

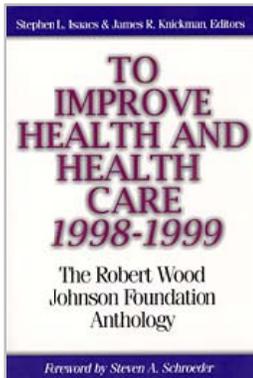
# Providing Care—Not Cure—for Patients with Chronic Conditions

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Robert Wood Johnson Foundation

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## *Editor's Introduction*

The Foundation's goal of improving the way services are organized and delivered for people with chronic conditions has proven particularly elusive.

The realities are daunting: a disorganized array of actors deliver services that are driven more by financing rules than by the needs of chronically ill individuals. Moreover, because acute care is often covered by insurance whereas more caring services—such as homemakers' visits—are not, the services offered to chronically ill people are skewed toward treating acute episodes of illness rather than coordinated approaches addressing a whole array of their needs. A logical approach to organizing services would be to start with the needs of people who have chronic conditions and then figure out how to meet those needs most effectively.

This chapter by Lisa Lopez, a freelance writer specializing in health care, analyzes the strategies and accomplishments of two significant investments by the Foundation to improve the way services for chronically ill people are organized and delivered. One of the programs—Chronic Care Initiatives in HMOs—attempts to improve the medical care of individuals with chronic illness enrolled in managed care. The second program—Building Health Systems for People with Chronic Illness—focuses on better approaches to coordinating both medical and supportive care services, such as assistance with activities of daily living.

Both national programs underscore the need to expand the services covered by insurance or health plans so that nonmedical as well as medical interventions are covered. They emphasize, as well, the importance of coordinating the different providers needed by a person with complex chronic conditions.

Findings from these two programs have helped define a new generation of Foundation investments aimed at improving services for chronically ill people. Currently, the Foundation is beginning new national programs to improve the clinical management of the long-term medical needs of the chronically ill. Other national programs are being designed to increase the capacity of the long-term care system to meet the supportive needs of the chronically ill.

Cathy's life in a large group home in Keene, New Hampshire, where she was placed after leaving a state school for the mentally disabled, was more nightmare than reality. She was anxious and couldn't sleep at night. She didn't speak to anyone. Administrators sedated her as often as they could, and she could not see a doctor or a dentist unless she was first sedated. During the day, she spent fitful hours biting and kicking. At one point, neighbors phoned the police when a disruption in the house got out of hand. Even medication could not release her from the attacks on herself. When her family visited, they felt guilty and hopeless. "I used to wonder if this was what Cathy's life was like all the time," her twin sister, Carleen, later recalled.

Like many others before her, Cathy was responding to her environment—a controlled, homelike setting, but one with prescribed conditions and activities and with little, if any, choice for individuals. Carleen and her husband, Chuck, had often thought of bringing Cathy home to live with them and their two young children, but Cathy's unpredictable outbursts made the idea seem unworkable. After much thought, however, they decided on a six-month trial, and Cathy moved in with them in March 1995 with the hope that a new local program, the Monadnock Self-Determination for People with Developmental Disabilities Project, would help them manage her needs. A project team helped them devise a budget using Cathy's Medicaid dollars, with which they would seek the services Cathy needed. In this project, individuals and families—not the state—choose the services a person needs.

In a matter of days, Cathy's responses to her life reversed themselves. She began sleeping through the night and participating in her family's activities—going shopping, playing with the children and celebrating birthdays and holidays. She no longer required sedation for her medical and dental visits. She communicated her wants through hand and head gestures, and was aware of activities around her. Although the family went through periodic challenges with Cathy, being at home with her loved ones has brightened her life. This resulted from allowing Cathy to have better control over her circumstances. "She is able to cope better, and can handle almost anything," Carleen remarked later. "She feels better about herself, and that she is being listened to."<sup>1</sup>

#### HIGHER AIMS FOR CHRONICALLY ILL PERSONS

The Monadnock project is funded by the Robert Wood Johnson Foundation as part of the Building Health Systems for People With Chronic Illnesses Program. It is just one of many projects the Foundation supports that provide social and medical services for the chronically ill and the disabled. Since 1991, the Robert Wood Johnson Foundation has made more than \$200 million in grants in the

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area of chronic care. Of this, more than \$50 million has been granted to three national programs with more than 1100 projects that seek new ways to provide health and supportive care services for chronically ill and disabled people like Cathy. These programs are Chronic Care Initiatives in HMOs; Building Health Systems for People with Chronic Illnesses; and Faith in Action, the interfaith volunteer caregiver project discussed in Chapter Seven.

