

# Public-Sector Managed Behavioral Health Care: III. Meaningful Consumer and Family Participation

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A careful reading of recent advocacy statements reveals an emerging consensus about three interrelated principles for managed mental health care: first, cost containment, priority setting, and even rationing can be ethically acceptable (1) if, second, the fact of limits and the reasons for limit-setting policies are openly shared, and, third, consumers and families play a meaningful role in shaping those policies. This column, the third in a series about public-sector managed care (2,3), focuses on the role of consumers and families.

All major advocacy statements endorse consumer and family involvement. The National Alliance for the Mentally Ill, acting on its slogan "Nothing about us without us," has as a key criterion in its managed care report card that "consumers and family members must assume an integral role in the governance and oversight functions of the managed care organizations" (4). The Bazelon

Center for Mental Health Law and the Legal Action Center assert that consumers and families should be "partners in planning" at the level of the contracting process itself (5).

The National Mental Health Association makes consumers and families central to each of its nine standards for "consumer-centric managed mental health and substance abuse programs" (6). Even the organization most firmly opposed to the current U.S. market-based system—the National Coalition of Mental Health Professionals and Consumers—proposes as an alternative a series of "clean methods of cost control" in which consumers and families play a central role in managing care (7).

With such pervasive support for consumer and family involvement, the question is not whether to involve consumers and families but how best to do it. There are two fundamental reasons for wanting consumers and families to play a central role in guiding the care management process. First, the quality improvement movement holds as a central tenet that quality can be neither defined nor improved without consumer and family participation (8). Second, as we have argued elsewhere, consumers, families, and the public cannot be expected to trust health care systems that do not hold themselves accountable for demonstrating that their limit-setting policies are reasonable and fair (9,10). A system cannot be, or cannot be seen as, reasonable, legitimate, and fair if it does not respect the values and

personhood of the consumers and families the system is intended to serve.

We agree with Geller and associates (11) that "research should focus on how consumers in state or county mental health authorities influence policies, contribute to dialogue, and represent the consumer perspective." This column uses fieldwork in Massachusetts to give practical guidance based on the promising approach that is being applied by that public system.

## A multipronged strategy for involving consumers and families

Massachusetts has the nation's first—since 1992—and largest Medicaid behavioral health care carve-out program, with approximately 450,000 enrolled members. Since 1996 the Massachusetts Behavioral Health Partnership, a for-profit company owned by ValueOptions, has held the contract. The state currently involves consumers and families in managing managed care in four ways.

♦ A consumer advisory council whose members include consumers and advocates meets monthly, joined by staff from the carve-out company, high-level representatives of the purchaser (the Massachusetts Division of Medical Assistance), the State Department of Mental Health, and other key state agencies. The council tries to focus on a small number of potentially high-leverage issues.

A meeting attended by the senior author featured an extended discus-

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sion of proposed guidelines for treatment of depression. The group spent substantial time critiquing the guidelines on the basis of consumer experience with medications. They made the excellent suggestion that guidelines should address not simply what to prescribe but also how the clinician can best collaborate with the patient to make it likelier that the regimen will actually be followed. The group prepared a report to present to the carve-out medical director.

♦ A family advisory council functions much like the consumer advisory council. Representatives include family members associated with the Alliance for the Mentally Ill (AMI), the Parent Professional Advocacy League (PAL), and other organizations, along with unaffiliated but committed and knowledgeable family activists. Representatives of the purchaser and other state agencies were again active participants.

In a review of their work during the past year, family members emphasized that whatever the professional network provides, family members are often the most involved and knowledgeable "case managers." The family advisory council provided an opportunity to exert direct influence on the movers and shakers of the system and educated family members about the most effective forms of intervention.

When asked about the council's most important accomplishment, council members cited their work to influence the annual performance standards for the carve-out company. Family advocates were especially influential in establishing two of the 24 standards for 1999: "develop[ing] and distribut[ing] printed resource materials for families/guardians intended to assist in maximizing youths' treatment experience" and "implement[ing] an enhancement to the existing intensive clinical management model that targets approximately 65 children/adolescents." (The intensive clinical management model was described in an earlier column in the series on public-sector managed care [2]).

♦ A statewide peer educators project is training peer educators to conduct recovery workshops, using a

workbook developed for the purpose (12). Peer-led sessions help persons with psychiatric disabilities to understand the recovery process and develop practical skills. Double Trouble in Recovery, a program for persons with mental illness and addictions, is offered to the dual diagnosis population.

