consumer governance prior to the HMO Act. The most notable examples were Group Health Cooperative of Puget Sound and Group Health Association in Washington, DC. In these HMOs consumers elected the board of trustees and there was a culture of consumer participation.[79]

By the end of the 1970s the effectiveness of health planning agencies and the idea that consumer voice would be a force for positive change in health policy was questioned by many although never adequately assessed.[80] The Reagan administration defunded federal health planning agencies in 1986 and instead encouraged the use of markets to reduce health care spending.

James Morone, who has written the leading book on the history of participation in American politics, argues that citizen consumer voice in health planning made enduring contributions.[81] He contends that it changed the political agenda, wrested authority from medical professionals, and shifted authority from the medical profession to public and

private health care organizations. Such changes are ironic, for they spurred the growth of managed care and for-profit medical institutions.

There are few empirical studies evaluating the costs and benefits of consumer participation or the pros and cons of different approaches. Yet analysts have noted failures and successes.[82] Some note the trade-offs in program efficiency and democratic participation.[83] Others doubt whether such programs produce increased accountability.[84] Still others think that the goals of participation should be made clear in designing the programs.[85] James Morone suggests that such programs are based on a "democratic wish": the idea that "direct participation of a united people pursuing a shared communal interest" will overcome conflicts between diverse interests and groups and solve problems of government.[86]

This idea waxes and wanes, but does not disappear.[87] Witness the state of Oregon's recent process combining public deliberation and representation to set health care priorities for health care coverage for Medicaid and uninsured groups.[88] Morone suggests that the democratic wish does not work as proponents of popular participation often expect that it will. Yet it has, he argues, been a central instrument to bring about political and social change. Consumer voice might then help transform managed care in ways that will improve it. Nevertheless, there are many challenges to making consumer voice an effective instrument of change.

II. How to Represent Health Care Consumers

Organized Constituencies

The idea of representing health care consumers is appealingly simple but how can it be done? Who should speak for consumers? There are many ways to select consumer representatives and different institutional means to channel consumer voice. The nature of American politics, however, probably makes it necessary to have organized constituencies to effectively represent them.[89]

This poses a fundamental problem, because currently there are few organized consumer health constituencies. Everyone is a potential medical consumer, but most people do not need extensive medical care. When individuals do, it is frequently for an acute injury or illness so they won't remain a medical consumer for long. As a result, few people have strong or lasting identities as medical consumers, and this inhibits forming health care consumer constituencies or long-term consumer involvement.[90] The result: although there are many consumer advocacy groups, there are few organized consumer health constituencies.

There are some important exceptions. People with chronic illnesses (e.g., AIDS, breast cancer, renal failure, diabetes, or polio) have special concerns and long-term interests. They have often organized groups around their health concerns to promote greater funding and better treatment. There is also an active women's health movement and a disabilities rights movement which have organized groups to advance their interests on medical and other matters. The elderly have also organized on health issues, particularly regarding the Medicare program. Such groups can effectively represent their constituency.[91] They provide a model for organizing other constituencies around specific diseases or status (gender, age cohort, ethnic group), or through one's place of employment. Although these groups are not organized to represent consumers on managed care issues or within managed care organizations, they are familiar with health issues and consumers. In many situations, disease specific groups may advocate for changes in MCOs that will affect quality of care and patients' rights generally. Such groups are likely to make MCOs more responsive to patients and to improve the quality of care for all consumers. Disease specific and other interest groups may therefore be a vehicle for improving quality for all health care consumers.

However, there are limits to representation through interest groups. Interest groups excel at representing their own constituency by focusing on their narrow concerns. The problem is that not all consumer interests are easy to organize. As is true for American politics generally, those interests that are not organized will be neglected.[92] Furthermore, most health care constituencies currently organized don't have managed care as their focus. Nevertheless, for practical purposes, drawing on organized constituencies is probably the most effective way to represent health care consumers. Such groups will promote consumer welfare better when they are broad-based coalitions of discrete interest groups. Consumer advocates can and should organize such consumer groups.[93]

Institutional Consumer Advocates

An alternative or complement to organized constituencies representing consumers is to have institutions that are designated to advocate for consumers. These could include a government agency for health consumer affairs, a division of consumer affairs in an Attorney General's Office, or a consumer representative in state health care insurance commissions or departments. It could also include Ombud in MCOs and other health care organizations.

Representatives in Attorneys General Offices. Many states have established divisions to advocate for consumers in utility hearings.[94] Often situated in the state Attorney General's office, these units take part in rate-setting. Such offices have been very effective in analyzing finance and equity issues and in convincing rate-setting bureaus to heed their advice. A consumer affairs unit following the utility model could be established in state offices that regulate insurance or health care. They could evaluate information that managed care firms disclose and recommend policy changes or oversight if needed.

Such representatives could develop expertise and be in a position to influence the decisions of the regulatory agency.[95]

Ombud.[96] MCOs and state or federal agencies could create Ombud programs for health care consumers. Some MCOs have already done so.[97] They serve several functions. They provide information and assistance to individuals in resolving problems they have with an organization. Ombuds also inform the organization of problems it has and, where appropriate, suggest changes in organizational policy or procedures. They also advocate for consumers, both to resolve individual problems and change policy. There are several examples of ombud or independent assistance programs for health care. The National Health Law Program is coordinating ombud in six sites.[98] The Center for Consumer Rights in California has also created an independent assistance program.

There are two main models: (1) those independent of the organization they investigate, and (2) those that work within the organization they investigate. Ombuds independent of the organization have much more freedom but not necessarily much clout with the organization. Those working within the organization are likely to have access to officials and information and better relations but also divided loyalties and less discretion. To be effective, ombuds need security of tenure, independence, resources, clout, and political savvy. The role requires a combination of skills: cajoling insiders informally, making use of the press, building allies with outside groups or public agencies to put pressure on an organization, and writing reports that command respect.

Legal Services Organizations. Through grants to state legal aid organizations, the federal government provides legal aid for the poor. Legal service organizations provide assistance to individuals, often on issues involving Medicaid, Medicare, and other health care programs. Legal aid organizations have expertise on the common legal problems the poor and elderly encounter. They are an important institutional base for representing the poor on health care problems involving managed care.[99]

III. Potential Health Care Constituencies

Disease Specific Groups

Many advocates for people with specific chronic illnesses have designated constituencies (e.g., for AIDS, Gay Men's Health Crisis). Having a focused concern gives such groups a defined mission and facilitates advocacy. Depending on their political clout these groups can be very effective. Can individuals with other diseases or medical conditions also form constituencies to promote their interests? Yes, for certain illnesses, but not for many others. For purposes of organizing it helps to have a chronic medical condition. It also facilitates organizing if the individuals likely to be affected share a common status or background (being a woman, or gay). People with episodic or acute illnesses are less likely to identify themselves as a group or to organize. Thus people who have a wide variety of non-chronic diseases are unlikely to organize as constituencies.

The Elderly and Other Age Cohorts

Since the creation of the Medicare program in 1966, the elderly have become a potent political force on health care issues. Medicare entitled them to health care benefits, which concentrated their interests in program benefits and policies. The elderly mobilized easily because their interests were clear: they are more likely to use health care than younger people and program benefits affect them directly. As a group they also have more income and leisure than the average American. Groups such as the American Association of Retired Persons have represented the health care interests of the elderly. Other groups, such as the Medicare Rights Center (New York), have formed to advocate for Medicare beneficiaries.

Today there are attempts to expand health insurance to cover the young. Groups such as the Children's Defense Fund have made such an effort one of their priorities. However, there are certain obstacles to youth becoming an organized health care constituency. Individuals under 18 can't vote, typically do not have serious illnesses, and are economically dependent on parents or guardians. They also will outgrow their group membership as they age. These factors make it harder to organize the young than the elderly as a constituency for health care.

Gender

Starting in the late 1960s, women organized to advocate for their rights in employment, education, health, and other areas of social life. They opposed stereotypes that portrayed them as less capable than men and employment discrimination, which blocked job opportunities. Although they did not conceive of themselves as health care consumers, as women they encountered common problems with the way doctors and the health care system treated them. The fact that there was already a women's movement and women's groups facilitated mobilization around health care issues.

