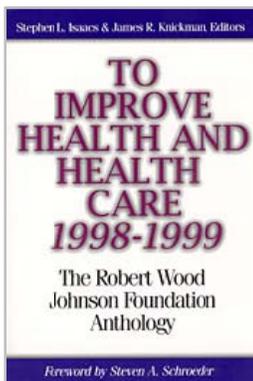




Chapter Seven,  
excerpted from the Robert  
Wood Johnson Foundation  
Anthology:  
**To Improve Health  
and Health Care,  
1998–1999**



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## *Editor's Introduction*

*Faith in Action* is a program that encourages voluntarism as a strategy for meeting the needs of chronically ill people. The Foundation sees voluntarism as one leg of the three-legged stool needed to build an effective system of chronic care. The first leg is public programs that provide home care and other supportive services, because many people with chronic conditions lack the resources to pay for services themselves. The second leg is private financing tools that let people plan for the services they will need if and when they become frail. Perhaps the most important leg is volunteers. Informal mechanisms—particularly families and friends—have been the main source of care for the chronically ill. The number of people engaged in this kind of work needs to be expanded as the aging of the population increases the number of people with chronic illness.

Over the past few years, the Faith in Action initiative has attempted to build a large service program—not just a demonstration—quickly. It has now given grants to more than 1,100 religious coalitions around the country. In this chapter, Paul Jellinek, a Foundation vice president; Terri Gibbs Appel, a former Foundation program officer; and Terrance Keenan, a senior consultant to the Foundation, discuss the logic of this approach and the issues that arose in implementing it.

Faith in Action is the Foundation's largest initiative encouraging voluntarism, but it is not the only one. For many years, the Foundation supported a concept called Service Credit Banking, in which healthy elders would volunteer to provide services to frail elders and receive "service credits," which the caregivers could cash in later in life when they themselves might need volunteer services. Another major initiative—the Reach Out Program—supports volunteer efforts by physicians to care for uninsured and indigent patients. More recently, the Foundation has begun to explore how volunteers might help improve the after-school lives of young people. The importance of mentors is becoming clear from recent research and voluntarism—especially in urban areas—is often seen as one way of increasing contact between young people and caring adults.

Certainly, voluntarism has received national attention through the efforts of General Colin Powell and others to promote community volunteering. Nationwide, his America's Promise campaign has received widespread publicity and praise. The groundswell movement may gather even more momentum over time.

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In the same way, the Faith in Action program may be entering a new phase of development. Even as this book is being published, the Foundation is considering the next steps in its support of this initiative, and of voluntarism in general.

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**B**ob Barclay, a sixty-nine-year-old retired research chemist, is a quiet, unassuming bachelor who lives alone in a house he bought 26 years ago in a working-class suburb of Trenton, N.J. He serves as a lector at Our Lady of Sorrows Church on East State Street, and over the years has done some volunteer work for Catholic Charities, but other than that he has kept pretty much to himself. "I'm a very private person," he said not long ago.

Yet in the winter of 1995, in his own quiet way, Bob Barclay became something of a hero to a small group of people in need in his community when he signed on to become an interfaith volunteer caregiver. "I saw a notice in the church bulletin, and I knew I could do this," he said. What Barclay knew he could do was become a volunteer driver for people who had chronic health problems or disabilities that made it hard for them to get out of the house.

"I had done this for my mother for many years, and she had only recently passed away," he remarked. Barclay's mother, who had lived with him for more than twenty years until she died at age ninety-one, had suffered from increasingly debilitating arthritis and had needed a great deal of help getting around, "including a lot of chauffeuring," Barclay said.

There were plenty of other services Barclay could have signed up to provide as an interfaith caregiver—shopping, respite, home repairs, personal care, meal preparation, or even just visiting—but others in the congregation had already volunteered to do those things. What was missing was somebody who could provide transportation, especially in the daytime, because that's when people need to get to the doctor or the bank or the hairdresser. "That's what attracted me—the notion of transportation," Barclay said. "It would be quite impersonal and, as I said, I've always been a private person."