In some cases, the programs have improved the quality of life for people with chronic illness or with disabilities simply by providing them with more options for care—and for less than the cost of care in traditional programs. In Cathy's case, her life improved significantly, and at a cost that was 75 percent of what the Medicaid system paid for the young woman to live in the group home.

Chronic care became a specific Foundation priority in 1991. Although the Foundation had funded a number of programs in past years that focused on specific diseases such as AIDS, Alzheimer's and chronic mental illness, Foundation staff members realized that there was a need to look at the challenges all these illnesses shared. These challenges had to be overcome in order to improve care, says Dr. Lewis G. Sandy, the Foundation's executive vice president. "There had to be better integration and coordination of care, focusing on both medical and nonmedical needs," Sandy notes. "The overall orientation of the medical care system is disease specific, powerfully oriented toward acute care, and so pervasive that it is difficult to move people toward different models of care." Moreover, he said, there remains a stigma associated with mental illness and disability.

In the United States, perhaps one hundred million people live with some type of chronic condition such as hypertension, the effects of stroke, HIV, or a mental or physical disability.<sup>2</sup> These conditions cost \$470 billion a year for medical services alone.<sup>3</sup>

Even with this investment in what is often considered the best health care in the world, however, the United States has not adequately addressed the needs of chronically ill or disabled people. They are often caught in a fragmented system in which public and private benefits are tailored to those with acute care needs, or limits are placed on the choices that would allow them either to reduce their pain or to improve their quality of life, or both.

Although chronic conditions cannot be cured, private health insurance emphasizes medical services that have a curative focus. Insurance coverage is much spottier for the nonmedical services that people with chronic conditions often need, such as supportive housing, the installation of bathtub railings, getting

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access to devices that can help them return to work, and help with daily activities that would allow them to make the transition from a nursing home to their own home.<sup>4</sup> The aging of Americans will surely increase the need for care among this population and further burden the current fragmented system of care. By 2030, almost 150 million people are expected to have a chronic condition. Of these, an estimated 42 million will be limited in their ability to work, to go to school or to live independently.<sup>5</sup>

Changing the structure of our current system of care to meet the care—not curative—needs of people with chronic conditions will mean changing the attitudes and the behavior of health care organizations, federal and state policy-makers, physicians and other health professionals. It will require that these institutions explore new ways of financing and delivering care and services.

Chronic Care Initiatives in HMOs and Building Health Systems for People with Chronic Illnesses examine such alternatives. These programs represent only two of the Foundation's initiatives in chronic care, and each has a distinctive focus. Chronic Care Initiatives in HMOs explores innovations in managed care systems. Building Health Systems for People with Chronic Illnesses funds projects that cut across medical and supportive care sites as well as chronically ill populations. Each of these programs includes a variety of projects that target a number of areas, from primary care and risk assessment for the frail elderly, to independent living for the mentally and physically disabled, to education that encourages doctors to work as teams in managed care plans.

The two national programs demonstrate how care can be delivered using a commonsense approach to building clinician and patient interaction and decision-making. In many cases, for instance, the projects funded under the national programs make use of or restructure existing resources within an organization and a community rather than develop new efforts. The project directors hope their experiences will prompt consumers, policy-makers, health plans, community-based organizations and others to begin to discuss new ways to care for the chronically ill, and to learn lessons for the future.