The issues raised by the women's health movement started with reproductive rights, birthing, and gynecological issues. It soon expanded to include a much wider range of issues. It now even includes advocacy for using women as research subjects so that differences in physiology will be considered in developing medicines and medical procedures. It also includes advocacy for better treatment of women with cardiovascular and other diseases that are often neglected because doctors don't perceive them as affecting women to the degree that they affect men. What is notable about the women's health movement is its resiliency. The issues and strategies have evolved, but the ability to mobilize women around common issues has not diminished even among women who do not view themselves as feminists or politically active.

Ethnic Goups

Ethnic groups are a potent force in American politics. They have electoral influence and a net of related community and national organizations to represent them. Could they be a vehicle for representing health care consumers? In part, they could. The question is whether health care issues are a prominent enough issue to be the focus of their concerns. It is likely to be so when particular illnesses or health care issues affect them disproportionately and are not being adequately addressed in other ways. However, illness or health care issues are not the basis for their being a constituency or, in the American experience thus far, for their forming interest groups.

Employees

Most people receive their health insurance through their employer, which makes groups representing employees, such as labor unions, a natural forum to represent health care consumers. However, less than 14% of the American work force is unionized, so this approach would not work for the majority of Americans.[100] For those employees who are unionized this could be an effective means to represent worker interests. Unions already have an organizational means to express their views to employers, resources to address employee concerns, and a system of electing leadership to represent the views of members. Most unions bargain over the extent of health benefit coverage and costs of insurance for employees. Some unions have sponsored Taft-Hartley health plans, which purchase health care for employees. Still, unions have not typically joined employers in representing employee views in purchasing cooperatives that buy health insurance for large employers or made representing employee health care interests a significant part of their mission. Yet unions could become a significant vehicle to represent consumer/employee voice if they chose to do so, as could other employee organizations that might be formed for this purpose.[101]

Independent Consumer Advocacy Groups

Several consumer groups (including the National Health Law Program, Families U.S.A., and the Public Citizen Health Research Group, Consumers Union, the Center for Health Care Rights) advocate for consumers on health issues without having a precise or narrowly defined constituency to which they must answer.[102] These self-appointed consumer advocates are often very effective at lobbying for legislation or changes in regulation, initiating strategic litigation, analyzing consumer health care issues, assessing choices available to consumers, and speaking truth to power. They represent consumers before state and federal legislatures, monitor the actions of private firms and governmental institutions, and disseminate information to consumers. They have performed important functions by championing a patients' bill of rights for MCOs, and assessing federal and state laws regulating managed care (Families U.S.A.); by advocating for the poor and elderly and assisting in coalition building (the National Health Law Program); by criticizing the abuses of MCOs and advocating for health system reform beyond incremental change (Public Citizen Health Research Group); by evaluating MCOs (Consumer's Union); and by creating ombud programs and analyzing consumers rights (Center for Health Care Rights). They are likely to continue to be key sources for representing health consumers in national forums. However, they are unlikely to be vehicles to represent consumers at the local level or within individual MCOs.

IV. Choosing Consumer Representatives

Often MCOs or other organizations will need a consumer representative. Such representatives can either be appointed or elected.[103] If appointed, the representatives can be chosen by consumer groups, governmental agencies, MCOs, or by a neutral party. Alternatively, a board of two of more such groups can choose the representative.[104]

Appointments

There are advantages in having established consumer organizations appoint consumer representatives. There is a greater chance that they will represent a constituency and the organizational representative will have greater credibility than most unaffiliated individuals. The organization also will be able to provide resources, expertise, and experience to assist the representative and they will have some formal or informal means to ensure that the representative is accountable to the group. On the other hand, critics can always ask whether the organization in fact represents consumers beyond its members.

But which consumer health organization should represent consumers? Usually there is more than one that would like to assume the role. Choosing the organizational representative is more difficult than choosing who should represent workers in labor-management negotiations. There, the National Labor Relations Act establishes procedures for employees to vote for union representatives and for designating a union as the exclusive agent of employees for bargaining with management over employment contracts. One way to address this issue is to have the leading consumer health groups form a coalition or consortium for purposes of choosing representatives.[105]

If organizations that represent constituencies are not used to represent health care consumers, then one needs to seek out appropriate individuals through other means. How might health care consumer representatives be chosen? What individuals might perform such roles? Many people now believe that representatives should reflect the social, ethnic, or other characteristics of the population they represent. By virtue of their similar characteristics such individuals are assumed to have the viewpoint and opinions of the group and

to be able to represent its interests. Being poor was one of the main qualifications for selection of a substantial portion of the members of Neighborhood Health Centers established under the War on Poverty programs in the 1960s. Similarly, a program targeting youth would try to involve young persons as representatives. Often racial or other ethnic background is considered sufficient to represent a particular racial or ethnic group. For health care issues, individuals might be chosen because of their medical characteristics. For example, people with different diseases or disabilities could be chosen to represent the point of view of persons with their specific conditions. Choosing representatives because they reflect the social or medical characteristics of the group they represent, however, assumes that most individuals in such a class or ethnic group will have similar views and interests. That's not necessarily so. Choosing representatives to look like the represented group with nothing more in common offers symbolic representation.

Many people believe that if an individual is chosen to represent the members of a particular MCO the representative should be a member of the MCO. Membership will ensure some familiarity with the organization but it will not necessarily ensure that the representative has knowledge of health care issues or expertise, or that he or she is an effective advocate, qualities which are more important than organizational membership.

Elections

There are some advantages in electing rather than appointing representatives. Elected representatives can be removed if they do not reflect the voters' views or otherwise perform poorly. There are fewer issues concerning the representative's legitimacy. The most practical way to elect consumer representatives is through existing organizations representing defined constituencies because we lack a tradition or other institutional means to elect consumer representatives from the public at large or to represent a region.

Consumer representatives could be elected by members of each MCO.[106] Such representation is the exception rather than the rule, the main example being Group Health Cooperative of Puget Sound (GHCPS), whose members elect its governing board. Although GHCPS has had an effective board, consumer governance is not feasible for for-profit MCOs that must be responsive primarily to stockholders. But consumer representatives that did not have ultimate responsibility for governing the MCO could be elected in most MCOs. It's not clear, however, that there will be much participation in such elections. Even at GHCPS, which has a long tradition of being consumer governed, voter turnout for election of trustees has been low, around 5% for most of the last decade and only up to 15% for the last few years when there were controversial issues.[107]

Although the idea of electing consumer representatives for MCOs may seem daunting there are some models of such organizational democracy. Most schools have Parent Teacher Associations (PTAs) that are elected and in some school districts the associations can even control funds they raise for hiring additional teachers. Even when they do not control funds, PTAs can exert voice and can command respect from school administrations for a range of issues. Some cities have active "block associations" of neighborhood residents. Tenants have formed renters' associations. If individuals can become involved and elect representatives in such local associations, they might do so for consumer associations in MCOs if such associations had real power or influence.

V. Will Consumer Representatives Have Influence?

A formal means to choose consumer representatives is necessary for effective representation, however, it is not sufficient. A seat on a board or committee has value based on what the representative can do. In some instances the representative's influence may be minimal because the board or committee on which the representative serves lacks power or influence. This fundamental point is often ignored. Considerable effort is spent in creating representative mechanisms without considering the influence representatives would have. Often consumer representatives serve on boards that have only symbolic value or token influence.

Even if a consumer representative sits on a board that has power, the consumer voice may be drowned by others. A single consumer representative serving on a board of twelve individuals will have little impact on the outcome of votes. Of course, the consumer representative can try to persuade the majority of the board. However, reason is enhanced when backed by power. The persuasiveness of a consumer representative is strengthened if the representative is backed by consumer groups that must be taken into account because they can influence consumer enrollment in MCOs or use their clout to get legislation enacted.