The leaders of the program are active members of the advisory groups and use observations fed in by participants in the groups as a source of quality-relevant information. For example, members of the recovery groups made clear that Spanish-language services were deficient. This recognition led to program improvement.

♦ Finally, the Massachusetts consumer satisfaction team initiative is a consumer-coordinated project designed to assess consumers' satisfaction with the services they receive. After extensive training, pairs consisting of consumers, family members, or both conduct a consumer-developed survey through face-to-face interviews with current service users. This central component of the carve-out company's quality improvement program builds on experience in Philadelphia, Milwaukee, and the state of Georgia (13,14).

The initiative itself resulted from a combination of extended negotiations and planning among the Division of Medical Assistance (the purchaser), the Massachusetts Behavioral Health Partnership (the managed care organization), and advocates. The surveys are getting under way in mid-1999. Insofar as they yield quality-relevant findings, those findings will go first to the provider organization and then to the carve-out company staff responsible for managing the clinical network.

### Three practical lessons

Rodwin (15) observed that at its best, a robust consumer and family voice "can help build stronger organizations by putting managers in touch with the experience and desires of their customers, the patients." At its worst, duplicitous organizations could co-opt consumers and families or use ostensible participation as a kind of fig leaf. Although

the Massachusetts experience is a process, not an outcome, we believe it provides three suggestions about how consumers and families can attain meaningful influence on managed care performance.

First, the Massachusetts Division of Medical Assistance is a decidedly hands-on, activist purchaser. It does not simply choose among choices presented by the marketplace—it works continuously with its vendor, the carve-out company, toward agreed-on objectives (16). It does not simply receive summarized reports of satisfaction from the vendor—it hears consumer and family input directly from consumers through its presence at the councils. Thus while consumers and families do not directly purchase the services they receive, they have multiple forms of access to the actual purchaser.

Second, consumers and families focus their activism on key points of leverage in the care management process. The carve-out medical director reported that he incorporated much of the feedback he received from the consumer advisory council about a schizophrenia guideline into that guideline. The family advisory council contributed significantly to the development of performance standards with high relevance to families.

Further, the consumer satisfaction team initiative, which is just beginning, will present consumer viewpoints on the quality of clinical services to the providers of those services and to the network managers as well. The peer educators project is a source of extensive informal feedback based on what the peer leaders learn from participants in the recovery groups. Clinical guidelines, performance standards, quality assessment, and a wide base of informal information from consumers actively working at recovery are powerful channels for a meaningful consumer and family voice.

Third, it appears to us that the purchaser, the carve-out company, consumers, and family members are collaboratively managing the nitty-gritty aspects of consumer and family involvement very effectively. Coun-

cil agendas are not overloaded. Ample time is devoted to a small number of important topics, which are often revisited in later meetings. The consumer satisfaction teams organized an extensive training program, and considerable thought is being given to exactly how the feedback can be made most useful to the providers and the managers of the network.

Access to the ear of the purchaser, focus on key points of leverage, and careful management of the actual process of consumer and family involvement do not guarantee that consumers and families will actually play an important quality-improving role in the care management process. Nor does anything in the Massachusetts process guarantee that the consumers and families who interact with the carve-out company and the purchaser accurately represent the entire universe of service users in Massachusetts. But if further experience in Massachusetts and other states confirms that these three elements are necessary conditions for promoting reasonable and fair care management policies, they will be important pointers for any system that seeks public acceptance as a legitimate, trustworthy, and fair manager of care. ♦

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### References

1. Boyle PJ, Callahan D: What Price Mental Health: The Ethics and Politics of Setting Priorities. Washington, DC, Georgetown University Press, 1995
2. Sabin JE: Public-sector managed behavioral health care: I. developing an effective case management program. *Psychiatric Services* 49:31-33, 1998
3. Sabin JE, Daniels N: Public-sector managed behavioral health care: II. contracting for Medicaid services: the Massachu-

setts experience. *Psychiatric Services* 50: 39-41, 1999

4. Hall LL, Edgar ER, Flynn LM: Stand and Deliver: Action Call to a Failing Industry. Arlington, Va, National Alliance for the Mentally Ill, 1997
5. Judge David L Bazelon Center for Mental Health Law and Legal Action Center: Partners in Planning: Consumers' Role in Contracting for Public-Sector Managed Mental Health and Addiction Services. Report prepared for the Substance Abuse and Mental Health Services Administration Managed Care Technical Assistance Series. Rockville, Md, Substance Abuse and Mental Health Services Administration, 1998
6. Graham M: Standards for Consumer-Centric Managed Mental Health and Substance Abuse Programs. Alexandria Va, National Mental Health Association, 1998
7. Miller IJ: The Time Has Come to Choose the Replacement for Managed Health Care. Commack, NY, National Coalition of Mental Health Professionals and Consumers, 1999
8. Blumenthal D: Quality of care: what is it? *New England Journal of Medicine* 335: 891-893, 1996

