RWJF *Retrospective Series*

Chronic Care Programs

A Grantmaking Priority for the Robert Wood Johnson Foundation

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Preface

A sign in our Princeton office is a daily reminder of our enduring promise to the American people. It reads:

We pledge to tackle the greatest challenges to good health and health care for as long as it takes to achieve lasting results.

Living up to this promise is no easy matter. We wouldn't be in business if it was. After all, the ongoing threats to the health and health care of the American people and to our communities truly are among the greatest challenges to our society's well-being and security. The Robert Wood Johnson Foundation intentionally was created to help society overcome them.

We have been at it for the better part of half a century. Through the decades, our finest efforts have transformed important aspects of life in America: reversing the public's most lethal social norm—the use of tobacco; creating a kinder, gentler new system of care at the end of life; introducing the 9-1-1 emergency medical response system.

All told, we have backed up our promise by investing a total of $9 billion in national programs and grantmaking across the full spectrum of national health and health care needs. In the process, we continually learn about what works, what does not work, and why. Starting in 1973, the Foundation used evaluations to assess individual programs. Gradually, we grew into a process of transparent, third-party scrutiny of entire bodies of work, making ourselves accountable by relying on the same evidence-based assessments that we ask of our partners and grantees.

The result is a growing body of no-holds-barred retrospective appraisals of some of our most ambitious and well-known bodies of work. Reports on tobacco and end-of-life care, each a noted success, are available here. This third retrospective examines our decades-long attempt to overhaul how the health care system deals with patients with chronic illnesses and disabilities.

Improving chronic care, an RWJF area of interest since the early 1970s, emerged as a major long-term priority in the 1980s. Eventually, Foundation leadership over three decades approved thousands of grants costing more than $1 billion. Nonetheless, as this independent, outside evaluation unblinkingly concludes, we fell far short of our own good intentions.

The good news: Two-thirds of the programs did, indeed, help advance chronic care improvements. A particular standout is the highly regarded "chronic care model."

The bad news: Inadequate and uncoordinated Foundation strategies, tactics and grantmaking undercut the potential transformative value of the effort.

Unfortunately, neither Foundation nor program officials at the time sorted out which was the higher priority: helping a relatively small number of individuals receive better care—or changing the overall system itself.

The evaluator was Jonathan A. Showstack, PhD, MPH, of the Philip R. Lee Institute for Health Policy Studies at the University of California , San Francisco. He is an expert on assessing how an organization's characteristics affect its work in health care.

Showstack found that RWJF supported good programs that helped improve the care of people with chronic conditions, but "the whole was not greater than the sum of the parts." The finding, while disappointing, is, unsurprisingly to us today, accurate.

Still learning as we go, we take to heart the central truth of the chronic care retrospective: Exciting, profound change across an entire system of care demands integration of strategic planning, achievable objectives, coordinated tactical actions, staying power, and resources commensurate with the size of such a huge target.

In that sense, this chronic care retrospective already is inspiring the promise of our philanthropy positively—and prospectively.

Risa Lavizzo-Mourey, MD, MBA
President and Chief Executive Officer
Robert Wood Johnson Foundation

Introduction

In early 1991 the Board of Trustees of the Robert Wood Johnson Foundation (RWJF) authorized three new grantmaking priorities: 1) to assure that Americans of all ages have access to basic health care; 2) to improve the way services are organized and provided to people with chronic health conditions; and 3) to promote health and prevent disease by reducing substance abuse.[1] According to former Foundation President Steven Schroeder, MD, the second goal, the subject of this retrospective assessment, was intended to encourage a new "integrated, coordinated approach" to care, and emphasized "not the groups served, but the service system itself." All three priorities were implemented over the following decade in a series of programs and initiatives.

This review provides an overall assessment and critique of the strategic development of RWJF's chronic care priority; the application and implementation of this priority through the creation of new Foundation initiatives and programs; and the impact of this strategic priority on the development of new systems of care for persons with chronic illness and on the field of chronic illness care.

The emphasis of this review was on the structures and processes used to define and fund the chronic care priority and the relationship of those structures and processes to the successful achievement of the goals of the priority. Information was gathered from a variety of sources, including 1) RWJF documents (e.g., Program Results Reports, submitted to the Foundation by outside evaluators of RWJF-funded programs, and other internal documents that were made available to the review); 2) scientific literature and other publicly available documents regarding the historical prevalence and costs of chronic illness and disabilities, and about the Foundation's programs; and, 3) in-person and telephone interviews with current and former Foundation staff, program directors and others associated with Foundation-funded chronic care programs; and, clinicians, researchers, and health policy analysts who are familiar with the field of chronic illness care. (See Appendix 1 for a list of interviewees.)

Documenting and measuring the impact and influence of funded programs on the actual care received by persons with chronic conditions and on the field of chronic illness care was an important, but secondary objective, due to the limitations of both the available evidence and the time and resources available for such a wide-ranging assessment. There was no attempt to re-evaluate programs; rather previous evaluations of specific programs (to the extent that they were available) were used.

In early 1991 the Board of Trustees of the Robert Wood Johnson Foundation authorized three new grantmaking priorities…[including] to improve the way services are organized and provided to people with chronic health conditions…[which was] intended to encourage a new "integrated, coordinated approach" to care, and emphasized "not the groups served, but the service system itself."

While this review includes the wide range of chronic care-related programs funded by the Foundation starting in the 1970s, the focus is on the programs created and funded soon after the 1991 chronic care priority was implemented. Because the Foundation's end-of-life programs have been the subject of a previous review, they were not included in our analysis, and less emphasis was placed on Foundation programs related to disability and long-term care since they will be the subject of future retrospectives. (Appendix 2 provides a comparison of the results of this review with two previous published reviews on the Foundation's end-of-life and tobacco programs.)

We have attempted to make clear in this report the distinction between descriptions and interpretations of events, with the understanding that memories of an event, as well as judgments about its importance, are sometimes necessarily affected by an observer's own knowledge, perceptions, and experience. Thus, while we believe that our descriptions and analysis meet the scientific standard of reproducibility, we recognize and caution that other understandings and interpretations of these events may be reasonable.

The structures, processes, practices, and programs included in this review are specific to a particular period, roughly from the early 1990s to the early 2000s. To interpret and assess the structures and practices during this period, there is reference to structures, practices, and major changes in directions and priorities in earlier and later periods. There was no intent or effort, however, to assess or judge practices in these other periods, and none should be inferred from the analyses and discussions herein.

Section 1
Chronic Care Programs

A time line for each of the Foundation's 80 chronic care-related national programs between 1979 and 2010 is presented at the beginning of Appendix 3. Descriptions of these programs are also included in that Appendix.

To assist in the understanding of the many programs supported by the Foundation, chronic care-related national programs and ad hoc-funded projects were classified into nine themes intended to represent relatively discrete substantive funding areas (e.g., Theme I includes programs designed to affect the management of chronic illness in the acute care sector), and then each program or project was assigned to one of three chronic care–related groups according to how closely each program related to the intent of the 1991 chronic care priority.

It is important to note that these themes were developed for descriptive purposes for this review in order to identify logical groupings of programs, particularly those that may have interacted with or may have been synergistic with other similar programs. In fact, as described in more detail below, while there was occasional overlap of and interaction among programs with similar goals, we found little evidence of actual thematic development and funding of groups of programs or of a synergistic coordination among funded programs.

