Strengthening the Consumer Voice in Managed Care: IV. The Leadership Academy Program

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Since the publication of Albert O. Hirschman's classic analysis of "exit" and "voice" (1) as the two fundamental strategies by which we influence the public and private enterprises we rely on for services and goods, "voice" has been a central metaphor for consumer participation. Robust consumer/citizen voice provides the foundation for effective civic advocacy. It is a key component of the democratic process itself.

We believe that to be effective in managed care, consumer voice requires four components. Two were discussed in previous columns—support from the managed care organization (2,3) and reliable enforcement of the consumer role (4). This column discusses a third—enhancing consumer skills for effective "speaking." In the next column we will discuss the skills required for effective clinician and organizational "listening."

The need for enhanced advocacy skills is not unique to behavioral health consumers. The National Health Council, an umbrella organization whose core membership includes more than 50 voluntary organizations that represent more than 100 million people with chronic conditions, has created an "advocacy toolbox" (available at www.nhcouncil.org/toolbox.htm) "to share specific tools for making advocacy more effective and efficient."

There are, however, special challenges in the behavioral sector. Discrimination and stigma can lead officials to discount consumer perspectives ("What do they know?"). Paternalism can lead clinicians to undervalue consumer insights ("Doctor knows best"). Consumers may be disempowered by loss of confidence ("What do I have to offer, and who would listen to me?"). And some behavioral conditions—as well as the medications used to treat them—can impair cognitive and expressive processes.

In this column we describe the Leadership Academy, a prominent program for strengthening consumer advocacy skills, as a model of skills training and a source of practical lessons on improving managed care and the mental health system itself.

History of the Leadership Academy

In the early 1990s, Robert Hess and Cynthia Clapper, of the Idaho Bureau of Mental Health, wanted to increase the involvement of consumers and families in the planning and evaluation of the state's mental health services. They concluded that this could be accomplished only if consumers and family members improved their system-level advocacy skills. With funding from the federal Center for Mental Health Services, they hired consultants who had experience with this kind of skill development for people with physical disabilities (5) and formed a new organization—the Idaho Leadership Academy. The consultants adapted a workbook that had been developed for consumers with physical disabilities for use by mental health consumers. Between 1993 and 1995, the academy presented five skill development workshops for 160 consumers and families around the state.

In a way that is unusual for grassroots programs, a study was conducted to assess the impact of the Leadership Academy (6). Over a 27-month period, graduates took 1,345 action steps, including writing letters, going to meetings, raising funds, and becoming members of oversight groups and boards. Graduates identified 400 outcomes from their advocacy, including opening of a respite care facility, presentation of antistigma education programs, and formation of an ongoing coalition of activists.

In 1994 Robert Hess moved from Idaho to another rural, mountainous state—West Virginia—as director of the Office of Behavioral Health. Hess joined with the West Virginia Mental Health Consumers Association and the West Virginia Alliance for the Mentally Ill to explore ways in which the state could strengthen consumer and family participation in oversight of the mental health system. The group was impressed by Idaho's experience with the Leadership Academy, and in 1995 the West Virginia Lead-

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ership Academy for Consumers and Families obtained its own grant from the Center for Mental Health Services to launch a program.

Thus far, the West Virginia Leadership Academy has conducted 16 training sessions, producing 350 graduates. It holds quarterly conference calls and annual conferences that link the graduates in a common enterprise. Most important, in 1998 the West Virginia Mental Health Consumers Association received a Center for Mental Health Services grant that has allowed it to develop CONTAC (Consumer Organization and Networking Technical Assistance Center), through which the Leadership Academy program has now become a presence in 16 states.

How the Leadership Academy program works

As initiated and evaluated in Idaho and further developed in West Virginia, the Leadership Academy program consists of two basic elements—structured three- to four-day training events and follow-up networking activities designed to reinforce the learning and to support its application (7).

The training events use a participant manual (available from CONTAC at www.contac.org) that contains 19 highly practical lessons on topics such as the etiquette of consumer involvement, identifying issues, gathering information and making reports, conducting effective meetings, and forming advocacy organizations. The trainers are all consumers who have themselves been trained in adult education skills. Participants consistently describe the Leadership Academy training as focused on building skills, acknowledging strengths, encouraging belief in the positive potential of constructive activism, and, in its overall impact, inspiring.

As excellent as the curriculum and the participant manual appear to be, the follow-up networking activities are at least as important. The skills that are learned at the training events will wither if they are not used. Activism is by nature a collective process, and having graduates join with others to pursue common purposes is a key skill-building technique of the Leadership Academy. It is learning by doing. Here are vignettes from five states:

♦ Colorado began implementing Medicaid managed care in 1995 with a strong focus on having consumers actively guide, develop, and monitor the process. As a result, the Mental Health Assessment and Service Agencies—which hold the Medicaid service contracts—sponsor consumers from each service area to participate in Leadership Academy training. The graduates play key roles in the advisory boards to the contractors and state committees.

♦ Maine held its first academy training event in May 1999. In the ensuing years graduates formed a statewide nonprofit consumer organization that is engaged in active dialogue with the state on improving public services.

♦ The Massachusetts Division of Medical Assistance (Medicaid) became convinced that consumers with advocacy skills were crucial for it to be an effective purchaser of services. It required its carve-out vendor to support a consumer organization that carries out Leadership Academy training, follow-up activities, and training of providers by graduates.

♦ The Virginia Mental Health Association chose the Leadership Academy as a vehicle for fostering a strengthened statewide consumer voice. With help from a community action grant from the Center for Mental Health Services, the Mental Health Association has conducted two academy training sessions and a "train the trainer" session to develop local faculty.

♦ When West Virginia started public-sector managed care in 2000, the managed care organization recruited a Leadership Academy graduate as community and consumer affairs manager to educate patients and families, respond to complaints, and conduct other forms of liaison and outreach.

Conclusions

The ten-year story of the Leadership Academy suggests that, just as it takes a village to raise a child, cultivating effective consumer voice requires extended organizational supports.

The Leadership Academy's skill-building curriculum is excellent, but without follow-up assistance for collaborative projects that foster networking and continued learning, it would accomplish as little as isolated continuing medical education programs do. The genius of the Leadership Academy is to treat the highly engaging skill-building workshops as a starting point, not as an end in themselves. Skill building requires the practice provided by working on collaborative advocacy projects with fellow consumers.

Managed care organizations themselves must provide some of the key supports for enhanced voice. Some organizations already seek effective consumer partners. They welcome, listen to, and hire Leadership Academy graduates. Other organizations may need prodding, for which advocates will need skills ranging from persuasion to negotiation to confrontation. Still other key supports for enhanced consumer voice come from the purchaser, generally Medicaid. Public purchasers are typically more oriented toward seeking consumer participation than private purchasers are (8).

In the history of the Leadership Academy, the federal government, primarily through the Center for Mental Health Services, has played a role it alone can fill: defining national objectives for strengthening the human capital required for effective services and funding such key initiatives as the consumer-run technical assistance center at the West Virginia Mental Health Consumers Association and the community action grants that have encouraged a growing number of state and local initiatives.

The Leadership Academy experience suggests that consumer voice can be strengthened through training and practice but that the process requires ongoing support. The U.S. health care "strategy" places too much faith in market forces ("exit") as the guiding hand for its health care system. All health care systems, whether single payer or market-based managed care, require effective consumer voice and civic advocacy to help address the challenge of caring for individual patients and the needs of a wider popu-

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lation in ways that are clinically informed, ethically justifiable, and politically acceptable (9,10). Programs like the Leadership Academy make an important contribution. ♦

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