Sometimes consumer representatives may lack influence because they are unfamiliar with the issues or untrained in disciplines that would help them work with health care and management professionals. Some observers have advocated training for representatives to improve the effectiveness of consumer participation. The Citizen Advocacy Center has worked for several years providing such training.[108] However, good training can't make up for deficiencies in the resources, organizational support, or networks the representative can command.[109]

Representatives may lack the time, funds, and other support to evaluate claims that management and other groups make,

conduct research, assess how consumer interests are affected by different proposals or policies, write reports, mobilize support, and perform similar activities. Such resources for consumer representatives can be provided either by the organization in which the consumer serves or a consumer group.

An MCO or state agency can put its own professional staff in the service of consumers. This might be administratively simpler than other approaches. Staff drawn from the MCO is likely to be familiar with managed care issues and perhaps have greater access to information from the organization. Moreover, advocacy staff drawn from the MCO can also promote consumer-oriented values in the organization that probably would facilitate consumer proposals being accepted by operating personnel. The experience with the consumer advisory board suggests that proposals are more likely to be implemented if they are supported by the organization's staff as well as top management.

MCO staff members, however, will have divided loyalties and might not provide consumer representatives with the kind of neutral analysis or effective consumer advocacy they desire. Consumers would also be limited by whatever information the MCO staff provides. An alternative would be for the consumer organization or consumer representative to hire their own professional staff. An advantage of using consumer organization staff is that they are likely to have expertise in areas of consumer concerns and share consumer perspectives. There may also be economies of scale since the same staff could provide information and analysis for representatives serving in several different forums. Drawing on staff of consumer organizations would also encourage communication between the organization and consumer representatives. It would promote accountability of the representatives to the organization.

It will be easier for MCOs to raise funds for professional staff than it will be for consumer groups because MCOs can assess the fee as part of the premium for all their members. This is an efficient mechanism to raise funds and the means to collect them are already in place. The argument for such premium-based funding is simple. The services will benefit all members, and so the cost of services should be shared by all. Moreover, if all MCOs fund consumer representatives this way, no MCO will be at a competitive disadvantage. Such a consumer representation fee could be tried as an experiment by states, perhaps through its regulation of health insurance, and continued or eliminated, depending on the experience.

Chapter III: The Range of Ways Through Which Consumer Voice Can Influence Managed Care

I. Consumer Influence from within MCOs

Avenues for consumer voice, participation, and representation within MCOs are relatively unexplored.[110] In at least one other industry, there has been some experimentation with representing consumer views. A study of the auto supply industry by the economist Susan Helper showed that firms with combined systems for soliciting both employee suggestions and consumer voice achieved greater cost savings and improvements in quality than firms which did not use both employee and consumer voice.[111] Helper concluded that representing consumer voice within firms is particularly valuable when there is a long-term relationship between producers and consumers, conditions that appear to hold for managed care.[112]

Voice, participation, and representation within MCOs would offer additional benefits not available through consumer involvement in outside groups that can influence MCOs. Such representatives would be close to the consumers served, aware of local problems, and positioned to focus on them. There might also be greater willingness for consumers to become involved in institutions that would directly affect the health care they received.

The systematic representation of consumer views could be part of the process by which MCOs learn, adapt, and improve. The views of consumers could be represented in oversight, governance, and advisory boards as well as in the management of operations. Data on complaints and grievances as well as opinion surveys reveal consumer views. There are several examples of how this might work.

Oversight Boards

Many organizations provide for oversight by quasi-independent officials. Banks and other financial institutions have auditors. Government agencies have inspectors general, and both private and public organizations have experimented with ombud. These officials typically have authority to conduct investigations and obtain confidential information.

MCOs could create oversight boards modeled on inspectors general or auditors that report to a consumer board or a board with consumer representatives as well as to top management. Such a board would play a role *only* when there were significant problems, scandals, or the appearance of impropriety. However, their existence would bolster public confidence and consumer trust.

Governance

Consumer representation on a governing board would allow voice and participation in the direction of managed care organizations through consumer representatives. The power and operation of these boards varies widely, yet all may provide some opportunity for consumer representation.

For-profit MCOs are usually monitored by a board of directors which oversees management and has power to dismiss the Chief Executive Officer. Elected by shareholders, directors are supposed to act in shareholders' interests—not consumers. However, a few corporations have appointed a trustee to represent environmental interests (for example, Exxon after the Valdez oil spill). And in recent years organized labor has purchased stock and been represented on the board of directors of some firms, for example, United Airlines. Consumer representatives might also be granted a seat on the MCO boards. However, without a constituency that owned stock they would have less clout.

A board of trustees directs nonprofit MCOs. They are supposed to act in the interest of the public, which includes but is not limited to consumers. However, typically there is no election or other mechanism to ensure that trustees represent the interests or views of consumers and it is usually management who nominates or chooses trustees. Nonetheless, nonprofit MCOs could place consumer representatives on their boards.

A cooperative is the easiest means to represent consumers in governance since it is the consumer members who vote for trustees. Group Health Cooperative of Puget Sound, which has existed since 1947, has health plan members vote for trustees. Even with consumers electing trustees, there are

difficulties in fostering consumer participation and voice. And in the current health care market, starting a new cooperative would be difficult since a new nonprofit organization would have difficulty gaining access to capital or a significant membership.

Operations

Trustees and top management set the direction of a firm. Others control daily operations which are crucial to organizational success. With increasing frequency MCOs have physicians and other providers serve on committees or participate in groups that set medical protocols and organizational policies. Consumer views could also be represented on various MCO boards and committees that deal with operations. These might include boards reviewing grievances and appeals, committees that set policies for benefits covered, and committees that address particular issues of operations.[113] Voice in day-to-day operations could well have the greatest impact on how consumers experience managed care.

Complaints and Grievances

Many states require MCOs to have an internal grievance process. The National Committee for Quality Assurance (NCQA) also requires an internal grievance process for its accreditation, however NCQA accreditation is not necessary for MCOs to operate in all states. Federally qualified HMOs must also meet provisions of the HMO Act of 1973. These provide an opportunity for consumers to voice their complaints or to appeal an MCO's denial of service. Complaints can be a source of information for management to supplement opinion surveys. Such mechanisms are a useful, yet limited, vehicle for individual consumer voice. Most consumers with problems do not bother to file complaints or appeal organization decisions, and many individuals do not have the resources to adequately represent themselves in the appeals process.

Many, if not most, MCOs review appeals internally according to their own organization's criteria. Such processes can weed out errors made by individuals in applying organizational standards and may help alert MCOs to problems of which they are not aware. However, they cannot help correct other problems resulting from MCO standards that consumers or others believe are inappropriate. To resolve such problems there needs to be review by independent parties not chosen by the MCO.

Two approaches in particular could foster the role of participation and voice. First, MCOs might place members or consumer representatives on the committee that reviews complaints and appeals, perhaps as a majority. Second, MCOs could be required to publish information about the complaints received and their resolution. The first approach allows consumers a role in administering standards. The second would help ensure that problems receive the attention of top management, as they would seek to avoid negative publicity from unfavorable reports.

Advisory Boards

Advisory boards can be used in multiple areas of an MCO, including oversight, governance, and operations. Advisory boards can range from those created with specific mandates and limited time spans to standing boards or committees of general jurisdiction that can offer continuing feedback and address numerous issues as they arise. Some of the most effective advisory boards are those convened to address specific issues. They have a focus and bring together people chosen for a distinct task. For example, several electric, gas, and telephone companies have convened advisory groups for advice on creating billing statements that are easier for consumers to read and understand. Kaiser Permanente has recently convened a blue ribbon advisory panel to advise them on improving their system for arbitrating malpractice claims. Advisory boards are frequently used to represent the views of consumers or other groups. They allow firms to obtain advice, satisfy demands for change, and yet still leave management discretion in decision-making if they do not wish to follow the advice.

Public Opinion Surveys and Focus Groups

MCOs typically survey consumer opinion using focus groups, satisfaction surveys, exit polls, and other approaches. Such information helps management obtain information to gauge consumer wants and correct problems. It can be used for marketing purposes as well. If conducted properly, surveys can more accurately and precisely measure opinion of MCO membership of particular groups within MCOs than can voice expressed through representative institutions or advisory boards. Surveys also allow opinion gathering on detailed issues, something that representative institutions are not designed to do. Another advantage of such information to the firm is that it is usually confidential and there is little risk that the process of obtaining information will cause embarrassment, stir up consumer dissatisfaction, or lead to new consumer demands.