To differentiate grants that were related to the intent of the 1991 chronic care priority from grants that were derived from or related to other Foundation priorities (e.g., access, substance abuse, cost containment, obesity), chronic care-related grants were separated from nonchronic care-related grants. The classification schema included three chronic care groups: **Group 1 (Definitely Related)** includes programs and grants that, according to most of our interviewees, were definitely related to the intent of the 1991 chronic care priority; **Group 2 (Closely Related)** includes programs and grants that were identified by some of the interviewees as less directly related to the intent of the priority; and **Group 3 (Distantly Related)** includes programs and grants that were mentioned by at least one of our interviewees, but appear to be somewhat more related to other Foundation priorities. A fourth group includes programs that were not mentioned by our interviewees as related to the 1991 chronic care priority and that appear to be related to other Foundation priorities (e.g., access, substance abuse, cost containment, obesity, human capital).

While there was occasional overlap of and interaction among programs with similar goals, we found little evidence of actual thematic development and funding of groups of programs or of a synergistic coordination among funded programs.
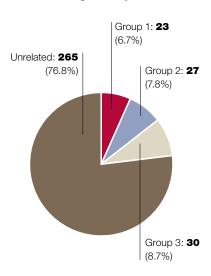
FIGURE 1

National Programs by Chronic Care Group, 1972–2010

Group 1: **23**
(6.7%)

Group 2: **27**
(7.8%)

Unrelated: **265**
(76.8%)

Group 3: **30**
(8.7%)

We applied the classification schema to the Foundation's 345 national programs between 1972 and 2010 (Figure 1). Eighty national programs (23.2%) were classified into one of the three chronic care groups (23 [6.7%] in Group 1; 27 [7.8%] in Group 2; and 30 [8.7%] in Group 3), with the remaining 265 national programs [76.8%]) classified as Unrelated. (Appendix 4 lists the national programs within each classification group.)

Between 1972 and 2010, the Foundation made 21,164 individual grants for a total payout of $7.6 billion (Table 1). The Foundation's Office of Program Management estimates that approximately two-thirds of the grants were within one of the Foundation's 345 national programs, while one-third were ad hoc grants outside of national programs. Of the 21,164 grants, national programs in Groups 1, 2, and 3 accounted for 4,343; 306 ad hoc grants were classified in one of the three chronic care groups, for a total of 4,649 grants classified in the three chronic care-related groups (22% of all grants). Group 1 accounted for 4 percent of all grants, Group 2 for 11.9 percent, and Group 3 for 6.1 percent.

Between 1972 and 2010, the 4,649 chronic care grants were awarded a total of $1.21 billion, 16 percent of the total of $7.6 billion in grants awarded by the Foundation from 1972 through 2010. Grants in chronic care classification Group 1 accounted for 3.7 percent of total dollars awarded, those in Group 2 accounted for 5.2 percent, and those in Group 3 accounted for 7.1 percent. The 16,574 grants that were classified as Unrelated were awarded approximately $6.4 billion, 84 percent of the total.

The yearly amounts between 1975 and 2010 paid out to grants in Groups 1, 2, and 3 (all chronic care-related grants) are shown in Figure 2. There was a rise in the 1980s in the total payout to chronic care grants, peaking at $37.6 million in 1989. The total payout devoted to chronic care grants fell in the early 1990s. It was not until 1998, when the amount rose to $41.8 million, that the payouts to chronic care grants exceeded the 1989 level. Starting in the late 1990s, awards to chronic care grants steadily increased, peaking in 2003 at $86.5 million, then declined to approximately $50 million in 2006 and have held steady since.

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TABLE 1

Grants and Payouts by Chronic Care Group, 1972–2010

Chronic Care Group	Number of Grants	Percentage of Grants	Amount Awarded (in millions of dollars)	Percentage of Dollars Awarded
Group 1: Definitely Related	852	4.0%	$279.6	3.7%
Group 2: Closely Related	2,510	11.9%	$391.6	5.2%
Group 3: Distantly Related	1,287	6.1%	$537.5	7.1%
Subtotal	**4,649**	**22.0%**	**$1,208.7**	**16.0%**
Unrelated Programs	16,515	78.0%	$6,367.5	84.0%
Total	**21,164**	**100%**	**$7,576.2**	**100%**

Yearly payout totals in Group 1 (the group most closely associated with the 1991 chronic care priority) showed little change throughout the 1990s, holding steady at approximately $10 million through 1998 (Figure 2). Yearly payouts declined in both Groups 2 and 3 in the early 1990s. Payouts began to rise in the late 1990s for all three groups, peaking in 2003 (Group 1: $17.3 million; Group 2: $31.3 million; Group 3: $37.7 million), and then declining during the middle and late 2000s.

The dollar amounts paid out to chronic care grants in context of all the grants awarded by the Foundation between 1975 and 2010 is shown in Figure 3. In the 1990s, total Foundation awards increased substantially but chronic care awards fell; in the late 1990s and the 2000s chronic care awards rose and fell in parallel to the Foundation's total awards.

As a proportion of total awards (Figure 4), chronic care awards (including all three chronic care groups) peaked at 32.5 percent in 1989, then fell through the early and mid-1990s to a low of 12.8 percent in 1996. Chronic care awards peaked again in 2001, reaching 21 percent of total awards, then fell to approximately 12 percent of awards in the later years of the decade.

The rise and fall in chronic care awards over the years tended to mirror the Foundation's overall grantmaking. Awards to chronic care programs began in earnest in 1980, peaked in the late 1980s, and then fell in the early 1990s. Starting in the late 1990s, chronic care awards rose to another peak in the early 2000s, but then fell back to 1990 levels in both dollars awarded and proportion of total awards.

What is striking...is the lack of evidence that the 1991 chronic care priority had a strong influence on either the number of chronic care grants awarded or the resources devoted to chronic care.

What is striking in these data is the lack of evidence that the 1991 chronic care priority had a strong influence on either the number of chronic care grants awarded or the resources devoted to chronic care at that time. In fact, if one did not know that a chronic care priority was established in 1991, one might conclude from these data that, starting in approximately 1989, there was a decision to decrease the relative support of chronic care programs. At most, the data show that the Foundation continued to provide support to chronic care programs from the early 1980s to the mid-2000s, albeit at a relatively modest level. Possible reasons for the relatively minor impact on the resources devoted to chronic care programs after the establishment of the 1991 chronic care priority are discussed in the following sections.