But Bob soon discovered that it wasn't always so easy to keep things impersonal. One of his regular passengers was Mary, an eighty-five-year-old widow who lived alone and needed transportation for her medical appointments. "There was the dentist, the cardiologist, several eye doctors and the psychiatrist,"

Barclay said. "Actually, she seemed to me to be in reasonably good health for someone her age, but she suffered from panic attacks. She would often think she was having a heart attack or a stroke."

Barclay said that after a while, despite his natural reserve, "we did get to know each other quite well, and it was a pleasant surprise. When I brought her back from her appointments, she would want me to stay and talk to her for a while. Sometimes as long as two hours."

Mary had no real social contacts anymore, Barclay said, because she could no longer drive and many of the people she had known had died. "But I was always surprised at what she would know about what was going on in the parish and in the township," he said. "Mostly, I think she was just lonely."

Another of Barclay's regular passengers was a woman named Karen—"a quiet, private person like me, on the other end of the scale from Mary," Barclay recalled. Eighty-four years old and unmarried, "she lived alone in a house on Vincent Avenue, a couple of blocks from the church. She had a real bad heart, and she died suddenly just before Christmas last year," he said.

With Karen, Barclay said, the conversation was always "strictly business—just the time and the place she had to be." But as her condition worsened and she became increasingly frail, "She would hold onto my arm," he said.

Bob Barclay is not the only quiet hero out there. There were others at Our Lady of Sorrows Church who saw the item in the church bulletin, went to an organizational meeting and received the necessary training. Including Bob, there are now twenty-five active interfaith volunteer caregivers at Our Lady of Sorrows, up from eighteen last year. And just as Bob Barclay is part of a larger group within his church, Our Lady of Sorrows is itself part of a larger interfaith volunteer caregivers coalition that has come together in the Trenton area with a \$25,000 start-up grant from the Robert Wood Johnson Foundation. The coalition, which is made up of thirteen urban and suburban congregations, expects to continue to grow in the coming years, and already has several hundred volunteers—including the twenty-five from Our Lady of Sorrows—and in 1997 provided some 7,470 hours of care throughout the region.

The Trenton-area coalition is not the only one of its kind—it is one of hundreds of interfaith volunteer caregiving coalitions operating in towns and cities all across the country, many of them also initiated with funding from the Robert Wood Johnson Foundation. The National Federation of Interfaith Volunteer Caregivers, a membership organization that provides technical assistance and support to new and

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established coalitions, currently has 1,378 member coalitions, up from a hundred in 1992, and there are several hundred others—no one is sure exactly how many—that do not formally belong to the Federation. In other words, there are tens of thousands of people out there who, like Barclay, are volunteering their time and their energy to provide care and support to the many Americans, young and old, who have been cut off from their communities and from everyday life by chronic health problems.

#### THE GROWING NEED

The problem of chronic care in America is staggering. Almost one hundred million people in this country have one or more chronic conditions. More than forty million of them—one in six Americans—have some kind of functional limitation as a result of their condition. And although the elderly are more likely to have a chronic health problem than other age groups, Americans of all ages are affected, including twelve million children.<sup>1</sup>

These large numbers come as a surprise to many of us. Maybe this is because we tend to think of chronic conditions categorically rather than as a group. We are accustomed to thinking of arthritis, paralysis, asthma, heart disease, cancer, diabetes, AIDS, blindness, deafness, mental retardation, Alzheimer's and the many other chronic illnesses and disabilities as separate and distinct conditions. What we lose sight of is that although these conditions are distinct biologically and clinically, their impact on people's ability to carry on with their everyday lives is often depressingly consistent. No matter what their particular condition may be, people with serious chronic health problems frequently require some level of assistance with ordinary activities of daily living such as feeding, bathing, dressing, housekeeping, transportation, and, for those who live alone, companionship.