#### MANAGED CARE AND CHRONIC CONDITIONS

At first glance, chronic illness and HMOs do not seem to be a natural fit. The capitated financing of managed care provides incentives to enroll healthy people who have below-average needs for medical services. In addition, like the fee-for-service system, managed care plans such as HMOs have traditionally operated as systems that are structured more for delivering care to people with acute, short-term needs than for delivering care to people with lifelong chronic conditions such as diabetes and arthritis.

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Moreover, delivering—and improving—care to people with chronic illness requires providers and health plans to change provider and patient behavior in several ways:<sup>6</sup>

- Moving from a focus on cure to a focus on the relief of symptoms.
- Making the patient a critical part of the care process.
- Creating active roles for the patient's significant others, such as immediate family.
- Expanding the boundaries of care among providers and between traditional medical and social services.
- Tying patient satisfaction to clinical outcomes.

Despite these challenges, HMOs do have the potential to adopt such approaches. For one thing, HMOs can intervene on a system level rather than an individual level, and this allows a person's care to be coordinated within a health plan's available resources rather than in a fragmented way. Second, the primary care orientation of HMOs emphasizes generalist physicians, nurse practitioners and other providers, whose care may be more appropriate for patients with chronic illness than specialty practices. Third, the HMO system of paying for care on a prepaid, capitated basis gives these organizations the flexibility to allocate resources where needed, including those that focus on home- and community-based services, outreach and case management. Fourth, capitated payments can create an incentive for HMOs to provide cost-effective care in the most appropriate settings.<sup>7</sup>

#### THE CHRONIC CARE INITIATIVES IN HMOs PROGRAM

Chronic Care Initiatives in HMOs, a \$5.6-million, four-year program, was begun in January 1993 with the aim of testing innovative projects that focused on six areas:

- Offering innovative ways to provide posthospital care to those with chronic conditions in order to reduce rehospitalizations.
- Developing and coordinating services for high-risk populations, such as children with mental or physical disabilities and adults with depression or dementia.
- Evaluating ways to provide primary care to HMO enrollees who are in nursing homes.
- Coordinating services for people with multiple, complex problems that require multidisciplinary teams of providers, as well as family caregivers and community resources.
- Assessing new ways to deliver primary care for persons with chronic conditions.
- Conducting cross-cutting assessments of care.

The program has funded 21 different projects to date.

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Peter D. Fox, the national director of the program, notes the importance of three research priorities: evaluating case management in HMOs, reorganizing primary care to enhance the delivery of services, and improving the delivery of primary care to nursing home residents.

Reorganizing primary care is perhaps the best example of how HMOs can use existing resources to manage care for the chronically ill, Fox says. Armed with the ability to provide a more population-based approach to care, he notes, HMOs can identify problems at both the secondary prevention stage (identifying and treating the disease at an early point) and the tertiary prevention stage (reducing impairment, disability and suffering).

Case management was at the heart of the program, says Teresa Fama, its former deputy director. "We saw case management as being the glue in service delivery for people with chronic conditions," she says. Simply put, that meant influencing physicians to change their traditional approaches to delivering care and helping patients become more active participants in their care. Fama and Fox note that two projects in particular provide good illustrations of how reorganizing primary care and influencing provider behavior can improve health care delivery for chronically ill HMO members. The first—undertaken by the Group Health Cooperative of Puget Sound—works directly by restructuring care around specific chronic conditions. The second—undertaken by the Henry Ford Health System—works indirectly by training physicians in the care of patients with chronic conditions.

The intent was to take the chaos out of the delivery of primary care, and at the same time improve results among its enrollees with chronic conditions. The goal was to integrate the management of chronic care into its existing system of primary care. By 1998, many managed care providers began to experiment with chronic disease management approaches. However, back in 1995, this approach was innovative both in its timing and in its focus on the primary care system.

*Group Health Cooperative Reorganizes Primary Care*

The Group Health Cooperative of Puget Sound, or GHC, a 500,000-member Seattle-based HMO, was one health plan that felt it could reorganize its internal processes to improve care for the chronically ill. In 1995, it introduced a Chronic Care Clinic in an effort to restructure the way physicians and their staff practiced.