Total Annual Payout for Chronic Care-Related Grants, 1975–2010
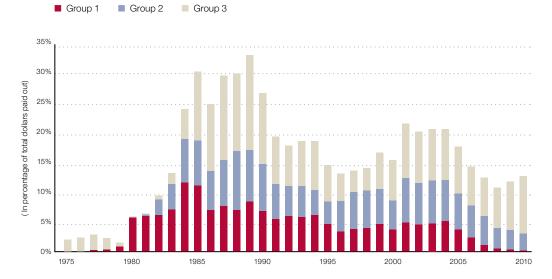
■ Group 1 ■ Group 2 ■ Group 3

Total Annual Payout for All Grants, 1975–2010

■ Group 1 ■ Group 2 ■ Group 3 ■ Unrelated Programs

Figure 4

Chronic Care Payout as a Portion of Total Payout, 1975–2010

■ Group 1　■ Group 2　■ Group 3

Section 2

Priority Development and Implementation

Priority Development—Chronic Care Re-affirmed as One of Three Major Priorities

In July 1990 Steven Schroeder, MD, an internationally known expert in primary care with a strong interest in public health, became president of the Robert Wood Johnson Foundation. During Schroeder's recruitment interview with the RWJF Board of Trustees, citing the Foundation's mission to "Improve the health and health care of the American people," he challenged the Trustees by suggesting that while the Foundation had many successes and achievements related to the health care part of the Foundation's mission, the Foundation had been less successful in developing programs related to the health component. He suggested that if he were to become president he would place more emphasis on improving personal and population health, particularly focusing on the great damage being done by both illegal substances and certain legal substances such as tobacco. This suggestion produced an active discussion during the interview and continued to be controversial in the early years of Schroeder's presidency.

Shortly after Schroeder became president of RWJF he initiated a personal review of the Foundation's programs as well as a staff process to review the Foundation's priorities. Two committees consisting of senior and mid-level staff were given similar assignments of identifying new priorities for consideration by the Board of Trustees. At a staff retreat in late 1990, the reports from these committees were discussed and it was agreed that three priorities would be recommended for consideration and approval by the Foundation's Board of Trustees: improving access to care, addressing issues related to substance abuse, and improving the care of persons with chronic illness.

The suggested priorities were presented to the Board at a special meeting in February 1991, and, after much discussion and a significant amount of debate, adopted by the Trustees. The three adopted priorities were:

- Assure that Americans of all ages have access to basic health care

- Improve the way services are organized and provided to people with chronic health conditions

- Promote health and prevent disease by reducing substance abuse[1]

The major part of the discussion of the proposed priorities focused on whether the Foundation should make a major effort to address substance abuse, and, if so, which substances and which populations. After much debate, it was agreed that the focus would be on underage use of tobacco and alcohol.

In contrast to the discussion about the substance abuse priority, the Trustees readily accepted the recommendations regarding access and chronic conditions. The access priority was seen as a continuation of the Foundation's emphasis in this area and, with national health insurance seemingly "just around the corner," an area that the Foundation could and should focus on. In this context, access was defined primarily as poor access to the acute care system due to lack of health insurance and focused on helping people pay for and use the existing acute care service system, such as through the promotion of broader health insurance coverage.

The inauguration of President Clinton in January 1993 and the possible enactment of national health insurance lowered the access priority's urgency somewhat since a national plan would accomplish a major objective of the priority. The Foundation shifted toward developing programs to support the anticipated increase in access that would be brought about by national health reform.

The chronic care priority was based in large part on the understanding that the current acute care system did not address effectively the needs of persons with multiple chronic conditions, those who needed continuing and/or long-term care, and those with various types of disabilities.

In a sense, complementary to the access priority, which focused on acute care, the chronic care priority was based in large part on the understanding that the current acute care system did not address effectively the needs of persons with multiple chronic conditions, those who needed continuing and/or long-term care, and those with various types of disabilities. Access to acute care for persons with chronic conditions was an important step, but needed to be accompanied by improvements in both the way that acute care was organized and delivered, as well as by improvements in access to, payment for, and organization of the long-term care and disability care systems.

The chronic care priority was considered, both by the staff committees and by the Trustees, a re-affirmation of a broad and important program area—a signal that the Foundation continued to be concerned about the organization and delivery of services to persons with complex, long-term conditions. According to numerous interviewees, the chronic care priority was neither intended to set a new direction for the Foundation nor to define a particular focus within the broad field of chronic illness care.

Much of the effort and energy in the Foundation in the early 1990s was related to the substance abuse priority. The newness of the substance abuse priority, the controversy surrounding the definition and implementation of the priority, and the importance of the priority to the Foundation's new president, all resulted in a general shift in emphasis toward this priority and away from the access and chronic illness priorities.

With the focus and energy on substance abuse and the excitement regarding a possible sea change in access, the chronic care priority took somewhat of a back seat. Because the chronic care priority was defined as a "steady as she goes" re-affirmation of a historic Foundation interest, and because there were many active Foundation programs that could be defined (broadly) as related to the care of persons with chronic conditions (e.g., the SUPPORT project[2] and others), there was, at least initially, limited enthusiasm for greatly expanded efforts related to chronic care.

Priority Implementation—Reorganization to Align With Goals

In his "President's Message" to the Board of Trustees in July 1991, Schroeder described the initial organizational response to the three new priorities:

> "**Recent Organizational Changes:** Perhaps the most important change followed from our strategic planning efforts last fall. In that process we included members from groups that had previously been totally or partially removed from the grant development process: evaluation and statistics, communications, and financial monitoring. Members of these groups contributed importantly to the planning process as well as to the team building that resulted from that effort. As a result, we developed a new organizational structure that is intended to preserve the inter-disciplinary creativity discovered in the planning process while maintaining the accountability necessary for program monitoring."—*President's Message for Board of Trustees meeting, July 1991*

The new organizational structure described by Schroeder foreshadowed the Foundation's implementation of a "professional services model" in the late 1990s, which focused on the multidisciplinary development and oversight of programs. The initial steps, however, consisted of a modest reorganization of the Foundation's professional staff.

Shortly after the naming of the new priorities, in mid-1991 three priority-specific Goal Development Working Groups (GDWGs) were formed. These groups were intended to be forums for ideas that were to be developed and presented by program staff. GDWGs had "conveners," not "chairs," that is, their role was more discussion and debate than vetting. These discussions were intended to surface, frame, and mold, as well as challenge new ideas. This process was consistent with the Foundation's organizational model, which valued and promoted creativity and a competition among ideas.

With regard to the chronic care priority, Schroeder noted the difficulty in changing the way chronic care is delivered:

> "The reform of systems for those with chronic conditions requires fundamental change in how medical care and supportive services are organized, financed, and distributed. The early work for this group, therefore, has focused on common elements among the various categories of recipients and illnesses so characteristic of previous grantmaking. Thus, we are searching for similarities in the approaches to such conditions as dementia, AIDS, chronic mental illness, and alcoholism in order to develop common strategies for reform."—*President's Message for Board of Trustees meeting, July 1991*

Early 1990s—The "Let a Thousand Flowers Bloom" Era

There was little emphasis on or effort toward the development of an overall strategy for the chronic care priority, even within the chronic care GDWG. A second, related issue was that resources were not allocated specifically and prospectively to the chronic care priority or the other two new priorities.

Described by various interviewees as the period of "let a thousand flowers bloom," the "wild west," and the "cowboy" era, the early 1990s were defined by the reliance on and competition among program staff to generate new ideas for grants; and by the lack of strategic and financial guidance to program staff. Program staff members were very much on their own as they developed new ideas for programs. They were "lone rangers," as one program officer put it. The lack of a clear strategy was described by many Foundation staff members who were interviewed. Some felt that the lack of a strategy allowed for the expression of creativity. As one program officer put it, "There was no plan, no strategy, you were just supposed to think creatively about what really needs to happen to move the ball toward improved access and quality of care, or…the [Foundation's] mission [of] health and health care for all Americans." Another stated that, "Things were not scripted or controlled; people were allowed to express their creativity."