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5. Lopez-Ibor JJ Jr, Ayuso Mateos JL, Robriquez Gamazo M, et al: PCP-ICD-10: A computer program and network for psychiatric intervention, in *Proceedings of the Tenth World Congress of Psychiatry, Symposium on Information Data Systems*. Edited by Vistosky H, Mak FL, Lopez-Ibor JJ. New York, World Psychiatric Association, 1996
6. Marks I: CORM: a computerized system for clinical outcome and resource monitoring, in *Proceedings of the Tenth World Congress of Psychiatry*, *ibid*
7. Marks I: Overcoming obstacles to routine outcome measurement: the nuts and bolts of implementing clinical audit. *British Journal of Psychiatry* 173:281-286, 1998
8. Greist JH: Computer interviews for depression management. *Journal of Clinical Psychiatry* 59(suppl 16):20-24, 1998
9. Marks I, Baer L, Greist JH, et al: Home self-assessment of obsessive-compulsive disorder. *British Journal of Psychiatry* 173:406-412, 1998
10. McDonald CJ, Overhage M, Dexter PR, et al: Canopy computing: using the Web in clinical practice. *JAMA* 280:1325-1329, 1998
11. Modai I, Sigler M: A computerized laboratory alerting system for patient management in a psychogeriatric unit. *MD Computing* 15: 95-99, 1998
12. Modai I, Valevski A: Computerized patient information system in a psychiatric unit: five-year experience. *Journal of Medical Systems* 17:309-316, 1993
13. McDonald CJ: Protocol-based computer reminders: the quality of care and the non-perfectibility of man. *New England Journal of Medicine* 295:1351-1355, 1976

9. Daniels N, Sabin JE: Limits to health care: fair procedures, democratic deliberation, and the legitimacy problem for insurers. *Philosophy and Public Affairs* 26:303-350, 1997

10. Daniels N, Sabin JE: The ethics of accountability in managed care reform. *Health Affairs* 17(5):50-64, 1998
11. Geller JL, Brown J-M, Fisher WH, et al: A national survey of "consumer empowerment" at the state level. *Psychiatric Services* 49:498-503, 1998
12. Spaniol L, Koehler M, Hutchinson D: *The Recovery Workbook*. Boston, Boston University Center for Psychiatric Rehabilitation, 1994
13. Annual Report, 1998. Philadelphia, Consumer Satisfaction Team, Inc, 1998
14. Handbook, Georgia Evaluation and Satisfaction Team. Atlanta, Department of Mental Health, 1995
15. Rodwin MA: The neglected remedy: strengthening consumer voice in managed care. *American Prospect* 34(Sept-Oct): 45-50, 1997
16. Bullen B: What Is a Prudent Purchaser? Washington, DC, National Association of State Medicaid Directors, 1998

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2. Weiss EM: Deadly restraint: a nationwide pattern of death. *Hartford (Conn) Courant*, Oct 11, 1998 [This article and subsequent articles are available at [www.courant.com/news/special/restraint](http://www.courant.com/news/special/restraint).]
3. Megan K, Blint DF: Deadly restraint: why they die: little training, few standards, poor staffing put lives at risk. *Hartford (Conn) Courant*, Oct 12, 1998
4. Weiss EM, Altamari D: Deadly restraint: patients suffer in a system without oversight. *Hartford (Conn) Courant*, Oct 13, 1998
5. Altamar D: Deadly restraint: "people die and nothing is done." *Hartford (Conn) Courant*, Oct 14, 1998
6. Weiss EM: Deadly restraint: from enforcer to counselor. *Hartford (Conn) Courant*, Oct 15, 1998
7. How the Courant conducted its investigation. *Hartford (Conn) Courant*, Oct 11, 1998
8. Freedom From Restraint Act of 1999, S 736 IS, 106th Congress, 1st session (Mar 25, 1999) [The text of this act and of the others discussed in this paper are available through the Library of Congress legislative information service at <http://thomas.loc.gov>.]
9. Compassionate Care Act of 1999, S 750 IS, 106th Congress, 1st session (Mar 25, 1999)
10. Patient Freedom From Restraint Act of 1999, HR 1313 IH, 106th Congress, 1st session (Mar 25, 1999)