A major challenge facing the nation is how to meet that need as we move into the twenty-first century. So far, we have relied largely on family and friends to do the job. In fact, for seven out of ten persons with chronic conditions, family and friends are the only source of support. And although family and friends will undoubtedly continue to be the mainstay of chronic care in this country, the current arrangement is beginning to wear thin. Already, one out of four Americans is providing some form of assistance to a person with a chronic condition, and as the baby boomers age and life expectancy rates for the elderly continue to rise, the demand will grow even greater. At the same time, the capacity of family and friends to shoulder the burden on their own is declining. Over the next several decades, demographic shifts will reduce the proportion of Americans in the average age range for caregiving—fifty to sixty-four.

Moreover, women, who until now have done most of the informal caregiving, have been entering the workforce in record numbers, sharply reducing the amount of time that they can make available.

As the contours of this problem come into focus, it seems unlikely that as a nation we will be able to finance our way out of it. Policy-makers these days are desperately seeking ways to reduce future spending for health and social programs, not expand it. Moreover, the same demographic forces that are undermining existing informal care arrangements will also make it increasingly difficult to subsidize expanded chronic care services in the future. New ideas are needed, and interfaith volunteer caregiving is one new idea that the Robert Wood Johnson Foundation has been exploring.

#### THE CONCEPT

The basic notion of helping a neighbor in need is deeply rooted in the world's major faiths. Giving of oneself is widely recognized as a path to spiritual fulfillment, and has been espoused and practiced throughout the ages. Indeed, most religious congregations in America today offer at least some opportunities for members to volunteer their time in the service of others. Given that some two-thirds of all adult Americans belong to a religious congregation, this represents a vast potential resource to support and supplement the caregiving that families and friends currently provide to people who need chronic care. Some level of caregiving does go on in many congregations; however, it is usually on a very small scale, no more than a handful of people who do what they can on an informal basis. This is partly because there is often a range of volunteer opportunities to choose from in any given congregation, and those who are inclined to volunteer disperse themselves accordingly.

But the more fundamental problem is that most congregations by themselves simply don't have the resources necessary to staff and oversee their volunteer programs adequately. As a result, these programs are often poorly organized and not well promoted. Without a paid individual responsible for organizing and managing the program, volunteer efforts of the kind needed to help those with chronic illness will almost invariably fall far short of their true potential.

This is where interfaith volunteer caregiving comes into the picture. As a concept, it is remarkably simple. Rather than each congregation trying to develop and sustain its own volunteer effort to help the chronically ill and the disabled, a group of congregations representing the community's various faiths comes together, hires a paid director, and establishes a single caregiving program that draws its volunteers largely from the participating congregations to serve the entire community. By banding together in this way, in other words, the congregations are able to create a program large enough to justify hiring a paid

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director and, together with other organizations and individuals in the community, they should eventually be able to share the cost of that position and sustain it over time. Having a paid director who is responsible for the program in turn makes it possible to have a better-organized, more structured program that is more attractive to volunteers, who otherwise might not have come forward or, if they had, might not have been adequately utilized. Furthermore, because of the program's ecumenical character, religious proselytizing by the volunteers is not permitted—and this tends to make their services more acceptable to those in need of care.

The Robert Wood Johnson Foundation began its funding of interfaith volunteer caregiving in 1983 under the directorship of Dr. Kenneth Johnson, an internist who had worked closely with earlier Foundation programs for the elderly as well as for mothers and infants. A national demonstration program was announced under which the Foundation would award three-year grants of \$150,000—that is, \$50,000 a year—to fifteen communities around the country on a competitive basis. The program received a thousand letters of intent, signaling a strong interest in the concept and prompting the Foundation to increase the number of sites it was willing to fund from fifteen to twenty-five. The twenty-five sites were spread across the map, and included communities ranging from urban New York City, Memphis and San Antonio to rural La Grande, Oregon and Belhaven, N.C. Over the three-year life of the program, the sites recruited 11,000 volunteers and served 26,000 people, an average of more than 1,000 per site.