The process of going from idea to funded program was described variously by interviewees as "lobbying," "convincing," "unstructured." One senior program officer described the "horse trading…I'll support your program if you'll support mine;" other former program staff said, "people were not teams, but interest groups;" and, "In the past, you needed your own program to be respected at the Foundation." There was not a specified path, with defined hurdles, gateways, and decision points. Rather, it was more of a consensual process where good ideas gradually gained acceptance and support.

Continuing a Foundation practice from prior years, in the early stages of program development there was little clarity about the size of available resources; that is, there was no prospective allocation of resources to specific priorities, program areas, or new programs, at least until fairly late in the program development process. It was not clear to staff at what point their program proposals would have been developed enough or had gained enough support for a funding decision to be made or what amount of resources would be available for the new program. The emphasis was on the development and vetting of ideas for new programs, with the implicit assumption that the appropriate size (if not exact budget) of the program would emerge from this process. This fairly nebulous budgeting process existed for all program development, but may have been felt more acutely by program staff with an interest in chronic care given the step-child nature of this priority compared with the focus on substance abuse and the excitement around access with the prospect of a Clinton national health plan.

In a general sense, it is clear that discussions about a potential program's budget began in a relatively informal way as the program progressed through the idea-vetting process. Specific detailed discussions among program staff regarding a program's size and budget, however, often did not occur until very late in the program development process. Budget recommendations and decisions were apparently made by a relatively small group of senior staff, with the Foundation's president, and possibly executive vice president and financial staff, making the final decision. This unstructured and often opaque budget process made the program development process difficult for, and raised the anxiety among program staff. During the project development

process, it was often unclear, for example, how much funding would be available for a proposed program and over what period of time.

Another factor that affected programs in development, as well as those already funded, was the sometimes yearly variation in the total amount available for funding current and proposed programs. A substantial portion of the Foundation's investments were in relatively volatile assets such as stocks, and since the Foundation needed to maintain the IRS-mandated 5 percent distribution of assets per year, the amount of money available for both new and existing programs was sensitive to and varied by investment fluctuations. Major declines in investments in the early 1990s and early 2000s resulted in pull-backs in the amount of funding available for currently funded programs, as well as increased uncertainty among Foundation staff about the potential availability of funds for new programs.

Thus in the early 1990s, given the opacity of the funding process, the knowledge that some current programs could be cut back, and the focus on the new substance abuse priority, staff understood that opportunities for expansion of grantmaking in chronic care were limited.

Mid-1990s—Modest Success for Modest Programs

In his July 1993 message to the Board, Schroeder noted early efforts in response to the chronic care priority were to generate data and program models:

> "**Progress Toward Our Goals**…our progress and level of activity have varied across the goal groups, reflecting differing historical foundation investments, strategic opportunities, and national circumstances. …

> "**Improving Health Systems for People with Chronic Illness**
> Programs directed at people with chronic illnesses are not new for RWJF, but our attempts to stimulate systemic changes represent a new strategic direction. This goal area, while equal in importance to our others, attacks a less visible problem. No easy sound bite captures the problem, such as '37 million uninsured,' '400,000 deaths a year from cigarettes,' or '14 percent of the GNP.' Much of our early work under this goal area has been to generate data and program models that will give the issue more visibility, particularly now when health care reform is under debate. …

> "Simultaneously, we have moved forward to replicate on a larger scale some earlier programs. Our increased attention to replicating successful programs also responds to external criticisms that foundations tend to 'hit and run' with their service demonstrations. Examples of our efforts include the *Faith in Action* program's announcement in early July of its intent to expand the Interfaith Volunteer Caregivers model to an additional 900 sites, and programs currently are under way to expand other past efforts in dementia day services, chronic mental illness programs, and service credit banking. In addition, our program on long-term-care insurance…continues to be the only game in town when it comes to affordable coverage."—*President's Message for Board of Trustees meeting, July 1993*

In April 1996, Schroeder updated the Board on the progress of the three major priorities established in 1991 (access, substance abuse, and chronic care) and the "minor priority" of cost containment:

> "How well have we performed with our four programmatic goal areas that were adopted five years ago?…

> "Our chronic disease goal area is less well established historically, and our current programs are more modest than those of our access goal. Two prominent recent contributions have been our increasing support for a national network of voluntary, community-based programs for the chronically ill (e.g., *Faith in Action* and our new programs for the developmentally disabled), and our highlighting the problems of care for dying patients. Both these program areas bring the added benefit of embodying within them strong value statements that can help to bind us together as a nation. It is likely that future programs will address ways that care can be improved in some of the more common chronic illnesses such as diabetes, cancer, and heart disease, as well as in palliative care."—*President's Message for Board of Trustees meeting, April 1996*

He went on to discuss the need for the Foundation to become more focused in its grantmaking:

> "There is an inherent tension in philanthropy between the wisdom of being focused and the excitement of exploring new fields. Many of you [members of the Board of Trustees] commented in your interviews with Sid Wentz [CEO] and me last year that you felt we could benefit from an even tighter focus, and we agree. There is room for us to focus our grantmaking in the access programs as well as in chronic disease—should we stay with those goals. In other words, within existing goals we can be more selective about what we choose to support."—*President's Message for Board of Trustees meeting, April 1996*

Late 1990s and 2000s—Focus Shift from Specific Illnesses to Quality of Care

By the late 1990s, the Foundation's focus on chronic conditions had changed from broad initiatives that attempted to address multiple chronic conditions with a single solution to programs that focused on specific chronic conditions, issues of quality, and improving the medical care delivered to persons with chronic illness (as opposed to social and economic issues such as maintaining chronically ill persons in their homes).

In the late 1990s, the Board approved a major organizational restructuring of the Foundation into the Health Group and the Health Care Group. This change was intended to give more prominence to the "health" component of RWJF's mission, partly in response to the concern that issues related to health (typically medical) care tended to dominate health policy discussions and actions, often to the detriment of policy and program development related to long-term care, social services, health promotion, and disease prevention. As shown by Michael McGinnis, MD,

at that time a senior vice president of RWJF and head of the Health Group, and William Foege, MD, MPH,[3] many of the most important contributors to mortality in the United States (e.g., tobacco use, obesity, and alcohol) were most effectively addressed outside of the acute medical care system. The acute care system had few answers other than to treat the adverse outcomes and exacerbations of chronic conditions. Importantly, the Foundation's chronic care programs were included in the Health Care Group, under the new program objectives of Clinical Care Management and Supportive Services.

As forecast in Schroeder's April 1996 message to the Board, by the early 2000s there was a shift from programs that focused broadly on the settings of care of persons with chronic conditions (e.g., acute, long-term, and rehabilitative care) to a more disease-focused agenda (e.g., asthma, diabetes). It is not entirely clear why this transition occurred, although it may have been influenced by trends in the health care system toward the development of treatment guidelines for specific illnesses, by the development within the Foundation in the late 1990s and early 2000s of outcome indicators for programs (which may be easier to define for specific conditions and illnesses than for broad populations), and possibly by a concern on the part of Foundation staff that recent broadly defined programs had not achieved the hoped-for positive results.