From the consumer perspective most surveys of consumer opinion are limited because they are not instigated, directed, interpreted, or routinely accessible to consumers.[114] They remain a management tool and can be used for management's purposes. If consumers directed what would be surveyed and controlled the dissemination, such information could become a powerful tool for consumers.

Consumer groups could design surveys, and decide what questions are asked and how the answers are disseminated. Neutral outside groups, too, could design and carry out surveys. In any event, if groups outside of MCOs carry out a survey of several MCOs, this would facilitate comparison

among organizations. If made public, such information could affect the choice of health plans by employers and consumers, which in turn could prompt MCOs to respond to consumer concerns.

II. Consumer Influence on Managed Care from Outside MCOs

Today, there are more opportunities for representing consumers in institutions outside of MCOs than from within. The policies and actions of both private groups and public agencies influence MCOs.

C*onsumer Influence in the Public Sector*

The public sector influences MCOs mainly through public purchasers, legislatures, administrative agencies, legislatures, boards or commissions, ombud, grievance and appeal mechanisms, and courts.

Through legislatures, administrative agencies, the executive branch, and independent commissions, government has authority to act on behalf of the public, including consumers. Such public authority can provide a variety of ways to oversee MCOs for consumers. The most important are noted below.

State and Federal Legislatures. Elected by the public at large, legislatures are the classic democratic means to represent the public's views. Our system of interest group pluralism, however, assures that the best organized groups will be better able to influence legislators and are therefore most effectively represented.[115] It is typically producer or provider groups—rather than consumers—that have concentrated interests and are most influential.

However, on some issues consumer groups are able to marshal effective public support and form strategic alliances to enact legislation they favor. The recent outpouring of legislation restricting drive-through deliveries and gag rules, and other regulation of managed care, show that consumer voice can result in legislation that changes how MCOs operate. The advantage of legislation is that it creates binding legal authority. Nevertheless, it is only one of several avenues for consumer voice, and it has limitations. It is easier to pass than implement legislation. Legislation is also time consuming and cumbersome. Moreover, it is usually more appropriate when used to address general problems, set broad standards or create regulatory authority than to resolve detailed problems in the organization of managed care.

One potential use of legislation would be to create new institutions—both within and outside of MCOs—in which to represent consumers' views. Proposals promoting such organizational democracy will be viewed as radical and are unlikely to be enacted anytime soon. Ironically, experiments in organizational democracy might come about voluntarily as MCOs decide they would prefer to have consumers play a greater role within their own organizations rather than have them exercise their voice through legislation. Recent voluntary consumer protection standards proposed by the industry are an example of the managed care industry's response to consumer protection legislation and the prospect of greater governmental supervision.[116]

State and Federal Agencies. MCOs are now subject to divided oversight by multiple state agencies with diverse missions. These state agencies include those that regulate insurance, health care, private and charitable corporations, and Medicaid programs, as well as Attorney General Offices, which in most states have general jurisdiction to protect consumers. None of these agencies were established for the purpose of overseeing managed care in a comprehensive way. The requirements of the agencies also vary. Some oblige MCOs to report information, while other state agencies approve an MCO benefit package and other terms of the contract with consumers. Still other agencies can investigate or sanction MCOs.

Consolidating some of these functions in a new agency would have advantages.[117] The new agency could oversee health care or managed care, acquire expertise, and develop a focus. Activities that now take place in different agencies could be coordinated more easily. If established with appropriate powers, the new agency would have tools that do not exist currently to represent consumers.

There are, however, limitations to a new agency. It may lack the political independence and strong mission for consumer protection that the Attorney General and other directly elected state officials now have. It might also lack the powers, resources, or expertise of other state agencies. Also, if a single agency oversees all of health care or managed care, representing consumers may not take as high a priority given its multiple missions.

Today, several states have an office to advocate for consumers in utility rate-setting hearings or health insurance. It may conduct research, analyze evidence, and make recommendations in hearings. Such consumer bureaus serve as a model for representing consumers in managed care or health care more generally. Although such intervenors have focused on financial issues for consumers (cost savings from lower premiums/rates), intervenors in managed care could also focus on broader issues including quality of care.

The Office of the Attorney General is a particularly appropriate site for a managed care consumer advocacy bureau. Attorneys General have an independent source of authority as they are directly elected. They perform multiple functions including enforcement of consumer protection law, lobbying for new consumer legislation, resolution of consumer disputes through

alternative dispute resolution, and public education on consumer issues. These features make the Office of the Attorney General institutionally flexible and competent to address new consumer issues. Other bureaus in various state agencies could also advocate for health care consumers if they were granted appropriate authority.

Federal agencies also oversee MCOs through various federal programs. These include the Health Care Financing Administration, responsible for Medicare; the Department of Labor, which the Employee Retirement Income Security Act authorizes to supervise employee benefits, including health benefits of self-insured firms; the Veteran's Administration; and the CHAMPUS (Civilian Health and Medical Program of the Uniformed Services) program. Consumers could be given more voice in policies that these agencies adopt.

The Health Care Financing Administration (HCFA) has a list of 150 consumer advocacy groups which it consults on various initiatives. All groups are invited to a monthly meeting; usually about 45 attend. HCFA also consults with advocacy groups when issues arise. Recently it consulted consumer groups on marketing guidelines for HMOs and a booklet on consumer rights in HMOs. Several states also have consumer representatives on Medicaid advisory boards, and states have Medical Care Advisory Committees for Medicaid. The latter have not focused on managed care and have not generally had significant influence.[118] Several states have also held hearings in developing their Medicaid managed care programs.

State and Federal Boards or Commissions. State and federal governments frequently establish commissions, task forces, or boards to oversee a program or to investigate a problem; these groups can include consumer representatives.[119] Some are ad-hoc or short-term, for example, the Presidential Commission on Consumer Protection and Health Care Quality and the California Managed Health Care Improvement Task Force. Each of these has members who were appointed to represent the interests of consumers. Other long-standing commissions which influence policy include the Medical Payment Assessment Commission (MedPac), the former Physician Payment Review Commission (PPRC), and the Prospective Payment Assessment Commission (ProPac). These commissions do not have representatives appointed specifically to represent the interests of consumers; however, it may be appropriate to have consumer representatives in the future.

State and Federal Ombud Program. State and federal governments could establish ombud programs for managed care plans that they oversee in Medicare and Medicaid.[120] Several states have established such programs.[121] Given appropriate new legislation they might also create similar state or federal programs for firms in the private sector as well. A useful model for such a program is the nursing home ombud created by the Older Americans' Act.

Nursing home ombuds have two main functions: (1) to advocate for individuals in nursing homes and other institutions for long-term care; and (2) to advocate for policy changes and to promote the development of citizen organizations and resident and family councils. The Institute of Medicine evaluation of the long-term ombud program suggests that it is more difficult to successfully advocate for policy changes and integrate state policy than to perform individual advocacy services. Policy advocacy might be easier to perform if the program were not so decentralized.

The federal government funds the nursing home ombud program and specifies the functions to be performed, but administration is carried out by states. State Units on Aging direct most programs and either report to the Governor or to larger agencies of which they are a part. The State Units on Aging often contract with public or private nonprofit agencies to carry out their responsibilities, but some hire staff and supervise volunteers directly.

State programs vary, of course, but all investigate and resolve complaints, monitor nursing home compliance with law, and disseminate information. Ombud are directed to advocate for residents of long-term care facilities rather than serve as neutral parties. Nursing home residents are guaranteed direct access to ombud services. States, too, generally are required to guarantee ombud access to nursing homes and patient records.

Medicare Appeals/Center for Health Care Dispute Resolution. The Health Care Financing Administration hires an independent group, the Center for Health Care Dispute Resolution (CHDR), to review Medicare beneficiaries' appeals from denial of claims or services. The independent review that CHDR performs allows consumer voice to be heard by evaluators outside MCOs, and the information CHDR receives is available to administrators in the Health Care Financing Administration. Although the information is public, it is not publicized. Publishing and disseminating this information might make MCOs with problems more attentive and spur corrective actions.