"The primary care practices were continuing to function in a lot of ways like miniature emergency rooms," says Brian Austin, the manager of the Sandy MacColl Institute for Healthcare Innovation at

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GHC. "All the attention was being given to the next patient coming through the door, and at any given time clinicians would have to rotate their attention from condition to condition. It was hard for them to have a concentrated time with either a patient or a single condition. We were trying to find an oasis in the clinicians' day where they could concentrate on a single condition and work as a team, and to allow patients who had similar conditions to meet with one another and share some coping and management skills."

Enter the Chronic Care Clinic. Group Health Cooperative officials had studied and somewhat patterned the Chronic Care Clinic after England's miniclinic days—a system in which the National Health Service organizes practices around a single condition. English providers bring in nonphysician health care practitioners and designate one morning to treat just diabetics or asthmatics or the frail elderly. The efficiency of that model and the positive outcomes among patients led GHC to try it in Seattle, Austin says. The Chronic Care Clinic focuses on four main areas:

- Conducting thorough patient assessments to detect potential complications.
- Introducing techniques that help patients manage their own condition.
- Providing physicians and their staff with clinical guidelines.
- Improving patient satisfaction through education and psychosocial support services.

Two chronically ill populations—the frail elderly and diabetics—were chosen to participate in a study to assess this approach. In all, 19 GHC physician group practices participated in the study; 25 physician groups continued their usual practice and were designated the control group. Each of the practices had about 20 chronically ill patients in all, between the two categories. Patients in the study met every three or four months in groups of four to eight. Their sessions with practitioners covered a range of topics, from exercise and general management of their condition, to more specific issues the patients wanted to address. They also met individually with their own doctor and nurse. Patients also often met with a pharmacist either before or after the group session, especially during their first Chronic Care Clinic visit. Nurses made follow-up telephone calls to help patients adhere to their care plans and to schedule new appointments.

At the beginning of the study, providers were trained to work together and were encouraged to establish team meetings. They were also given clinical guidelines on basic care for the condition they selected. These guidelines, called Diabetes 101 and Geriatrics 101, were in turn tied to the objectives of the Robert Wood Johnson Foundation grant and to GHC's own clinical guidelines. With diabetes, for example,

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clinicians measured individuals' physical function, glucose control, reduction of microvascular complications, and changes in patients' behaviors, such as exercise, foot care and diet.

For the frail elderly, GHC clinicians worked with geriatricians to create a new clinical guide. To measure its effectiveness, physicians were asked to concentrate on reducing falls and on drug side effects, managing depression, managing incontinence in older women, and managing impaired function. "We tried to keep it fairly simple," Austin says.

The first-year results are based on reports by physicians and patients. They show increased satisfaction among clinicians and among the diabetic and elderly patients. Overall, physicians and other staff delivered active versus reactive care, and patients became more involved in managing their conditions and were less passive than they had been before the Chronic Care Clinic was introduced. One benefit was that pharmacists could more easily identify and communicate potential drug interactions to both providers and patients, and could more readily discuss prescription needs with the physicians, who were better able to follow up with their patients.

During the study, Austin points out, providers demonstrated a surprising willingness to try new ways of organizing their practices in order to communicate better with and more actively treat their patients, even in a time of enormous change. (GHC's central region was undergoing a major reorganization.) "All seemed to feel that they weren't doing as good a job with their chronic care patients as they thought they had"—before the Chronic Care Clinic—"and that there was a lot more they could do," he says. By the end of 1998 the GHC project expects to have results indicating how often patients use the clinic's services. The findings should provide a picture of the extent to which the primary care doctors and other providers improved their services.

When the findings become available, the HMO plans to distribute them both internally and externally. A "how-to" packet on the chronic care clinics has been prepared and is being shared with other practices. The plan is also considering the Chronic Care Clinic approach for patients with other chronic conditions such as asthma.