Several useful lessons emerged from the initial program. First, it appeared that the concept could be applied successfully in a wide range of communities. Churches, synagogues, and other houses of worship were able to come together, form local governing boards, recruit competent directors, mobilize volunteers, and provide informal care to substantial numbers of individuals in need, including respite to their families. It is also worth noting that a number of the coalitions that were not funded by the Foundation's program were able to obtain funding elsewhere. Some of these did go forward, but those that were not able to obtain sufficient funding to pay a director had real problems implementing the model, and these problems underscored one of the program's underlying premises about the value of having someone responsible on a full-time basis for organizing and managing each coalition.

A second lesson was that it took several years for most of the projects to develop into fully formed interfaith coalitions. Mature projects typically involved twenty or more congregations and served approximately five hundred individuals at any point in time—a substantial return for the cost of one project director. Often, however, projects started with just a handful of active congregations and had to

work hard during the first few years to persuade more skeptical clergy that interfaith caregiving was something that their congregations should become involved with. Many already felt overburdened with their existing obligations, and were hesitant to take on new responsibilities; others seemed to be uncomfortable with the interfaith dimension of the program.

Third, the interfaith model did appear to be sustainable financially beyond the three years of Foundation grant support. Of the original 25 coalitions, 20 are in operation today, more than 10 years after their original Robert Wood Johnson Foundation grants expired, and some have expanded their operations substantially. Principal sources of continuing support typically have included local funding agencies such as the United Way, local civic groups and businesses, and individual contributions, as well as the congregations themselves. Probably part of the reason for the projects' durability is that the operating costs—essentially, the director's salary plus minimal office and support costs—are modest, especially when they are spread across multiple funding sources. The transition period immediately after the conclusion of Robert Wood Johnson Foundation funding was not always easy, however. Often, the project directors were so preoccupied with the day-to-day task of organizing and managing their newly formed coalitions that they did not give their full attention to the issue of postgrant funding until their grants had almost run out. Also, during this initial demonstration program, the Robert Wood Johnson Foundation grants were large enough that very little local matching support was necessary. Consequently, when the grants ended, the shift to local funding sources was abrupt. This, too, made the transition more difficult than it might have been if local funders had been brought in earlier.

Finally, the thousand letters received in response to the program announcement suggested that there did seem to be a market for the idea of interfaith volunteer caregiving. The late Arthur Flemming, former Secretary of Health, Education and Welfare under President Eisenhower and chairman of the Foundation's national advisory committee for the program, saw the potential for a national movement and urged the Foundation to support the establishment of a new organization, the National Federation of Interfaith Volunteer Caregivers, to guide and nurture that movement. At that time, the Foundation rarely made any follow-up grants to try to broaden the impact of its demonstration programs. In this case, however, largely in response to Flemming's encouragement, the Foundation did provide a modest amount of start-up funding for the Federation, although with the understanding that funding to initiate new coalitions, at least for the moment, would have to be obtained elsewhere.

#### FUELING A MOVEMENT

Despite the Robert Wood Johnson Foundation's apparent reticence, the new Caregivers Federation was able to obtain additional funding elsewhere—notably from the Pew Charitable Trusts, the Public Welfare Foundation, the Commonwealth Fund, the Colorado Trust, and an anonymous donor. And slowly but surely, between 1988 and 1992, with Flemming as chairman, Johnson, the director of the Foundation's demonstration, as vice chairman, and a staff of two, the Federation helped to launch 150 new interfaith volunteer caregiver coalitions.

In so doing, the Federation not only increased the number of coalitions that had been in the original Robert Wood Johnson Foundation demonstration program by a factor of six; it also demonstrated that new coalitions could be launched with considerably less outside grant funding than the \$150,000 that had been awarded to those 25 original prototype projects.