In addition, increased policy concerns about the quality of care in both the acute and supportive services sectors led to a transformation of the chronic care priority; by the early 2000s quality had become the watchword, and the Foundation's chronic illness initiatives were generally (re)defined as efforts to improve quality of care for people with chronic conditions. A major impetus for the shift to a focus on improving the acute care system was the excitement and enthusiasm generated by the Chronic Care Model that had been developed by Edward Wagner, MD, and colleagues with the support of the Foundation.[5] The Chronic Care Model provided a way to address the dysfunction of the acute care system and improve the quality and outcomes of care for persons with chronic conditions. Thus, by the early 2000s the focus of RWJF's chronic illness programs had shifted to the quality of care being received by persons with specific chronic illnesses, especially how those persons are cared for in the acute medical care system.

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Section 3

Influences on Priority Implementation

As described above, the 1991 chronic care priority had little effect on the size and amount of Foundation awards related to chronic care in the years that followed and appears to have had a modest impact on the field of chronic illness care. This section describes and discusses factors that may have affected the overall impact of the priority, including the Foundation's organizational structure and processes in the early and mid-1990s.

The Foundation's Organizational Structure—A Professional/Academic Model

The identification, definition, and implementation of the chronic care priority were greatly influenced by the Foundation's internal structure and processes—its "organizational model." All organizations are (by definition) created, designed, and operated to achieve a particular outcome, whether it is to create a concrete product (the classic "widget") or a more distant and abstract outcome, such as an increase in knowledge or a change in broad health care systems.

Enterprises that are designed to produce relatively concrete products generally have a hierarchical organizational structure intended to create consistency of design and production within the organization. Organizations that focus on the production and dissemination of ideas and knowledge (e.g., academia and foundations) place much more emphasis on individual creativity and initiative, with less hierarchical structures. This gives the staff much more independence, with the ability to pursue their interests. While it is relatively easy to measure the productivity and success of the production of concrete products such as cars (e.g., profits, recalls, customer satisfaction), it is much more difficult to measure the generation and dissemination of ideas or the impact of programs on systems and populations.

RWJF historically used (at least through the early 2000s) what might be described as a professional/academic staff model, that is, a structure that supports the initiative, creativity, and independence of individual program staff. This model has been quite productive for the Foundation, with notable successes related to specific Foundation initiatives, for example, its tobacco and end-of-life programs.

The reliance on a professional/academic structure is common among foundations, which generally place significant grant development responsibility on staff. In the case of RWJF, the use of a professional/academic model is not surprising given that David Rogers, MD, the Foundation's first president, was a product of, and very successful in, medical academia, as were subsequent Foundation presidents. This was an organizational model that they knew to be highly productive scientifically and rewarding to creative academics, albeit with significant competition and pressure among participants. Most notably, this model has been supremely successful in academic institutions in developing new and innovative ideas. As Schroeder described:

> "We wish to preserve opportunities for individual creativity and to avoid the requirement that all programs be a product of consensus. Therefore, individuals will be free to generate their programs' ideas, with subsequent review by the goal development work groups." — *President's Message for Board of Trustees meeting, July 1991*

In a professional/academic model, the organizational structure is based on the expertise, creativity, and productivity of individual professional staff; it is a somewhat "flat" (as opposed to hierarchical) model, with new ideas for programs generated by professional staff within relatively broadly defined boundaries. This model tends to breed competition among staff, since success in this environment is often defined by identification with ideas that have gained support within the organization. Ultimately, individual staff members become the champion of their ideas, and, if these ideas win out among the competition, the "winners" often oversee the implementation of the resulting programs.

Similar to an academic environment, expertise generally equates with specialization, which may be beneficial when developing and testing academic theories; however, specialization may become problematic when the focus is the development of appropriate interventions intended to affect complex social systems if the particular expertise of an organization's staff does not encompass the knowledge and disciplines necessary to address complex problems and solutions.

"When I began working there, I found that the work was much harder than I imagined because of the environment in which there was a competition for ideas and that it was much more of an individually driven organization rather than a collaborative one."

Former RWJF Senior
Program Officer

Many RWJF program staff members were specialists and/or experts in particular fields when they arrived at the Foundation, and may have been hired, in part, because of their expertise. Yet designing successful grant programs that will have a positive effect in an environment as complex as health and health care requires broad knowledge ranging from the determinants of health to the organization and financing of the health and disability care systems, as well as a sensitivity to the personal, sociocultural, and political environments that these programs are intended to affect.

Thus a possible downside to the professional/academic model is that large strategic initiatives may require more organizational coordination than is likely to occur in a "flat" structure, including significant leadership direction, allocation of sufficient resources to develop and support multiple tactics within a broad strategy, and participation by program staff with a variety of specific expertise (e.g., in clinical systems, education, dissemination). Because this model relies on the expertise, interest, and initiative of individual staff, the "product" of this environment may be especially sensitive to the particular expertise of program staff, which ultimately defines the focus and outcome.

A professional/academic organizational model also requires program staff to be able to communicate, advocate, and successfully defend these ideas during the internal vetting process. The Foundation's organizational structure and processes created competition among staff to produce ideas; staff were rewarded in large part based on their success in this competition. A number of interviewees described the stress that they felt almost from their first day at the Foundation in this competition for ideas and among staff.

Of note, while this process requires academic expertise and is similar in certain ways to processes in academia, there are also major differences in both the vetting of ideas as well as the career requirements and rewards for professional staff at a foundation compared with those in academia. Working at a foundation essentially becomes a new career path, one that often leads most directly to either a career in foundations, albeit a narrow one, or a management position in the health or health care field. Because the rewards in academia are based largely on research and publications in a specialized field, working at a foundation may create a gap in an academic career that a young or even mid-level academic may not be able to bridge. A commitment to working at a foundation may mean forsaking an academic career or at least losing seniority when returning to or entering academia.

The vetting of ideas and the implementation of programs at RWJF also differed in certain important respects from academia. In academia, ideas and their application in research are generally vetted by peer reviewers outside the academic's own institution, while at RWJF almost all of the vetting of ideas and development of programs was done internally, at least until a relatively late stage in the development process.

Sustaining Programs and Program Areas

Changing social and health care systems is difficult at best and often requires intense effort over many years. Establishing and funding successful models and programs is only one part of the process of grantmaking; nurturing programs and deciding when to end a program or program area are two other highly important tasks. Several characteristics of grantmaking may make it difficult to sustain programs long enough to have a significant impact on systems.

By the end of the 1990s, to the extent that it was still considered a priority, the emphasis on chronic care had been transformed by the new (implicit) priority of quality of care.

By the end of the 1990s, to the extent that it was still considered a priority, the emphasis on chronic care had been transformed by the new (implicit) priority of quality of care. The emphasis on quality of care was responsive to major national health policy concerns and was consistent with the "improvement" part of the chronic care priority. The shift to an emphasis on quality did, however, lessen any remaining strategic focus on chronic care. The creation of the Health Group and Health Care Group in the late 1990s had the effect of diffusing the focus and diverting efforts away from chronic care. The transition in leadership in 2003 from Steven Schroeder to Risa Lavizzo-Mourey, MD, MBA, and the establishment of major new priorities also substantially reduced the Foundation's interest in chronic care.

The decision about whether to start a new program or program area occupies much staff time and interest. Program staff members typically have two major roles: developing new ideas and programs, and, once programs are funded, overseeing the substantive administration of the programs. Most of the rewards for staff are related to the first role, which requires an intense effort for a limited period of time and culminates in the satisfaction of and recognition for the successful creation of a new program.