*Managed Care College Targets Physician Behavior*

The Henry Ford Health System, which serves residents of southeast Michigan, includes a 500,000-member HMO, the Health Alliance Plan, or HAP. In 1993, the Metro Medical Group, which at the time was a division of HAP, launched the Managed Care College, an on-site medical education program for

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primary care physicians within the medical group. The idea was to combine medical education and actual clinical practice on site in order to improve patient care and results for patients with chronic conditions who were being treated by the health plan's primary care clinicians. Moreover, the medical group's leadership believed that this approach would encourage physicians to practice more cohesively, bring about changes that would improve care, and reduce inappropriate practice variations among the clinicians. At that time, the Metro Medical Group had 80,000 members and 120 physicians, 65 percent of whom were in primary care, and eight ambulatory sites. In the Managed Care College's second year, the Metro Medical Group merged with the larger multispecialty Henry Ford Medical Group, which was also affiliated with the Henry Ford Health System. The merger signaled the need to adapt the college to the needs of the larger physician group.

In the initial year of the program, enrollment was mandatory for all primary care physicians in the Metro Medical Group. Physicians—and some nurses—attended one four-to-five-hour session each month covering topics such as the role of primary care physicians in managed care, epidemiology, clinical practice improvement, and courses targeting the care and management of specific chronic conditions—type II adult diabetes mellitus, for instance.

After the two medical groups merged, the college faced the challenge of maintaining the core elements of the program while expanding to meet the needs of the larger health system. Although the sheer size of the Henry Ford Medical Group precluded mandatory enrollment, the college was expanded to include a two-track curriculum: an administrative track and a clinical one. Classes involved more hands-on learning, and the program was shortened to better accommodate physicians' schedules. In subsequent years, the college has added specialists to its enrollment and merged the two-track curriculum. Although specific courses vary each year, the core concepts have remained the same: clinical practice based on proven methods, teamwork, the clinician's role in managed care and quality improvement. Supplementing this core list are electives in ethics, finance, customer service and other topics. Core classes generally run from October through June on weekday afternoons and occasionally Saturday mornings. Since the college's inception, some 240 physicians, nurses, administrators and others have participated in the college's core curriculum, and some 500 have taken the elective courses. The college has seventy-six clinicians enrolled in the 1997–98 session.

What distinguishes this approach from current continuing medical education, according to project staff members, is the effort both to improve the physicians' understanding of managed care and to enhance

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the clinical skills of medical staff members in order to improve patient care. "What we know is that it has caused our staff to realize that managed care is more than capitation and cost containment," says Jennifer Elston-Lafata, a research scientist for the Ford System's Center for Clinical Effectiveness. "What they're gaining is a much broader perspective on what's involved with managed care."

The results have been fruitful in both administrative and clinical areas. After the first year, physicians were more likely than they had been to accept clinical guidelines in treating patients with chronic conditions (72% precollege versus 86% postcollege); 21 percent indicated that their clinical practice had changed for the better in the last year as a result of using the guidelines. Moreover, 41 percent of the physicians said they had changed their approach to treating their diabetic patients.

After the second and third year, significant changes occurred in the knowledge that physicians had about existing resources and in their ability to use them. For example, they indicated that they had become better informed about where to turn when they needed assistance with clinical resources (19% precollege, 85% postcollege).

The college is still analyzing data, but preliminary results show that third-year enrollees have already applied the lessons learned. For example, a number of physician teams devised a primary care guideline for managing depression and a standardized coding for depression, and are seeking ways to improve prescribing patterns. Other clinics established education programs for diabetic patients. Some medical teams worked on improving retinal examinations. One clinic offered counseling programs for teenagers as part of its childbirth program.

"There is a general impression here that the Managed Care College has made a cultural change in all quarters and has been instrumental in helping reorient the Henry Ford Health System's agenda and the approaches we take to working with staff on improvement projects," says Dr. John J. Wisniewski, the system's assistant medical director. "We did not anticipate that, and did not design any explicit way to measure that."

The Managed Care College is sharing its model of education and its preliminary findings with organizations outside its own health system. These include the Jefferson Medical College in Philadelphia, the Cleveland Clinic, the Armed Services University and Michigan State University. The college signed

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an agreement with the Medical College of Ohio in January 1998 to help it develop similar programs, Wisniewski says, and continues to expand a special curriculum for managed care nursing.