The Public Welfare Foundation, for example, provided seed grants of \$20,000 each to start 50 new coalitions, and approximately four out of five were still in operation six years after starting up.

#### THE FAITH IN ACTION PROGRAM

The potential to produce large numbers of sustainable interfaith volunteer caregiver coalitions with relatively modest seed grants caught the attention of staff members at the Robert Wood Johnson Foundation in the early 1990s as they began to consider what the Foundation could do to help improve the organization and delivery of care for Americans with chronic health problems. In truth, the interfaith projects had been largely overlooked by Foundation staff people since the original demonstration had come to a close in 1987. Instead, the focus tended to be on the big picture: doctors and hospitals and the financing programs that supported them. Yet although doctors and hospitals would clearly continue to play a necessary role in the provision of chronic care, it was becoming increasingly clear that medical care alone was not sufficient to meet the needs of the chronically ill and the disabled; there were vitally important supportive services that doctors and hospitals simply couldn't provide.

In describing the role of interfaith volunteer caregivers, Johnson noted, "Their relationship to the people they help is *friend*, not a patient or client relationship.... Interfaith volunteer caregiver programs fill gaps in the long-term care system. About 60 percent of their referrals come from agencies that are unable to respond. Who else is there to look after an old person living alone after being discharged from the hospital on a Friday afternoon? Who else will deliver meals on weekends and holidays? Who else can be

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called after office hours? Who else will transport without charge someone three times a week for chemotherapy at a hospital sixty miles away?"

By tapping into the latent capacity of the nation's faith communities, these caregiver coalitions had shown themselves able to respond to the growing need for informal care. Moreover, the Federation's experience in successfully launching large numbers of new coalitions for a fraction of the cost of the original 25 demonstration projects suggested the possibility of funding the start-up of new coalitions on an even greater scale.

In the past, the Foundation had typically limited its role to that of developing and testing new health service delivery models, with the expectation that if a particular model proved to be successful, its broader replication would be supported by others, including the federal government. For example, its demonstration programs to improve health care for the homeless and for people with AIDS had paved the way for the federal McKinney Act and the Ryan White Emergency Care Act, both of which made federal dollars available to help communities across the country replicate the service delivery models tested by those programs.

Interfaith volunteer caregiving, though, did not seem to be a likely candidate for major federal funding. For one thing, the heyday of federal expansionism was clearly coming to an end. Also, the fact that the model was faith-based could raise concerns about separation of church and state. Above all, interfaith volunteer caregiving was truly a community-based enterprise. A sense of local ownership was fundamental to the model. And so, in the summer of 1993, the Foundation announced a new \$23-million grant program entitled Faith in Action. Under the direction of Johnson, Faith in Action was designed to make available 18-month seed grants of \$25,000 to help start up more than 900 new interfaith volunteer caregiver coalitions throughout the nation over a four-year period. The Foundation also provided funding for the National Federation of Interfaith Volunteer Caregivers to offer technical assistance to communities interested in applying to the program. A national advisory committee representing the major faiths and headed by Barbara Jordan, the late U.S. Representative from Texas, provided oversight for the program. Although the Foundation had funded demonstration programs at this dollar level in the past, those programs typically involved much larger but far fewer grants. Never before had the Foundation sought to make such a large number of grants under a single program.

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In a way, this was a different kind of demonstration program. Because interfaith caregiving would ultimately have to emanate from and be supported at the local level, Faith in Action was designed to make enough grants throughout the country that over time there would be an interfaith coalition within reach of most communities around the country. The hope was that once people heard by word of mouth what a coalition in a neighboring community was doing, they would be motivated to start one in their own community. Some of this natural diffusion had already been observed among the first generation of coalitions in places such as Austin, Milwaukee and New Haven.