The success of a new program is also rewarded by positive interactions with new grantees who are, of course, exhilarated by having been awarded a grant. Once the new program is funded, however, the program officer's role changes to one of program oversight and management, which is much longer in duration and lower in intensity than grant development. It provides relatively fewer rewards within the Foundation, and may be accompanied by the drudgery, and possible conflicts, that program oversight may entail. In addition, the sometimes unclear goals and objectives for new programs, and the understanding that renewal of programs, while not impossible, has been historically unusual at the Foundation, may tend to discourage a strong commitment by program staff to new and ongoing programs.

There was also a characteristic response of staff at RWJF, and probably at other foundations, that might be called funding fatigue–the longer a program area or individual program lasts, the less interesting it may become for program staff and therefore less attention and energy may be devoted to its nurturing. The original champion who created the program has probably moved on, so the program may be managed by a new program officer who may have little investment in it. Funding fatigue might have a number of causes, including disappointment at the lack of achievement of what might have been (unrealistically) high expectations and goals for a program, which may have been needed initially to create interest in and "sell" the program. Interest in ongoing programs may also be lost as newer ideas receive more enthusiasm and attention. Funding fatigue may force the discontinuation of programs and program areas that are providing valuable services and having an important impact on a field, yet may not be producing "newsworthy" and notable outcomes. Funding fatigue is especially likely to occur in an organization, such as RWJF, that emphasizes and rewards creativity and development of new ideas, and places less value on implementation and nurturing of programs and program areas.

Lack of Strategic Response

In a chapter on the *Improving Chronic Illness Care Program* in the Foundation's 2006 volume of the anthology *To Improve Health and Health Care*, Irene Wielawski describes the lack of overall strategy and coherence of RWJF's programs related to chronic care and illness:

> What stands out from a review of these programs is how scattershot they were, addressing the isolated needs of people with particular handicaps but offering no systematic solution for patients, families, health care facilities and clinicians to collectively meet the challenges posed by chronic conditions. There also was little effort to utilize lessons across programs. After all, if residents in senior housing need help with chores and repairs, it's likely that people with health or mobility problems do, too. It wouldn't be stretching it to describe the Foundation's early chronic illness portfolio as an "acute care" approach to the symptoms of health system failure that ignored the underlying disease–an antiquated structure that divides patients by diagnosis and circumstance instead of comprehensively addressing chronic patients' needs. Anne Weiss, the senior program officer who heads the Foundation's quality team, characterizes these earlier initiatives as a form of "parallel play," borrowing a phrase used by developmental psychologists to describe toddlers playing side by side but with no apparent interaction. The Foundation's chronic illness initiatives of the

1980s and early 1990s, she says, "had general common ground, but some were systems-oriented and some were patient education-oriented and some had a different focus altogether."[4]

There may have been many reasons for the lack of a comprehensive strategy to implement the chronic care priority. At least through the early and mid-1990s, the strategic focus at the Foundation was on the implementation of the substance abuse priority and on the anticipation of health care reform, which was expected to provide many "targets of opportunity" for the access priority. The Foundation's flat organizational structure, with relatively little direction from the top and the expectation and encouragement of individual creativity from program staff, did not lend itself to collaboration and synergy in the program development and implementation processes. In such an organizational model, developing and implementing a tightly coordinated strategy required substantial direction by senior management and, perhaps, a narrowing of focus. Given the controversial nature of substance abuse, and therefore the focus and energy that was needed for its implementation, it is not surprising that senior management were not willing or able to devote a similar effort to developing and implementing a more strategic and integrated set of programs for the chronic care priority.

Use of Outside Experts and National Advisory Committees

RWJF was described by several interviewees, from both within and outside the Foundation, as an insular organization. Over the period included in this review, and likely today as well, the Foundation included staff with a wide range of expertise and experience. It's probably fair to say, however, that no organization whose goal is to affect as broad a set of issues as the health and health care of the American people can include all the information and expertise needed to develop effective programs. The Foundation has addressed this issue by recruiting persons from outside the Foundation to manage its major initiatives, particularly its national programs, and has included experts on national advisory committees for its national programs. In 1992, for example, of the then 45 currently active national programs and initiatives, 37 had program directors and 19 had advisory or review committees.[5]

Compared with the complexity of the issues being addressed, however, the Foundation's use of outside expertise seems suboptimal. Perhaps most importantly, there is no formal outside "peer review" process for program ideas. Outside experts are sometimes included in early discussions of potential programs, primarily in the idea development phase. Their expertise is sought to provide a better understanding of issues and possible interventions.

In the 1990s, the vetting of program ideas was often limited to internal program staff, with only occasional participation by outside experts and leaders. The roles of program directors, deputy directors, and national advisory committees (NACs) were generally quite narrow. While program directors were expected to represent their program in the field and address top-level strategy, with deputy directors acting in a more administrative role, the "field representation" was often relatively limited. Members of NACs act as reviewers to help the Foundation evaluate proposals to national programs, and then to provide periodic oversight of the program. In some cases, NAC members provided additional support by making site visits to assist grantees. Program directors were usually chosen by the Foundation fairly late in the program development process, and the chair and members of NACs were chosen after the program had been funded; there was

usually relatively little involvement of these experts in the actual process of program definition and development. Interviewees from both the Foundation program staff and grantees described the roles of the national program director and NAC members as part of the process of administrating programs, with few other leadership or program dissemination roles. Some of the NACs for chronic care programs, for example, did not have an identified chair, that is, the NAC was seen as simply a group of expert reviewers who could have easily performed this duty in their office, with no need or reason for an in-person meeting, let alone playing an ongoing role in overall program development and dissemination.

This relatively limited use of outside expertise often does not take advantage of the influence that a NAC consisting of national leaders in a field might have on the propagation of programs and ideas. The lack of involvement of the NAC in the program definition and development process may result in less investment by NAC members in the program, a reluctance to feel responsible for or even become more involved in that program. While there are benefits to being a NAC member (the association with other experts in their field, and learning from and helping grantees), the job of reviewing hundreds of proposals and then gathering once a year to hear reports on the progress of funded projects, without any direct responsibility for them, can be somewhat thankless and may not generate strong loyalty, or encourage further commitment of time and effort to a program's success.

A contrasting model would include a more active role for experts, especially the NAC and program director, from the early phases of the program development process through the implementation of the program. Ideally, the NAC would be convened at a point where full advantage could be taken of members' expertise to help further define the program, and could include taking a lead role in defining the program's goals and writing the program's grant solicitation. This would help invest these experts in the program and would encourage them to promote and assume a leadership role for the program. For example, it might be highly useful to name as chair of the NAC a national leader in the program area relatively early in the development process to help define and mold the program. The chair would also help choose other experts for the NAC and have input into the choice of program director. The result would be a resource for the Foundation of a group of committed experts and leaders in a field, and might have synergistic effects far beyond the limited influence of an individual program.

This model may present some risks for RWJF, especially individual program staff who may feel that they've lost some control over, and possibly rewards for, program development. The involvement of outside experts in program development also must be managed carefully, with a balance between an expert's investment in the process and an explicit or inferred commitment of the Foundation to the expert about their continuing role in and responsibility for the program.