THE BUILDING HEALTH SYSTEMS FOR PEOPLE WITH CHRONIC ILLNESSES PROGRAM  
The other national program directed at improving chronic care focuses on the difficult challenge of better coordinating the delivery of medical services and supportive services for the chronically ill. Building Health Systems for People with Chronic Illnesses is a \$13-million five-year initiative that began in 1993 and has supported 24 different projects around the country. The aim of the program is to identify new approaches for better coordinating the work that medical providers and supportive care providers—such as home care agencies, nursing homes and social service organizations—do for the chronically ill.

The program tackles a key anomaly with our caring system referred to earlier: insurance systems tend to fund acute medical care rather than supportive care for chronically ill individuals. The challenge is to find ways to reshape financing and service delivery systems so that the two types of services are coordinated and accessible to people in need.

Under this national program, the Foundation sought projects that have these goals:

- Integrating services so that care is provided across diverse settings, and systems of care link clinical and nonclinical support services.
- Reallocating resources by redirecting existing and acute-care-focused delivery and financing to better serve the chronically ill.
- Promoting early medical and non-medical interventions.
- Helping individuals maintain their independence for as long as possible in their own homes and communities.
- Giving the chronically ill and their caregivers a role in designing and improving their health care and support services.
- Reflecting models of care that can be used by people with different chronic health conditions.

Initially designed to look at a range of people with chronic illness and accommodate them within a single system, the program now focuses on three specific populations, project officials say: children with special health care needs, the physically and mentally disabled and the frail elderly.

"The dream was to address the disorganization of health care systems for people with chronic illness," says Dr. F. Marc LaForce, the national program director of Building Health Systems for People With Chronic Illnesses. "The program was based on the understanding that, given the tools and the support to live independently, disabled and other chronically ill persons could have a better quality of life." As the

program matured, housing and employment issues were recognized as important barriers to living independently.

One of the early projects run by Monadnock Developmental Services in Keene, N.H., had such an immediate and significant impact on care for the developmentally disabled that the Robert Wood Johnson Foundation decided to establish a new national program, also called Self-Determination for Persons with Developmental Disabilities, that now funds 23 projects in 12 states.

The Monadnock project was funded as a pilot project of Building Health Systems from November 1993 to October 1996, and it tested whether giving people with disabilities the freedom and the resources to make decisions about their own needs, with the help of friends and family, would improve their care and their quality of life. The project targeted people who had been institutionalized in state facilities. As a result of the program, some participants are now living independently and are employed. "The lesson we learned here was to throw away the old prejudices, and that even people with severe disabilities are capable of managing much of their lives," LaForce says. In this project, a case manager works with individuals and their friends and families to develop a plan for all needed services, as happened with Cathy, who was able to move in with her twin sister's family. The disabled person and his or her so-called circle of support—family and friends—develop a budget from Medicaid and state dollars, not to exceed 75 to 90 percent of previous service costs. The individual or the support network, or both, choose from an array of local resources—transportation, job skills training, physical therapy—to help the person live as independently as possible.

Besides Cathy, other individuals have had their lives changed for the better. An independent evaluation of the project by James W. Conroy, of the Center for Outcome Analysis in Ardmore, Penn., found that the quality of life improved significantly among 38 individuals who were studied after one year of the program. All those enrolled in the program said that their quality of life had improved in each of these nine areas: health, making personal choices, family relationships, seeing friends and socializing, getting out and around, day activities, food, happiness and comfort.

Researchers also found positive results among those enrolled, such as working with others and a reduction in challenging behaviors—self-injury, damaging property, social withdrawal. "This was an initiative that put control of resources in the hands of individuals who in the past had been taken care of paternalistically by systems that didn't empower them to do much of anything," LaForce says.

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Another effort that is attempting to integrate individuals into the community is called Enabling People with Disabilities to Reestablish Life in the Community, in South Portland, Maine. This project focuses on helping people with physical disabilities who are living in nursing homes move back into the community. As part of the program, the Alpha One Center for Independent Living, a local independent living center, is working with local housing agencies to improve access to assistive devices and housing for these people.