The logistic challenge of managing a grant program on this scale was formidable, and the Foundation, despite twenty years as a national philanthropy, had little experience to fall back on. Even more daunting was the uncertainty about what the response to the program would be. True, the original demonstration had prompted a thousand letters of intent, but the grants under that program were for \$150,000. Would there be as many inquiries for grants one-sixth that size?

The initial response was in fact disappointing. Although there were many inquiries (more than 10,000 by 1997), relatively few completed proposals were received during the first year, and only a handful were funded. Despite a relatively straightforward application process, applicants were expected to do a good deal of work before submitting a proposal, including actually forming a coalition that could receive the funding, establishing a local governing board, and securing local matching support of approximately \$10,000. All this appeared to take more time than anticipated, especially for applicants not experienced in applying for grants.

In the fall of 1994, in response to these low enrollment figures, eligibility for the program was extended to include health and social service agencies that wished to apply on behalf of interfaith caregiver coalitions. In addition, efforts to inform potential applicants about the program were stepped up, and periodic application deadlines were established in place of the rolling admissions approach taken initially. Subsequent to these modifications, there was a marked increase in the number of grants. Between June 1994 and May 1995, only sixty grants were awarded. But over the next twelve months, 279 grants were issued, and as of July 31, 1998, a total of 1,100 Faith in Action grants had been made.

The coalitions funded under Faith in Action are diverse. Half of them provide care to people of all ages with chronic conditions of all kinds. A third focus primarily on the elderly, one in eight is focused on

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people with AIDS, and others concentrate on the mentally ill, people with dementia, children with disabilities and people with chronic substance abuse problems.

Reports received from the first 409 funded coalitions after 12 months of operation indicate that the service most frequently provided is "friendly visit/telephone reassurance" (22%), followed by transportation (14%). Other commonly provided services include meal preparation and delivery, linkage with community services, shopping and respite. Almost half the volunteers are employed full-time or part-time, approximately a third are retired, and about one in 10 is a student. Among the recipients, 37 percent are over age seventy-four, but one in four is between 31 and 64 years old, and about one in eight is under age eighteen. Fully two-thirds of the recipients are either poor or "barely managing."

#### IMPACT

Although hundreds of grants have been awarded under the Faith in Action program and there are more to be made, their cumulative impact on the nation's chronic care problem so far is probably marginal at best. After twelve months of funding, the first 409 Faith in Action grantees had served 25,052 persons, an average of only about 60 per coalition. Although some are serving more and past experience suggests that these numbers will grow as much as tenfold over time, even at that enhanced level the coalitions will meet only a fraction of the total need in this country.

The hope is that over time there will be local and regional ripple effects that will give rise to more new coalitions. Yet, as Rabbi Murray Saltzman, Arthur Flemming's successor as chairman of the Federation of Interfaith Volunteer Caregivers, has pointed out, the full impact of interfaith caregiving could extend beyond simply the number of people served. By providing a structured opportunity for personal fulfillment through service to others, interfaith volunteer caregiving may be seen as part of a broader movement aimed at revitalizing Americans' sense of civic responsibility. This movement reflects a growing sense that although government and the market have important roles to play, they cannot by themselves solve the nation's most pressing health and social problems. At the presidential summit on voluntarism held in Philadelphia in 1997, speaker after speaker underscored how important it was for individual citizens to recommit themselves personally, through active volunteer work, to the well-being of their neighbors and their communities. Voluntarism of this kind was promoted not only as a way to help meet those needs that fall beyond the reach of government and the market but also as a way to restore a sense of purpose and vitality to the lives of those who make the commitment.

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Bob Barclay, reflecting on his experience as a caregiver over the past few years, seemed to agree. "It is something I enjoy," he said. "In a way, it's a kind of tribute to my mother. She isn't around for me to help anymore, but this gives me a way to help others with the same kinds of needs."

### *Notes*

<sup>1</sup> C. Hoffman and D. Rice, *Chronic Care in America: A 21<sup>st</sup> Century Challenge* (Princeton, N.J.: The Robert Wood Johnson Foundation, 1996).