Family Members as Monitors in a State Mental Hospital

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In 1983 the cooperative efforts of the Western Massachusetts Alliance for Mentally Ill Citizens and the Massachusetts Department of Mental Health led to the development of a program in which family members of patients at Northampton State Hospital monitor conditions at the hospital. The authors describe the process that generated the program, the training and duties of the family monitors, the role of the hospital administration and staff in the monitoring process, and the program's outcomes. They believe that the program gives families a much-needed role in the care of mentally ill relatives and that the staff-family collaboration it fosters strengthens the power of advocacy.

In recent years, recognition of budget limitations and insufficient services have caused mental health professionals and families with mentally ill members to join together to advocate for improvements in mental health services and research and in the quality of life of the mentally ill. In western Massachusetts, the Alliance for Mentally Ill Citizens (WMAMIC) was developed as part of this effort to generate viable solutions to the problems facing people in need of services. In their new roles as advocates, families have gained strength by changing their focus from one of "constant sorrow" (1) to one of strong and active advocacy and collaboration with professionals.

The District 1 administration of the Massachusetts Department of Mental Health supported the efforts of WMAMIC and provided families of patients in Northampton State Hospital opportunities to observe conditions in the hospital and to give feedback to administrative staff regarding their concerns. Subsequently the department's administrative staff agreed to a program of organized monitoring conducted by the families of hospital patients (2). The department believes that the relationship will strengthen mutual efforts to improve the services and the quality of care provided in the state system.

Administrative background of the monitoring program
In 1981 the need for organizational changes in the department of mental health became a major administrative issue. Despite deinstitutionalization and the development of community services during the last decade, the state hospital remained the most secure setting for many mental patients. Even with successful creation of

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comprehensive community programs in western Massachusetts, state inpatient facilities continued to have high admission rates and an average daily census ranging between 200 and 250 patients. But because of the lack of fiscal support and the department's prime commitment to developing community programs, some professionals and family members felt the hospital had received short shrift (3).

In October 1982 the department recommended and approved a plan to reorganize the state hospitals. Under the plan, all state inpatient facilities were to meet applicable statutes, regulations, and standards (2). Hospital units based on geographical catchment areas were created to promote management by area state mental health offices and to provide an effective continuum of outpatient and community services. Additional issues and problems identified included the public perception of state mental hospitals, the poor physical conditions in many of the hospitals, and hospital staffing patterns.

During this reorganizational effort to improve the state mental health system, WMAMIC proposed that the alliance and the department of mental health work together to improve the quality of life of patients in Northampton State Hospital. As a result of this proposal, the department and hospital administration assigned the authors to develop a program in which family members of hospital patients would serve as hospital monitors.

Program goals
As monitors, family members hoped to become educated about all facets of the hospital environment and thus be able to provide feedback to the mental health administration on the care being provided to patients. Alliance members explicitly sought dignity for the mentally ill and for the staff who serve them (4). They considered it part of their mission to use the monitoring process to eventually educate the public about the real issues facing patients and families. Alliance members believed the process had the potential to diminish stereotypes about the mentally ill and their families, particularly the stereotype that families are hostile to hospital staffs.

Consistent with their goal of improving the quality of life for hospital patients, alliance members also focused on treatment issues. They believed that treatment should be multimodal, including family therapy, for example, and should emphasize activities therapy. They were interested in psychiatric rehabilitation models stressing the acquisition of living, working, and leisure skills (5). Further, they sought to help the hospital and community work toward a more integrated service system that provides continuity of care during a patient's transition from hospital to community.

Relatives saw the monitoring process as a way of becoming more familiar with the mental health bureaucracy and of significantly changing the environment and services of Northampton State Hospital. Finally, many expressed the need and desire to participate in their relatives' healing process and to alleviate feelings of guilt over not having been part of their care in the past.

The monitoring process
A total of 20 monitors participated in the program during its first year. They ranged in age from 30 to 65, and 75 percent were women. Almost two-thirds of the group (13 monitors) were parents of current or former patients of Northampton State Hospital. Three monitors were siblings of patients, three were friends of parents or of the alliance, and one was a former spouse of a patient.

Orientation and training of monitors. Monitors are trained in two three-hour training sessions held in the evenings and led by hospital staff. In the first session, trainers and monitors discuss disappointing previous experiences involving a hospital milieu. Such discussion focuses on eliciting the monitors' concerns and expectations of their new roles.