State and Federal Courts. Consumers can use courts to voice their complaints and represent their interests on private and public disputes. Courts can order parties who cause consumers harm to pay compensation, or require private organizations to change their practices to conform to the law. The use of litigation to resolve individual disputes is very costly and often not economically viable except in class action lawsuits. Nevertheless, strategic lawsuits can change policy. For example, class action lawsuits were instrumental in getting HCFA to develop stronger due process rights in managed care.[122] Although other ways of representing consumer interests are often preferable, most parties do bargain with a sense of what they might win or lose if the dispute were resolved in court.

Consumers have used courts to bring suits against private firms that do not respect their rights and against governmental agencies that do not perform their oversight roles. Recently, a federal court found that the Medicare system of grievance and appeals did not provide due process of law and ordered changes in the program.[123] And the California Supreme Court allowed a suit to proceed which charged that an MCO had unfairly administered its binding arbitration system for resolving malpractice disputes.[124]

Consumer Influence in the Private or Nonprofit Sector

The main private and nonprofit sector influences on MCO policies come in four ways: from purchasers, private accrediting or standard setting agencies, ombud programs run by private non-profit groups, and public opinion surveys.

Purchasers of Health Care and Third-Party Payers. Third-party payers and purchasers of health care negotiate with MCOs over benefits, premiums, quality, and the terms under which services are provided. Employers have used their purchasing power to negotiate arrangements they prefer for their employees. In some cases they have imposed more stringent demands on MCOs than most governmental rules. Employers have represented their interests as individual firms and sometimes collectively through purchasing cooperatives which pool the purchasing power of several firms or governmental agencies. These include the Pacific Business Group on Health and the Washington State Health Care Authority.[125] Purchasing cooperatives can coordinate the views of disparate purchasers and bargain with MCOs. Because they control the flow of funds to MCOs, they can have extraordinary clout.

While purchasing cooperatives buy health insurance on behalf of their employee-consumers, it is employers who control what is purchased, and their interests are not always the same as employees. What is now lacking in purchasing cooperatives are mechanisms for directly representing consumers. Consumers neither control the funds nor have sufficient clout to have a significant role. In the future, employee-consumers might seek representatives on boards of purchasing cooperatives. Representatives might be appointed by unions, elected by employees, or jointly chosen by management and employees.

There are also some opportunities to represent consumers for firms that self-insure. Union or other employee representatives could participate in the oversight or management of the managed care plan. Representatives could provide advice or participate in the management or operation of health plans. Even with third-party payers, such as Blue Cross-Blue Shield or private insurers, there are opportunities for representing consumers.

Private Accrediting or Standard Setting Organizations. Several private organizations set industry standards or draft model laws for MCOs. These include the National Committee for Quality Assurance (NCQA), the Foundation for Accountability (FACT), the Joint Commission on Accreditation of Healthcare Organizations (JCAHO), and the National Association of Insurance Commissioners (NAIC). Most, if not all, now designate consumer representatives either to advise them or to serve on committees which develop standards. Representation of these groups is a constructive way to affect the practices and policies of the managed care industry.

Standard-setting organizations use a variety of ways to select consumer representatives. For example, the NAIC, which drafts model state laws on insurance, budgets $60,000 a year to pay the out-of-pocket expenses of the 12 consumer representatives who participate in their quarterly meetings and work groups. Approximately 1500 individuals, primarily from the insurance industry and state insurance agencies, attend the quarterly meetings. Consumer representatives take part in meetings and offer advice and comments on draft model laws. But only insurance commissioners or their staffs are on the committees that draft the model laws.

The funding for the 12 NAIC consumer representatives is awarded by the ten-person board that includes five insurance commissioners and five consumer representatives serving staggered terms.[126] The five insurance commissioners and three consumer representatives currently on the board select the two new consumer board members.[127] The board reviews applications from individuals or groups and decides which individuals would be most appropriate to fund, considering both the group represented and the financial needs of the organization.

The NAIC and other standard-setting organizations have chosen individuals with credible qualifications to represent consumers. Having consumer representatives ensures that some consumer concerns are heard. However, these representatives usually lack time and resources—and sometimes expertise as well. Currently, representatives are not accountable to consumers in general, although members of consumer organizations are likely to represent at least the views of those organizations.[128] The small number of consumer representatives in these standard-setting organizations also reduces their influence.

Standard-setting organizations such as NCQA and JCAHO also evaluate MCOs as part of the process of granting accreditation. The Health Care Financing Administration also inspects HMOs that participate in Medicare. Typically, consumer representatives do not participate in these inspections and lack access to the detailed findings.

Standard setting organizations affect the practices of the managed care industry across the board. Involving consumers at this level can have a national impact and may eliminate problems by ensuring that all MCOs conform to minimum standards. However, consumers may also seek opportunities to address the problems of individual MCOs and for this they will need to become involved within MCOs.

Privately Run Ombud or Independent Assistance Programs. Such programs can help consumers when they have difficulties in dealings with MCOs. Ombuds assist consumers with grievances, identify systematic organizational or industry problems, and make recommendations for addressing them. In brief, they represent consumer interests and voice their concerns.

The classic tension in ombud programs is between independence and control. Ombud programs lodged within a MCO or governmental agency may lack independence, either in action or funding, but they are likely to have greater authority and the ability to contact directly and influence key individuals who can resolve the problem. Freestanding programs are more likely to be independent but also perceived as outsiders; they have less influence and often lack knowledge of the most effective means to address the organizational problem. In general, the program's effectiveness depends on the skills of the individuals who run it and the way it is organized and financed.

One way to set up an ombud or independent assistance program is for the state to contract with independent organizations to perform these functions for an area. For example, the Center for Health Care Rights in Los Angeles, with funding from private foundations, runs an independent assistance program for members of managed care organizations in four counties in the Sacramento area.[129] It operates a hot line, makes referrals, offers advice, and collects complaint information for analysis, intervention, and public dissemination. It also assists individuals in filing appeals within MCOs.

One important feature of independent assistance/ombud programs is often overlooked: the link between individual assistance and advocacy and efforts to address systemic problems. With appropriate resources, programs that provide services for individuals are able to identify patterns that reveal problems best addressed through general organizational or policy changes. If these problems are then addressed, the ombud/independent assistance program will have helped all consumers, not only those who voiced their complaints and sought assistance. The broader the base of consumers served by the ombud, the more easily such systemic change is facilitated. However, certain populations, such as Medicare beneficiaries, may have special concerns. These might be better addressed by ombud programs designed to serve them exclusively. The Medicare Rights Center performs such a role now, and future assistance programs could be created to serve other groups.

Public Opinion Surveys. Surveys reveal the views of consumers who do not normally voice their opinions or actively participate in organizations. They also enable complex analysis of how the opinions or experience of consumers vary depending on several variables, including different social characteristics, diverse organizations or medical practices, and how these change over time. They can be a powerful tool to discern consumer views and perceptions. MCO management, consumer advocates, representatives, and public officials often use surveys to inform their choices.

There are advantages in having independent groups poll consumers using surveys and focus groups, rather than rely on the survey information provided by MCOs. It may be less biased. An independent group can also obtain information across MCOs using the same survey instrument, thereby facilitating comparison. In addition, independent groups can design surveys to obtain the information that consumer advocates and representatives need rather than rely on information obtained for purposes of marketing or other uses by MCOs.

The information that independent groups obtain from surveys is not a substitute for consumer participation. Information alone does not produce change. Nevertheless, the information can be reported to and used by consumer groups and representatives (as well as MCOs and public officials).

Chapter IV: Voice and Representation in Perspective

Today, MCOs benefit from public subsidies, exercise authority over individuals, and redistribute and ration resources. MCOs thus have enormous influence over the kinds of services that individuals receive and the quality of their lives. In effect, private institutions are assuming public functions. Yet, most individuals have little choice over whether or not they receive health care through such organizations.

