

Strengthening the Consumer Voice in Managed Care: I. Can the Private Sector Meet the Public-Sector Standard?

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For the past ten years we have been studying a basic question in health policy and applied ethics: Under what circumstances should patients and families, providers, and the concerned public accept limits as legitimate and fair?

Every behavioral health program must operate within the reality of finite resources. The only exceptions are for out-of-pocket payments for health care by the very wealthy. Finite resources entail limits, and limits create the problem of legitimacy (1). How can a health care system, whether market based as in the United States or single payer as in Canada, best set policies that are clinically informed, ethically justifiable, and politically accepted? We believe it cannot be done without more robust consumer participation. The public sector teaches crucial lessons about getting from here to there.

On the basis of studies of behavioral health treatment (2), cancer treatment (3), and insurance coverage for new technologies (4), we have concluded that programs that set limits on health care can achieve legitimacy only if they are held account-

able for the reasonableness of their limit-setting policies (5). In health care, "reasonable" policies are those that seek an optimal balance between the needs of individuals and those of the population. Fair-minded people may disagree about how best to balance the needs of individual patients and the totality of an insured population. But any health care system that pools funds to provide care for individuals as part of an insured population must seek that balance if it hopes to be seen as legitimate.

In a pluralistic society there are no universally shared moral principles that define the "right" balance among values. Outcome studies can tell us which treatments work, but they cannot tell us what goals to set or how to manage trade-offs among values. Consequently, legitimacy requires establishing fair policy-making processes in which stakeholder perspectives are recognized, considered, and valued. This is where the consumer voice comes in.

In the market-based approach that currently provides the framework for health care in the United States, power has shifted to employer and government payers and the managed care organizations they contract with and away from providers and consumers. Public payers, however, remain accountable to the public even when they "carve out" management responsibility for behavioral health care to a private, for-profit specialty behavioral health company. To meet this accountability, managed care partners are required by enlightened public payers to conduct themselves like public agencies. Such conduct

entails making policy in an open, transparent manner and drawing consumers and families into overseeing the program management process.

We contend that unless private-sector managed behavioral health programs emulate public-sector best practices with regard to transparency and consumer participation, the anti-managed-care backlash will intensify. The issue here is not how to make managed care palatable to its critics, but how limit-setting systems can achieve legitimacy. Even if health care in the United States moves to a single-payer system or another approach fundamentally different from the current one, that system will also have to address the challenge of setting limits that can be seen as fair and legitimate.

In a previous column, we described the techniques the Massachusetts Division of Medical Assistance and its behavioral health contractor, the Massachusetts Behavioral Health Partnership, use to foster consumer participation (6). In this column, the first in a series about strengthening the consumer role in managed behavioral care, we try to move beyond politically correct platitudes to specify the ingredients that make consumer participation important. In our view, consumer participation in Massachusetts contributes to the system's legitimacy by helping it achieve accountability for reasonableness.

Why is consumer participation important?

In democratic systems, power resides with the people, who generally exercise their power through elected representatives. When these representa-

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tives vote to enact laws and policies, they confer legitimacy on them by giving their consent, and through such consent, the consent of the governed. It seems an easy step of logic to infer that consumer participation contributes to legitimacy in health care in the same way—through representation and consent. However, this inference is erroneous.

When consumers actually govern a health care organization, representation and consent may indeed confer legitimacy on limit-setting policies. But true consumer governance is rare. The Group Health Cooperative of Puget Sound (7) is unique in both its size (600,000 members) and its longevity (54 years) among consumer-governed programs. However, in the vast majority of current managed care settings, representation and consent do not apply with any literalness. Most consumers are not elected to the roles they serve, and the roles themselves are typically advisory, not governance, roles. If representation and consent do not apply in a strict sense, does that mean that consumer participation can only be a sham?

We think not. Our fieldwork has convinced us that consumer participation plays a vital role in legitimacy—but by improving accountability for reasonableness, not through representation or consent. Consumer participation is crucial to three key elements of accountability for reasonableness—transparency in organizational policies and decisions, deliberation that properly recognizes the needs of both individuals and the population served, and the organization's capacity to learn from experience, especially from criticism and appeals. For organizations, cultivating accountability for reasonableness in the relationship with stakeholders is analogous to clinicians' cultivating a therapeutic alliance in their relationships with patients.