Often, disabled persons can receive Medicaid services only if they prove that they cannot live in the community without them, Jay M. Wussow, the deputy director of the program, points out. "But they can't do that until they move into the community," he says, and moving from the nursing home into the community involves a transitional cost. People in nursing homes who could live in the community can't make the transition without that assistance—and that takes money, Wussow says. To address the financing issue, Alpha One is using profits from a for-profit durable medical equipment subsidiary it runs to cover the actual care costs of transitional services, such as skills training. Because the project has the potential to be replicated elsewhere, the University of Southern Maine will evaluate it for the Foundation.

Addressing barriers to the employment of the physically disabled is the goal of Health Systems for Work Force Enhancement, a project funded with an 18-month grant to Employment Resources, Inc., or ERI, in Madison, Wis. The project is a public-private partnership that explores ways to break the health insurance barriers disabled people face when they return to work. Specifically, ERI is studying how disabled people can continue to receive Medicaid, health insurance, and long-term care insurance after they get jobs. It also works to enhance opportunities to employ disabled persons. The project attempts to reduce the fears people have when they face losing benefits after they return to work. ERI found that this fear was the greatest barrier to returning to work. "The way the system works now encourages individuals to stay unemployed because of the risk of losing home and attendant services as they earn salary dollars," LaForce says.

The 30 people enrolled in the program received Supplemental Security Income and Social Security Disability Insurance benefits that continued while they were undergoing rehabilitation, but faced the loss of their Medicaid benefits, which cover health care and the personal care services of daily living, if they were employed. These people will be guaranteed publicly funded health insurance and long-term care insurance, whereas a control group will not. As with the Alpha One project, the ERI project's potential to be replicated led to a separate Robert Wood Johnson Foundation grant to evaluate the project. In this

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case, the Oregon Health Sciences University will measure rates of employment and insurance coverage among people in the intervention and control groups.

Only anecdotal evidence now exists on the exact cost savings to the system, but ERI has found that there are some cost savings as people move off the disability rolls. Once the results are available, project officials will work with the Social Security Administration and the Health Care Financing Administration to provide ways to overcome the health insurance barriers that inhibit people with chronic disabling conditions from seeking employment. The long-term goal of a project like this one is to affect government regulations so that people can keep their benefits for a longer period of time, Wussow says.

Another project that attempts to empower chronically ill individuals is called Development of an Integrated Housing, Health and Support Services Network for Disabled Adults. Launched by the Corporation for Supportive Housing in Oakland, Calif., in July 1995, this three-year project aims at developing mental health and substance abuse treatment services for 750 previously homeless individuals with HIV/AIDS, mental illness and/or substance abuse problems. The Corporation for Supportive Housing has worked with community agencies to establish housing for people with these conditions in order to help stabilize their environment. Often, people recovering from drug addiction don't have stable housing—a critical component in helping them recover. The project is now in its third year. The aspect of combining health care and housing has already had preliminary success, program officials say. "Many of these people have gone from being homeless to more stable arrangements in a matter of a couple of years," Wussow says.

Given the project's focus on housing and support services to help people live as independently as possible in the community, officials are currently considering the next step, Wussow says: how to ensure the same employment opportunities for these individuals that anyone else in the community would have.

#### LESSONS LEARNED

Although it is too early to offer a definitive assessment, program directors and Robert Wood Johnson Foundation program officers for both Chronic Care Initiatives in HMOs and Building Health Systems for People With Chronic Illnesses cite a variety of lessons learned from the programs:

- *Existing systems and resources can be reorganized to enhance care.* As the examples cited in this chapter demonstrate, existing resources—whether HMO physicians and nurses, social services organizations, or community-based agencies—can be coordinated in order to link individuals

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with the medical and social services they need. HMOs can effectively provide chronic care management if they organize their systems so that they have a case management function in place, give physicians more clinical guidance and education, and provide patients with more tools for self-care. Beyond managed care systems, linking medical and nonmedical services can be important. Housing is a good example. "When I was thinking about issues of chronic care four or five years ago," says Marc LaForce, "I wasn't thinking about housing but how we could better integrate systems of medical care. One of the lessons we learned was that medical care is just one piece of a complex system that must be in place."