By and large, public policy treats MCOs as if they were merely private organizations that only incidentally affect the public. Yet the enormous influence that such institutions play in making policy suggests that the public should have a greater voice in the policies and processes of MCOs. Moreover, the usual approach to making organizations respond—letting individuals choose among competing providers—is not sufficient to make MCOs accountable to the public.

Relegated to the periphery of our health care system for most of the last 35 years, consumer voice and representation currently play only a minor role. There are, however, several models for representing consumer interests. This report explores the pros and cons of options to represent consumers. These include a variety of ways to exercise voice within MCOs and additional ways to represent consumers within public and private institutions that affect the policies of MCOs. We may also need to create new ways in which the consuming public can exercise its voice in MCOs.

There are, of course, also limitations of consumer voice. Unchecked, consumer voice could lead to as much imbalance as when the health care system is dominated by providers. Consumers might demand too many services. Consumer groups may become divided and polarize issues, leading to increased conflict[1.30] The idea of participation might become a goal in itself rather than a means to improve services for MCO members.[131] Consumer voice can make decision-making slower and less efficient and organizational planning more complex.[132]

However, these are not the problems of our health care system today, and they can best be addressed when consumer representation develops a more significant role. We currently lack a reasonable balance between consumer voice and management. The overriding problem of MCOs today is the absence of effective consumer voice or institutions to represent consumer interests.[133] Rather than too much consumer involvement, it is far more likely that MCOs and other organizations might create institutions to represent consumers that are symbolic rather than real.[134] Symbolic representation might then be used to contain consumer involvement in minor choices, or to co-opt consumers into supporting the decisions and plans set by management rather than promoting accountability.[135] There is also the risk of providers masquerading as consumers.

Today, the public needs a greater consumer role in the governance, operations, and oversight of MCOs. To be effective, representatives must have real authority and influence, rather than merely the ability to offer advice or participate in decision-making in a tangential way. The experience of public representation in other areas suggests that constituencies need to be organized to effectively represent consumers and that representatives need to be answerable to these constituencies. Training, funding, and support by constituency organizations are also important if representatives are to play an effective role.

Our future challenge is to foster balanced and effective use of consumer voice. Under the right circumstances, consumer involvement can put managers in touch with the experience and desires of customers and be a countervailing power to providers, insurers, and payers.[136] It can set priorities for benefit coverage, make public the means and criteria by which MCOs make decisions about rationing, and require managers to account for their decisions. It can set organizational standards. Enhancing consumer voice should not be merely another way to implement policy; rather, it can be a vehicle to transform it. Consumer voice can be an engine for change when other means don't work.

Notes

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58. A few courts, however, have imposed fair hearing requirements for physicians that are deselected from MCOs in the private sector *Potvin v. Metropolitan Life Insurance Company* 63 Cal. Rptr. 202 (Cal. Ct. App. 2d Dist. 1997).

59. *Goldberg v. Kelly*, 397 U.S. 245 (1970); *J.K. v. Dillenberg*, 836 F. Supp. 694 (D. Ariz. 1993); *Daniels v. Wadley*, 926 F. Supp. 1305 (M.D. Tenn 1996)) vacated in part, 1998 WL 211763 (6th Cir. Apr. 22. 1998). These rights have been codified into Medicaid Law (42 U.S.C. §. 1396a(a)(3); 42 C.F. R. § 431.200 *et. seq.*).

60. The Medicare program reviews all claims for services or reimbursement that are denied. It contracts with an independent group, the Center for Health Care Dispute Resolution, to review denied claims. A federal court of appeals ruled that Medicare beneficiaries are entitled to constitutional due process hearings whenever a managed care organization that contracts with Medicare denies the Medicare beneficiary services. Grijalva v. Shalala, 946 F. Supp. 747 (D. Ariz. 1996), *aff'd*, 152 F.3d 1115 (9th Cir. 1998), *vacated*, 119 S. Ct. 1573 (1999), *remanded* to 185 F.3d 1075 (9th Cir. 1999). *Grijalva v. Shalala*, 946 F. Supp. 747 (1996). However, the U.S. Supreme Court has remanded the case citing *American Mfrs. Mut. Ins. Co. v. Sullivan*, 119S.C.t. 977 (1999) which held that the actions of a contractor with a government program often do not constitute state action. It is likely that the district court will find that there is no state action when MCOs that contract with Medicare deny services to beneficiaries.

61. HR 2723 Bipartisan Consensus Managed Care Improvement Act of 1999, as amended and voted on October 7, 1999; S. 1334, the Patients' Bill of Rights Act of 1999, as amended and voted on July 15, 1999. These bills are awaiting reconciliation and the outcome of this process is uncertain. The Republican house leadership opposed the legislation and has appointed individuals to the conference committee that are likely to cut such protections.

62. Best, Arthur, and Alan R. Andreasen, 1977, "Consumer Response to Unsatisfactory Purchases: A Survey of Perceiving Defects, Voicing Complaints, and Obtaining Redress," *Law & Society Review* 11:701-42; Kolodinsky, Jane, 1993, "Complaints, Redress, and Subsequent Purchases of Medical Service by Dissatisfied Consumers," *Journal of Consumer Policy* 16(2):193-214.

63. Brennan, Troyen A., Lucian Leape, Nan M. Laird, et al., 1991, "Incidence of Adverse Events and Negligence in Hospitalized Patients—Results of the Harvard Medical Practice Study I," *New England Journal of Medicine* 325(3):210. Correspondence; Weiler, Paul, Howard Hiatt, Joseph P. Newhouse, William G. Johnson, Troyen A. Brennan, and Lucian L. Leape, 1993, *A Measure of Malpractice: Medical Injury, Malpractice Litigation, and Patient Compensation*, Cambridge: Harvard University Press.

64. Brieland, Donald, 1971, "Community Advisor Boards and Maximum Feasible Participation," *American Journal of Public Health* 61(2):292-96.

65. By 1982, over 155 federal grant programs imposed citizen participation requirements on the recipients. See Goldberg, Mark, 1982, "Evaluation and Procedural Reform," in Nelson Rosenbaum (Ed.), *Citizen Participation: Models and Methods of Evaluation*, Washington, DC: Center for Responsive Government (CP-014).

66. The Economic Opportunity Act of 1964 calls for the development of Community Action Programs (CAPs) and requires that these programs be "developed, conducted, and administered with the maximum feasible participation of residents of areas and members of groups served"; Miller, S. M., and Martin Rein, 1969, "Participation, Poverty, and Administration, *Public Administration Review* 29:15-25; Moynihan, Daniel P., 1969, *Maximum Feasible Misunderstanding: Community Action in War on Poverty,* New York: Free Press; Notkin, Herbert, and Marilyn S. Notkin, 1970, "Community Participation in Health Services: A Review Article," *Medical Care Review* 27:1178-201; Rubin, Lillian B., 1969, "Maximum Feasible Participation: The Origins, Implications, and Present Status," *The Annals of the American Academy of Political and Social Science* 385: 14-29; Morone, James A., 1990, "The War on Poverty As Democratic Wish," *The Democratic Wish*, New York: Basic Books/Harper Collins, pp. 218-252.

67. Jonas, Steven, 1978, "Limitations of Community Control of Health Facilities and Services," *Journal of Public Health* 68(6):541-43; Jonas, Steven, 1978, "A Theoretical Approach to the Question of 'Community Control' of Health Services Facilities," *American Journal of Public Health* 61(5):916-21.

68. Also, representatives to be selected democratically should be residents of the poverty area, the representatives should live in the geographic area they represent and special emphasis is given to the participation of those who are poor. The 1967 amendments further specified the composition of the Community Action Agency Board; Rubin, L. B., *Maximum Feasible Participation*, 14-29.
69. Brieland, Donald, 1971, "Community Advisor Boards and Maximum Feasible Participation," *American Journal of Public Health* 61(2):292-96.

70. Sardell, Alice, 1988, *The U.S. Experiment in Social Medicine: The Community Health Center Program, 1965-1986*, Pittsburgh: University of Pittsburgh Press; Metsch, Jonathan M. and Harry M. Rosen, 1976, "Consumer Participation in Health Care Delivery," *New York University Education Quarterly* 6:16-20; Metsch, Jonathan M. and James E. Veney, 1976, "Consumer Participation and Social Accountability," *Medical Care* 14:283-303.