What follows is a series of brief examples intended to illustrate how consumer participation can promote accountability for reasonableness by enhancing transparency, deliberation, and organizational learning. Future columns will amplify on this theoretical perspective with more detailed case studies.

Transparency

Secrecy precludes trust. The enraged response of both the public and providers to the idea of proprietary medical necessity criteria and a "gag rule" in the early days of managed care shows what happens when stakeholders believe they are being kept in the dark about crucial aspects of a fundamental good such as health care.

It is important to distinguish between the bureaucratic concept of "disclosure," which can be satisfied legalistically by arcane phrases hidden in the fine print of long documents, and "transparency," which connotes open and free exchange. The Massachusetts program cultivates transparency by involving consumers at multiple points of the management process through a consumer advisory council that meets monthly, a consumer satisfaction team, ad hoc task forces, and an open-door policy at both the purchaser setting, the Division of Medical Assistance, and the carve-out company, the Massachusetts Behavioral Health Partnership. The cultivation of transparency is the organizational equivalent of what clinicians do to cultivate a strong therapeutic alliance. "Disclosure" is a bureaucratic event. "Transparency" is a relationship and an ongoing process.

Deliberation

Simply "listening" to what consumers say does not create legitimacy. To be meaningful, the consumer voice must make a difference in what organizations do and ultimately in the outcomes that are achieved. Consumers become cynical about organizations that claim to listen but do not take action. The situation is complicated, however; valuing consumer participation cannot mean agreeing, because the values put forward by other stakeholders must also be considered.

Massachusetts cultivates an ongoing consumer role in deliberation by including consumers in key policy-making activities. Thus, in developing annual performance standards for the program (8), members of the consumer advisory council deliberate about their own top priorities for the year, after which they join providers, program managers, the Division of

Medical Assistance, and other stakeholders to integrate the different perspectives. Consumers reviewed all of the 16 performance standards incorporated into the 2001 contract; four of the standards had been directly proposed by the consumer advisory council. For example, the council emphasized the importance of enhancing consumers' advocacy skills, leading to a performance standard requiring development of a consumer leadership academy "to promote self-empowerment and recovery-oriented approaches."

Organizational learning

Most regulatory attention to improving managed care focuses on appeals, but these provide a very limited form of consumer input, given national experience that consistently demonstrates limited use of appeals mechanisms. Meaningful consumer participation requires more than the kinds of appeals processes that form the centerpiece of legislative and regulatory "reform."

Massachusetts cultivates the consumer role in organizational learning by ensuring that consumers have central formal and informal roles in a "try it—fix it" approach to policy. The consumer advisory council regularly reviews reports on the status of performance standards. The independently incorporated consumer satisfaction team conducts surveys of consumer satisfaction with services across the state. More than 25 consumer-led peer educator groups provide education and support for recovery and also create the equivalent of consumer focus groups. The consumer-leaders of the groups report the results to the managed care organization and the public purchaser at meetings and informally. For example, a series of critical anecdotes about emergency services led to a meeting of the managed care organization, the Division of Medical Assistance, the Department of Mental Health, and activist members of the Alliance for the Mentally Ill. At the meeting a series of problems were identified and an improvement strategy was put into place.

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Challenge to the private sector

As part of the political process, public-sector purchasers expect to be called to account for their decisions and policies. Wise public purchasers require the carve-out programs they contract with to behave like public agencies. This requirement entails active interaction with consumers on developing, implementing, monitoring, and revising managed care policies. When it works well, this kind of participation can result in better policies. As important as it is to have substantial consumer presence throughout the management process, what creates legitimacy is the influence consumers exert on the quality of managed care policies and practices, not simply the participation of specific numbers of consumers.

Employers and other private purchasers do not have the same formal accountabilities as public purchasers. However, the national backlash against managed care shows that the public is not satisfied with leaving accountability to market forces alone. Private-sector programs must also seek legitimacy through accountability for reasonableness. They should look to the best public-sector programs to learn how to involve consumers in this enterprise. Future columns will explore this topic in detail. ♦

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