Section 4
Discussion

Since its establishment in 1972, the Robert Wood Johnson Foundation has devoted more than $1 billion to programs to improve the lives of people with chronic illnesses and disabilities. The 1991 chronic care priority was created at a time of significant changes in the Foundation—a new president and a major, new, and controversial goal of reducing the harm caused by substance abuse. In this context, the naming of a priority to improve the care of persons with chronic conditions re-affirmed the Foundation's long-standing interest in this area and signaled to people within and beyond RWJF that the new leadership would not abandon what had been a core interest of the Foundation since its inception.

The intent of the chronic care priority was to encourage a new "integrated, coordinated approach" to care, and emphasized "not the groups served, but the service system itself." This was a laudable goal, almost breathtaking in its scope and courageous given the historic difficulty in making changes in the health care system. It might be argued that the priority was an overreach, that is, it was too broad and ambitious, and too difficult to achieve given available resources. It was the task of Foundation leadership and program staff, however, to take this broad vision and create a focused strategic plan, define a set of achievable objectives, and develop a coordinated set of programs that would provide an integrated and systematic assault on this huge and hugely important problem. This review suggests that, for a number of reasons, such a focusing of the goal and the development of a strategic plan to address this focus did not occur. Rather, the priority was interpreted as an umbrella under which a number of worthwhile, but relatively uncoordinated and disparate, programs would be developed.

The literature and documents reviewed and the interviews for this assessment suggest that the programs related to the chronic care priority had many important positive effects on the care and services that many people with chronic conditions received and several of the programs greatly influenced the field of chronic illness care. The *Improving Chronic Illness Care* program, for example, has had significant impact on the understanding and definition of appropriate chronic illness care.

The whole was not, however, greater than the sum of the parts. Few of the programs produced outcomes beyond the boundaries of the particular program or that lasted after the program's funding ended. Importantly, it is difficult to identify any lasting fundamental changes in the health care system that come close to achieving an "integrated, coordinated approach" to care, and emphasized "not the groups served, but the service system itself."[6]

Was the chronic care priority too broad, the goal too lofty? Even $1 billion spent over 30 years is dwarfed by the size and complexity of the medical care system, which accounts for one out of every six dollars spent in the United States, so what could be realistically expected of such an investment? These are issues that the staff of RWJF, from the presidents on down, have been concerned with since the Foundation's creation and are not easily addressed.

The traditional, and reasonable, answer within the Foundation has been that (to paraphrase) RWJF is well armed but there is not enough ammunition for a direct assault on the health care system as a whole; therefore, targets of opportunity should be attacked, which might then propagate into larger changes in the system. A prominent example of this strategy is the emphasis on demonstration projects, which when (if) successful can provide a model that can be emulated in government or private sector policies. Such a strategy is highly dependent, however, on the readiness and responsiveness of agencies and systems that are beyond the control of the Foundation, and therefore requires both excellent foresight and timing in the program planning and implementation process.

Demonstration projects were a key component of RWJF's efforts to improve chronic illness care, as were other types of projects and programs ranging from support of community-based initiatives to the generation of information about the prevalence and burden of chronic illness. While many, if not all, of these programs had positive outcomes and benefited people with chronic conditions, there is little evidence that the various demonstrations and other projects produced major changes in government or private sector policies related to care of persons with chronic illness.

Foundations provide what might be described as social venture capital to address needs that result from what economists call a market failure, that is, when the marketplace does not, or cannot, satisfy a specific social need. Among the most obvious market failures of interest to RWJF is the poor access to basic health services experienced by a substantial portion of the U.S. population. Lack of health insurance is often cited as the main cause of poor access and is therefore a target of the Foundation's programs to improve access to care.

Efforts to improve care provided to people with chronic conditions attempt to address the related market failure that, even if people have access to acute care, the medical care system may not be providing optimal care for people with complex chronic conditions. To improve the care received by persons with chronic conditions, however, requires more than simply providing access to the current medical care system; it also requires complex changes in many different types of medical, social service, and financing systems.

Efforts to improve care provided to people with chronic conditions attempt to address the related market failure that, even if people have access to acute care, the medical care system may not be providing optimal care for people with complex chronic conditions.

One reason for the apparent lack of overall impact on systems of care for people with chronic conditions may have been that the problems are simply too big, complex, and entrenched to be materially and observably changed by even a major set of initiatives funded by a large foundation. Other reasons may have been the unsystematic, tactical approach to program development and funding, the lack of strategic coordination of effort and synergy among programs, and, given the size of the problem and the relatively large resources of the Foundation, not enough resources being devoted to this priority.

Between 1972 and 2010, RWJF spent more than $1 billion on chronic care programs and $7 billion on other initiatives. These are substantial amounts that produced many benefits.

Between 1972 and 2010, RWJF spent more than $1 billion on chronic care programs and $7 billion on other initiatives. These are substantial amounts that produced many benefits. More broadly, however, these resources accounted for only approximately 0.003 percent and 0.02 percent, respectively, of the $37.1 trillion spent on health care in the United States between 1972 and 2010. Today in the United States, a billion dollars is spent on health care every *three and one-half hours*.

Thus, the substantial amounts granted by RWJF are actually very modest in comparison with the size of the issues being addressed, and therefore expectations of impact must be modest. The Foundation, however, has the ability to target its spending toward opportunities that might, at the margin, have a large impact on specific systems of care.

We conclude that the "parts" were almost all good and successful to one degree or another, but the "whole" was not greater because the resources allocated were not commensurate with the size of the broad target. Additionally the lack of strategic coordination of program identification, development, and implementation, resulted in a low degree of synergy among programs.

Section 5

Lessons Learned

The Foundation's implementation of the chronic care priority produced much that was positive for individuals, an accomplishment that should not be diminished by the lack of achievement of the difficult goal of making fundamental and lasting changes in our very large, fragmented, and often dysfunctional health care system. This review revealed a number of issues in RWJF's grantmaking that may have lessened the possibility of a more substantial impact, suggesting the following lessons that might be considered to enhance the Foundation's future grantmaking.

■ Develop a Strategic Focus

The 1991 chronic care priority provided a general direction for grantmaking, but did not include an overall strategic focus or any specific chronic care goals or objectives, nor were any defined during the process of implementing the priority. The definition of an overall strategic focus and explicit goals and objectives, either within the priority or during the implementation of the priority, might have had the positive effect of enhancing both the coordination and focus of the implementation of the priority within the Foundation and the results and products of the funded programs, both individually and collectively.

■ Match Goals With Resources

The intent of the chronic care priority was nothing less than very broad and fundamental change in the way health systems delivered care, the achievement of which might have required much of the Foundation's resources to the detriment of other priorities. As suggested by our comparison of the chronic care programs with the tobacco and end-of-life initiatives (Appendix 2), even with a necessary increased strategic focus, substantially more resources would be required to effect changes in systems of chronic illness care, probably significantly more than were committed to the chronic care priority.

■ Target Systems and/or Individuals

Efforts to change systems of care must be strategic, sensitive to potential "targets of opportunity," and based on a realistic assessment of the resources and time needed to change complex organizations and systems. Devoting resources to helping individuals receive better care through the support of specific chronic care services is laudable and not necessarily contradictory to a strategic effort to change systems of care. Addressing the complexity of systems of care, however, may require the commitment of substantial resources over an extended period to a broad range of interventions, initiatives, and demonstrations that may have only an indirect impact, at least initially, on individuals with chronic illness.