71. Peterson, Paul E., 1970, "Forms of Representation: Participation of the Poor in the Community Action Program," *American Political Science Review* 64:491-507.

72. Bellin, Lowell Eliezer, Florence Kavaler, and Al Schwarz, 1972, "Phase One of Consumer Participation in Policies of 22 Voluntary Hospitals in New York City," *American Journal of Public Health.* 62 (10):1370-78.

73. Notkin, Herbert, and Marilyn S. Notkin, 1970, "Community Participation in Health Services: A Review Article," *Medical Care Review* 27:1178-201; Social Security Act Title XIX, 42 U.S.C. §1396a (a)(4), 22(D); 42 C.F.R. §432.13(3).

For the most comprehensive discussion of consumer participation and voice in Medicaid managed care, see Perkins, Jane and Kristi Olson, Lourdes Rivera, and Julie Skatrud, 1996, *Making the Consumers' Voice Heard in Medicaid Managed Care: Increasing Participation, Protection and Satisfaction*, Chapel Hill, NC: National Health Law Program; Olson, Kristi Olson and Jane Perkins, 1999, *Recommendations for Making the Consumers' Voice Heard in Medicaid Managed Care: A Guide to Effective Consumer Involvement,* National Health Law Program. The first report finds nine main mechanisms for consumer involvement in Medicaid: advisory boards, hotlines, grievance processes, ombud programs, member advocates, focus groups, consumer surveys, Medicaid recipient employees, public hearings and forms. The second report makes recommendations.

74. *The National Health Planning and Resources Development Act of 1974*, Public Law 93-641. The Emergency Medical Services Systems Act, PL 93-154; Checkoway, Barry, 1981, *Citizens and Health Care: Participation and Planning for Social Change,* New York: Pergamon Press. Participation requirements were also included in other federal programs, including Urban Renewal and Model Cities. Unlike earlier legislation in the 1960s, subsequent legislation of the 1970s has been assessed as vague and non-specific with respect to the role and responsibilities for consumer participants.

75. Vladeck, Bruce C., 1977, "Interest-Group Representation and the HSAs: Health Planning and Political Theory," *American Journal of Public Health* 67(1):23-39.

76. Brown, Lawrence D., 198., "Some Structural Issues in the Health Planning Program," in *Health Planning in the United States: Selected Policy Issues*, Institute of Medicine, Vol. II, Washington, DC: National Academy Press.

77. Morone, James A., 1981, "Models of Representation: Consumers and the HSAs," in *Health Planning in the United States: Selected Policy Issues,* Institute of Medicine, Vol. II, Washington, DC: National Academy Press, 225-56.

78. Public Law 93-222, "The Health Maintenance Organization Act of 1973," Title XII §1301 (c) (6):

> Each health maintenance organization shall . . . (6) be organized in such a manner that assures that (A) at least one-third of the membership of the policymaking body of the health maintenance organization will be members of the organization, and (B) there will be equitable representation on such body of members from medically underserved populations served by the organization.

In 1978 the statute was amended. The revised and more extensive consumer representation provision, listed below, was deleted when the statute was amended again, in 1988:

> A) in the case of a private health maintenance organization, be organized in such a manner that assures that (i) at least one-third of the membership of the policymaking body of the health maintenance organization will be members of the organization, and (ii) there will be equitable representation of such body of members from medically underserved populations served by the organization, and (B) in the case of a public health maintenance organization, have an advisory board to the policymaking body of the public entity operating the organization which board meets the requirements of clause (A) of this paragraph and to which may be delegated policymaking authority for the organization.

See, Koseki, Lawrence K., 1977, "Consumer Participation in Health Maintenance Organizations," *Health and Social Work* 2(4):51-69.

79. Group Health Cooperative of Puget Sound has thrived. In 1997 it formed an alliance with Kaiser Permanente Northwest under which a new entity, Kaiser Group Health (KGH), is delegated responsibility for strategic planning and major financial decisions. Six members of the KGH board are appointed by Kaiser and five members are appointed by Group Health Cooperative of Puget Sound; Group Health Association in Washington, DC, had financial problems and voted to become part of Humana, Inc. in 1993. It was purchased by Kaiser Permanente in 1997.

For histories of both HMOs, see Berkowitz, Edward D. and Wendy Wolff, 1988*, Group Health Association: A Portrait of a Health Maintenance Organization,* Philadelphia: Temple University Press; Crowley, Walt, 1996, *To Serve the Greatest Number: A History of Group Health Cooperative of Puget Sound*, Seattle: University of Washington Press.

80. Rosener, Judy B., 1978, "Citizen Participation: Can We Measure its Effectiveness?", *Public Administration Review* 38(5):457-463.

81. Morone, James A., 1990, *The Democratic Wish*, New York: Basic Books/Harper Collins, 253-321.

82. Rosenbaum, Nelson, 1982, *Citizen Participation: Models and Methods of Evaluation,* Center for Responsive Governance: CP-014.

83. Burke, Edmund M., 1968, "Citizen Participation Strategies," *Journal of the American Institute of Planners* 34:287-94.

84. Metsch, Jonathan M., and James E. Veney, 1976, "Consumer Participation and Social Accountability," *Medical Care* 14:283-303.

85. Charles, Cathy and Suzanne DeMaio, 1993, *Lay Participation in Health Care Decision Making*.

86. Morone, J. A., *The Democratic Wish*.

87. Advisory Commission of Intergovernmental Relations, 1980, *Citizen Participation in the American Federal System*, U.S. Government Printing Office, Washington, DC.

88. Nagel, Jack H., 1992, "Combining Deliberation and Fair Representation in Community Health Decisions," *University of Pennsylvania Law Review* 140:1965-85. These issues arise in other countries as well. For a review of the literature, see Saltman, Richard B., 1994, "Patient Choice and Patient Empowerment in Northern European Health Systems: A Conceptual Framework," *International Journal of Health Services* 24(3):201-229; See also, O'Neill, Michel, 1992, "Community Participation in Quebec's Health System: A Strategy to Curtail Community Empowerment?", *International Journal of Health Services* 22(2):287-301.

89. Rodwin, Marc A., 1996, "Consumer Protection and Managed Care: The Need for Organized Consumers," *Health Affairs* 15(3):110-123.

90. Rodwin, M.A., "Patient Accountability and Quality of Care," 147-167.

91. *Ibid.*

92. Dahl, Robert A., 1969, "Epilogue," in *Political Opposition in Western Democracies*, New Haven: Yale University Press, 396-97.

93. Community Catalyst, 2000*, Health Care Justice: Linking Grassroots Leadership and Legal Advocacy*, Washington, DC: Public Welfare Foundations.

94. Spatley, William A., 1997, "State Utility Consumer Advocates," in Stephen Brobeck (Ed.), *Encyclopedia of Consumerism*, Santa Barbara: Beclo.

95. Gormley Jr., William T., 1986, "The Representation Revolution: Reforming State Regulation Through Public Representation," *Administration and Society* 18(2):179-190; Gormley Jr., William T., 1982, "Policy, Politics, and Public Utility Regulation," *American Journal of Political Science* 27(1):86-105.

96. The traditional Swedish term is *ombudsman*. There are two gender neutral variants: *ombud* and *ombudsperson*. I have chosen to use the shorter.

97. Health Insurance Plan of New York, for example, has an Ombud.

98. For a thoughtful report on Ombud programs see Perkins, Jane, Kristi Olson, and Lourdes Rivera, 1998, *Ombudsprograms and Member Advocates: Consumer-Oriented Approaches to Problem-Solving in Medicaid Managed Care,* National Health Law Program.

99. See, for example, Ferber, Joel D., 1998, “Medicaid Advocacy and Managed Care: The Missouri Experience,” *Clearing House Review* (March-April) 601-611.

100. Department of Labor, Bureau of Labor Statistics, <www.bls.gov/news.release/union2.toc.htm>.

101. Unions representing nurses and other health care workers would like to position themselves as patient or quality of care advocates, however their primary interest is in maintaining employment and working conditions of health care workers.