A didactic format is used, however, to familiarize the monitors with the structure of the department of mental health, its staff, and the hospital. This section of training, lasting several hours, is entitled "What to Look For in Institutions" (6). Several handouts pertaining to hospital policies and procedures are used so that monitors can prepare for the next training session.

At the completion of training, monitors and trainers sign a formal agreement stipulating the conditions for the monitoring process. The agreement also ensures that monitors will protect patient confidentiality, that they will not monitor wards on which their relatives are patients, and that they will work through the department of mental health to alleviate identified deficiencies in the hospital system.

Monitoring the wards. Monitors are given six-month ward assignments and make unscheduled site visits at least once a month. All monitors work in pairs and are accompanied by a different staff member on each visit. Before their first unscheduled visit, the monitoring teams meet with the unit director who coordinates and directs the activities of the ward to which they have been assigned. These orientation meetings have several goals:

- To outline the unit's functions and patient and staffing patterns
- To introduce the monitors to
the staff and thus pave the way for a cooperative process of unscheduled site visits

- To provide the monitors with a tour of their assigned ward
- To answer any questions the monitors may have about their assigned ward.

During site visits, which generally last one to one and one-half hours, the monitors record on monitoring forms the number of patients they see on and off the wards, as well as the number of direct care staff, supervisors, and doctors on the ward. They also rate the appearance of the patients and ward, briefly describe patients' and staff's activities, and, if they have chosen to visit during a mealtime, comment on the food and atmosphere in the patients' cafeteria. Questions arising during the visits are answered either by the accompanying staff member or by any other staff member on the ward.

Monitoring reports, which are signed by both monitors and the accompanying staff member, are handed in to the unit director after each visit. The unit director fills in the estimated completion date of needed improvements and the actual date improvements are made, and comments on the results of the changes. The unit director may also make additional comments to explain administrative constraints and fiscal limitations affecting proposed improvements.

Follow-up meetings are arranged with the monitoring teams and the unit directors every three months. Through discussion of the details of the visits, unit directors receive feedback from the monitors and answer any questions that have arisen since the training sessions or the orientation meeting. Hospitalwide issues are also discussed, as are the status of hospital plans to ameliorate identified problems.

Outcomes of the program

Program outcomes can be classified on a continuum ranging from subtle to obvious. The most important subtle outcome has been the change in the monitors' and staff's attitudes toward one another. During the first six months of the program, the monitors began to feel a lessening of staff resistance to their presence and function. As staff began to perceive the monitors as an influential source necessary to bring about long-overdue hospital improvements, their attitudes became more supportive and welcoming. The monitors and staff began to share their feelings of frustration and powerlessness, a process that had some salient effects. Both groups recognized the need to set priorities for hoped-for changes, to establish short- and long-term goals, and to objectify their experience from helplessness to assertiveness and activity.

More obvious outcomes include the hospital's efforts to make improvements and enforce changes. A new hospital policy mandated the wearing of name tags by all staff. More effective housekeeping procedures were developed, resulting in cleaner wards. According to the monitor reports for the first year of the program, ward appearance showed strong overall improvement.

Although patient appearance also improved, the trend was less strongly positive; improvements shown in the second and third quarters of the year did not appear to be fully maintained in the last quarter. Patient activities were also enhanced by providing additional recreational activities and equipment. In addition, visiting areas were made more appealing.

During the second six months of the monitoring program, the monitors concentrated less on routine facility and management issues and more on the clinical and programmatic aspects of hospital care. Their recorded concerns about the lack of therapeutic activities and supplies for existing activities, about the ratio of clinical staff to patients, and about adequate medical and psychiatric staff have resulted in more interactions between patients and staff and increased hiring of clinical, medical, and psychiatric staff.

Another outcome worth noting has been the requests for information from institutions interested in beginning a similar monitoring process.

Finally, the monitors identified a long-standing problem of asbestos in the ceilings of one hospital building. A seven-month project resulted in the replacement of the ceilings, and patients have moved back into the affected building.

Conclusions

Because the sample size of the monitors' ratings was too small to test for statistical significance, we acknowledge the need for further research into the effectiveness of a family monitoring model. However, we believe that this innovative model can be applied within any state hospital and within other patient settings. It supports the concept that professionals and families working together can strengthen the power of advocacy. The program gives both families and staff the clout to produce concrete and positive improvements in the delivery of services and the conditions of treatment. It can change the administration of programs and institutions and strengthen the ability of service providers and citizens to accomplish compatible goals. Most important, it allows family members to become part of the treatment process.

References

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