- *The behavior and attitudes of physicians can be modified to improve the care that they offer.* Few physicians are taught in medical school how to manage chronically ill patients. The Managed Care College and the GHC Chronic Care Clinic showed that physicians could work in teams and use their collective resources to better serve their patients. Although the doctors at the Chronic Care Clinic were initially concerned about the time a new process would add to their already busy schedules, the core concepts of the clinic—giving physicians' groups the time to work as a team and to focus on a specific condition and giving patients an opportunity to come together—succeeded in increasing physicians' acceptance of the group-care model.
- *Encouraging independent living and supporting consumers' choice in their own care services hold promise as ways of improving care of individuals with chronic conditions.* The models tried under the Building Health Systems for People with Chronic Illnesses Program have given individuals greater control over their care. They range from self-care techniques that can help patients cope with their illness to innovative financing mechanisms where individuals, not professionals, are given the resources to manage their own care.
- *Flexibility is needed to cope with marketplace changes, such as mergers, that can disrupt program and research efforts.* In the projects undertaken under the Chronic Care Initiatives in HMOs Program, research designs had to be changed frequently to accommodate changes in the health care system. For example, University of Colorado researchers had difficulty obtaining data for its patient care management project after the HMO where they were conducting research changed hands. And when the Metro Medical Group in Detroit merged with the Henry Ford Medical

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Group, it added a sizable and geographically diverse population to the Managed Care College, forcing changes in the project design.

- *Clinicians from different HMOs can work together to advance the field.* One example is the development of a new screening tool developed under the Chronic Care Initiatives in HMOs Program. In the fall of 1994, a group of twelve HMO representatives, along with two university-based geriatricians, began to meet to share ideas for providing care to their frail elderly members. Within two years, the group had developed a standardized tool and basic comprehensive geriatric assessment plan for identifying high-risk elderly patients. Today, more than three hundred health care organizations have asked to use the screening tool for the elderly patients in their plans.
- *Sharing experiences publicly can help expand awareness of innovations.* The Chronic Care Initiatives in HMOs Program was aimed at evaluating innovative HMO programs, but it went beyond that mandate and disseminated information widely. To this end, the program sponsored two chronic care conferences that gave clinicians and managers the chance to discuss their models of care, problems and potential solutions; those involved in the program published articles in professional journals, wrote books and issued reports.

Perhaps the most significant element to emerge from these programs, according to Rosemary Gibson, senior program officer for the Robert Wood Johnson Foundation, is the development of improved indicators to measure the quality of chronic care in HMOs. Researchers at six HMOs are testing the use of measures for four chronic conditions: childhood asthma, coronary artery disease, diabetes and major depression. Once tested and evaluated, some of these may be included in future versions of the Health Plan Employer Data and Information Set (HEDIS), a set of quality indicators published by the National Committee for Quality Assurance and widely used by health plans and employers. "If these measures become generally accepted," says Gibson, "they will affect the entire field."

## Notes

<sup>1</sup> E. Cummings, "Whatever It Takes: Stories of Self Determination from the Monadnock Region," Monadnock Self Determination Project.

<sup>2</sup> C. Hoffman and D. P. Rice; estimates based on the 1987 National Medical Expenditure Survey, University of California, San Francisco, Institute for Health & Aging, 1995.

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<sup>3</sup> See note 2.

<sup>4</sup> *Chronic Care in America: A 21<sup>st</sup> Century Challenge*, The Robert Wood Johnson Foundation, Aug. 1996.

<sup>5</sup> See note 2.

<sup>6</sup> P. D. Fox and T. Fama (eds.), *Managed Care and Chronic Illness: Challenges and Opportunities* (Gaithersburg, Md.: Aspen Publishers, 1996).

<sup>7</sup> See note 6.