102. Among the leading groups are Center for Health Care Rights, Consumers Union, Families U.S.A., the National Health Law Program, Public Citizen Health Research Group, and the Medicare Rights Center.

103. The pros and cons of electing versus having citizen groups select representatives in Community Action Programs is discussed in Altshuler, Alan A., 1970, *Community Control: The Black Demand for Participation in Large American Cities,* New York: Pegasus.

104. The National Association of Insurance Commissioners uses this model.

105. Governmental agencies or MCOs may not want to cede authority to consumer groups to choose consumer representatives. They might ask consumer groups to nominate a list of individuals from which the agency or MCO can choose consumer representatives. Or, the agency (or MCO) could propose names of representatives and ask for consumer groups to rate the individuals in priority.

106. Consumer representatives might also be elected for a region.

107. In 1996 GHCPS formed an alliance with Kaiser Permanente Northwest. Under that alliance governance of the GHCPS facilities is directed by a joint board jointly appointed by management at Kaiser and the consumer elected board at GHCPS.

108. Citizen Advocacy Center, 1995, *Public Representation on Health Care Regulatory, Governing, and Oversight Bodies. Strategies for Success,* Washington, DC; Citizen Advocacy Center, 1996, *Process for Selecting Patient Representatives for FDA Advisory Committees*, Washington, DC; Parker, Alberta W., 1970, “The Consumer as Policy-Maker: Issues of Training,” *American Journal of Public Health* 60(11):2139-53.

109. Brieland, Donald, 1971, “Community Advisor Boards and Maximum Feasible Participation,” *American Journal of Public Health* 61(2):292-96; Paap, Warren R., 1978, “Consumer-Based Boards of Health Centers: Structural Problems in Achieving Effective Control,” *American Journal of Public Health* 68(6):578-82.

110. For a review of current attempts to represent consumers in managed care, see Cohen, Rebecca A. and David A. Swankin, 1998, *Consumer and Enrollee Participation in Managed Care Plan Governance, Policy Making and Operations: A Survey of Health Plans and Legal Requirements*, Citizen Advocacy Center, Washington, DC.

111. Helper, Susan, 1996, *Exit, Voice and Cost Reduction: Evidence from the Auto Supply Industry*, a paper prepared for presentation to the Società Italiana degli Economisti.

112. These have been explored particularly where consumers are continuing relations between purchasers and suppliers and virtual integration or long-term relations through contracts. There are strong analogies to consumers in managed care. Most consumers have contractual relationships with MCOs for a year and so are locked in. Rather than purchasing discrete items, they are buying a bundle of services and an open-ended commitment by MCOs to provide necessary services. And the objectives of managed care are best achieved through long-term relationships which would increase the incentive for investment in preventive care that is costly up front.

113. Higgins, Meredith M., 1982, *Member Appeals for Payment of Non-Plan Care: Consumer Involvement in Review*, Proceedings of the 1982 Group Health Institute, Washington, DC: Group Health Association of America, 337-343.

114. Some consumer surveys are publicly available, notably consumer satisfaction surveys conducted by the National Committee for Quality Assurance as part of their HEDIS (Health Plan Employer Data and Information Set) measures. Most MCOs, however, carry out many more surveys than this for internal use and these are usually not subject to outside scrutiny.

115. Consumers tend to be under represented in groups that draft model legislation on insurance and other issues. See, Silber, Norman I., 1997, Consumer Participation in the Law-Drafting Process: Past, Present, and Future, *Advancing the Consumer Interest* 9(1):27-31.

116. In the summer of 1997, Kaiser Permanente and Group Health Cooperative of Puget Sound combined with Families U.S.A. and the American Association of Retired Persons in calling for federal legislation to enforce new standards for managed care and a consumer bill of rights. However, the American Association of Health Plans promoted a program called “Putting Patients First” and suggests that a good deal of proposed legislation is not necessary or even helpful. In the spring of 1998 the President’s Advisory Commission on Consumer Protection and Quality in the Health Care Industry proposed voluntary compliance with its proposed bill of rights. In the meantime legislation has been introduced in Congress and state legislatures which would implement some of the Advisory Commission’s recommendations and/or further regulate managed care.

117. The California Managed Health Care Improvement Task Force called for a new state agency to oversee MCOs. On May 1, 2000, Governor Wilson recommended to a Little Hoover Commission that such a department be created. The proposed reorganization became law on July 1, 2000.

118. Perkins, Jane, Kristi Olson, Lourdes Rivera, and Julie Skatrud, 1996, *Making the Consumers’ Voice Heard in Medicaid Managed Care: Increasing Participation, Protection and Satisfaction*, Chapel Hill, NC: National Health Law Program.

119. Palladino, Mary Kathryn, 1991, “Ensuring Coverage, Balance, Openness and Ethical Conduct for Advisory Committee Members under the Federal Advisory Committee Act,” *Administrative Law Journal* 5:231-274.

120. For a comparison of ombud programs in several countries and its potential applications to U.S. governmental agencies, see Gellhorn, Walter, 1996, *Ombudsmen and Others: Citizens’ Protectors in Nine Countries*, Cambridge: Harvard University Press; Gellhorn, Walter ,

1966, *When American Complain: Governmental Grievance Procedures*, Cambridge: Harvard University Press.

121. Perkins, J., K. Olson, L. Rivera, and J. Skatrud, *Making the Consumers' Voice Heard.*

122. Grijalva v. Shalala, 946 F. Supp. 747 (D. Ariz. 1996), *aff'd*, 152 F.3d 1115 (9th Cir. 1998), *vacated*, 119 S. Ct. 1573 (1999), *remanded* to 185 F.3d 1075 (9th Cir. 1999).

123. *Ibid*.

124. *Engalla v. Permanente Medical Group*, 15 Cal. 4th 951; 938 P.2d 903 (1997); Lynch, Eugene F., Sandra R. Hernandez, and Phillip L. Isenberg, 1998, *The Kaiser Permanente Arbitration System: A Review and Recommendations for Improvement*, (Blue Ribbon Advisory Panel on Kaiser Permanente Arbitration).

125. There are also public sector group purchasers of health care such as the California Public Employees Retirement System (CalPers).

126. Approximately 1463 individuals have registered for the 1999 winter meeting in Seattle. Of these, 948 are from the insurance industry, 394 from insurance department staff, 46 are commissioners, and 36 are consumers, academics or educators. The remainder were from the federal government, state government, news media, state legislators, special representatives or other countries.

127. Three of the insurance commissioners on the board are officers of NAIC elected by insurance commissioners. They choose the other two insurance commissioners on the board.

128. Silber, Norman I, 1997, "Consumer Participation in the Law-Drafting Process."

129. There are other notable programs run by non-profit agencies, such as the *Medicare Rights Center*, and plans run by for-profit groups, such as *Patients First* and *Care Counsel*.

130. Aleshire, Robert A., 1972, "Power to the People: An Assessment of the Community Action and Model Cities Experience," *Public Administration Review* 32: 428-443; Verba, Sidney, 1967, "Democratic Participation," *The Annals of the American Academy of Political and Social Science* 373:53-78, at 57-58.

131. Reissman, Frank and Alan Gartener, 1970,"Community Control and Radical Social Change," *Social Policy* 1: 52-55, at 54; Moynihan, Daniel P., 1969, *Maximum Feasible Misunderstanding.*

132. Notkin, Herbert, and Marilyn S. Notkin, 1970, "Community Participation in Health Services;" Metsch, Jonathan M and James E. Veney, 1976, "Consumer Participation and Social Accountability."

133. Rodwin, Marc A., 1997, "The Neglected Remedy: Strengthening Consumer Voice in Managed Care."

134. Fox, Daniel M., 1972, "Citizen Participation: A Substitute for Action." *Health Education Monographs* 32: 37-39.

135. For a summary of strategies used to thwart effective participation and also the problems in achieving effective citizen or community control, see, Ridel, James, 1972, "Citizen Participation: Myths and Realities," *Public Administration Review* 32: 211-219.

136. Increased political participation is a feature of modern political systems. See Huntington, Samuel P., 1965, "Political Development and Political Decay," *World Politics* 17:386-430 at 388-389.

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