■ Organizational Structure Can Strongly Influence the Success of Initiatives

The Foundation's relatively flat internal organization at the time that the chronic care priority was implemented in 1991 may have lowered the likelihood of the development of a coordinated implementation strategy for the chronic care priority. The lack of direction from RWJF leadership, as well as the opaqueness about the resources available for the priority, may have encouraged disparate and uncoordinated efforts and possibly signaled relatively less interest by the leadership in the priority.

An academic/professional staff model has potential benefits and limitations for the development of a new strategic initiative. This model is effective at promoting creativity and the identification of new program ideas, but may also make it more difficult to develop a coherent overall strategy. The model also has significant implications for the careers of people at the Foundation, and encourages competitiveness among program staff, which may discourage a collaborative working environment.

■ Integrate Outside Leaders and Experts Into the Program Development Process

The Foundation's use of external expertise and advice in the identification, development, and implementation of strategic initiatives and programs appears to be less than optimal. More active use and integration of outside leaders and experts (such as to vet new program ideas) might enhance the impact of individual programs and, perhaps more importantly, the likelihood that a strategic initiative will have an impact on systems of care and lead to system change.

■ A Priority Should Imply Focus and Funding, Not Simply a Re-affirmation of Interest

The 1991 chronic care priority was described at the time, and by many of the interviewees for this review, as an affirmation of a historic RWJF program area and a signal that chronic care remained an important concern of the Foundation. In retrospect, however, this may have been damning by faint praise and interpreted by Foundation staff as an indication that, given other new and important RWJF priorities, such as substance abuse, there would be lukewarm support of chronic care-related programs and of program staff whose expertise and interests were in chronic care and illness.

Endnotes

[1] Schroeder SA: "Special Report: New Priorities for the Robert Wood Johnson Foundation." *Health Affairs*, 10(2): 185–187, 1991.

[2] SUPPORT Principal Investigators. "A Controlled Trial to Improve Care for Seriously Ill Hospitalized Patients: The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT). *Journal of the American Medical Association*, 274(20): 1591–1598, 1995.

[3] "Actual Causes of Death in the United States." McGinnis JM and Foege WH. J*ournal of the American Medical Association*, 270(18): 2207–2212, 1993.

[4] Wielawski I. "Improving Chronic Illness Care." In To Improve Health and Health Care, Vol X. Isaacs S and Knickman J (eds). San Francisco: John Wiley & Sons, 2006. Available online at *www.rwjf.org/files/publications/ books/2007/AnthologyX_CH03.pdf*.

[5] President's Message for Board of Trustees meeting, January 1992.

[6] Schroeder SA. "Special Report: New Priorities for the Robert Wood Johnson Foundation." *Health Affairs*, 10(2): 185–187, 1991.

Appendix 1

List of Interviewees

Current RWJF Staff

Nancy L. Barrand, PhD, *senior adviser for Program Development*

David C. Colby, PhD, *vice president, Research and Evaluation*

Susan B. Hassmiller, PhD, RN, FAAN, *senior adviser for Nursing*

Laura C. Leviton, PhD, *senior adviser for Evaluation*

Jane Isaacs-Lowe, PhD, *senior program officer*

Molly McKaughan, Director, *Research Resources Center*

Robin Mockenhaupt, PhD, MPH, *chief of staff*

C. Tracy Orleans, PhD, *senior program officer / senior scientist, Research and Evaluation*

Paul A. Tarini, MA, *senior program officer*

Anne F. Weiss, MPP, *senior program officer*

Former RWJF Staff

Carolyn H. Asbury, PhD, Consultant, Dana Foundation *(former RWJF senior program officer)*

Marian E. Bass, Consultant, Grant Results Reporting Unit, RWJF

Alan B. Cohen, ScD, Professor of Health Policy & Management, Executive Director, Boston University Health Policy Institute *(former RWJF vice president, Research and Evaluation)*

Seth L. Emont, PhD, Principal, White Mountain Research Associates *(former RWJF senior program officer)*

Rosemary Gibson, PhD, Consultant *(former RWJF senior program officer)*

Robert G. Hughes, PhD, President and CEO, Missouri Foundation for Health *(former RWJF vice president and chief learning officer)*

Paul S. Jellinek, PhD, Consultant *(former RWJF vice president)*

Andrea I. Kabcenell, RN, MPH, Vice President, Institute for Healthcare Improvement *(former RWJF senior program officer, Research and Evaluation)*

James R. Knickman, PhD, President and Chief Executive Officer, New York State Health Foundation *(former RWJF vice president for Research and Evaluation)*

Doriane C. Miller, MD, Director, Center for Community Health Vitality, University of Chicago Medical Center *(former RWJF vice president)*

Richard C. Reynolds, MD, retired *(former RWJF executive vice president)*

Michael G. Rothman, PhD, Director, Department of Quality Improvement,
Johns Hopkins University *(former RWJF senior program officer)*

Lewis G. Sandy, MD, Senior Vice President for Clinical Advancement, United HealthCare
(former RWJF executive vice president)

Steven A. Schroeder, MD, Distinguished Professor of Health and Health Care,
University of California, San Francisco *(former RWJF president and CEO)*

Stephen A. Somers, PhD, President and Chief Executive Officer, Center for Health Care
Strategies *(former RWJF associate vice president)*

Others

Gerard F. Anderson, PhD, Professor, Director, Center for Hospital Finance and
Management, Health Policy and Management, Johns Hopkins University Hospital

Brian Austin, Associate Director, Center for Health Studies, Group Health Cooperative

Thomas S. Bodenheimer, MD, MPH, Clinical Professor, Department of Family &
Community Medicine, University of California, San Francisco

Sophia W. Chang, MD, MPH, Director of Chronic Disease Programs, California
HealthCare Foundation

Noreen M. Clark, PhD, Myron E. Wegman Distinguished University Professor Director,
Center for Managing Chronic Disease, University of Michigan

Shan Cretin, PhD, MPH, General Secretary, American Friends Service Committee

Edwin B. Fisher, PhD, Global Director, Peers for Progress: International Promotion
of Peer Support for Diabetes Management, American Academy of Family Physicians
Foundation and Professor Department of Health Behavior and Health Education,
School of Public Health, University of North Carolina at Chapel Hill

Paul B. Ginsburg, PhD, President, Center for Studying Health System Change

F. Marc LaForce, MD, Director, Meningitis Vaccine Project, Program for Applied
Technology & Health

Elizabeth A. McGlynn, PhD, Associate Director, RAND Health

Harold A. Pincus, MD, Vice Chair for Strategic Initiatives, Department of Psychiatry,
Columbia University, New York State Psychiatric Institute and Senior Natural Scientist,
RAND Corp.

Gary S. Rachelefsky, PhD, Director, Executive Care Center for Asthma, Allergy and
Respiratory Diseases, UCLA Medical Center

Stephen M. Shortell, PhD, MPH, MBA, Blue Cross of California Distinguished Professor
of Health Policy and Management and Professor of Organization Behavior at the School
of Public Health and Haas School of Business at the University of California-Berkeley;
Dean, School of Public Health, University of California, Berkeley

Edward H. Wagner, MD, MPH, MACP, Director, MacColl Institute for Healthcare
Innovation, Center for Health Studies, Group Health Cooperative

Appendix 2

Comparison With Reviews of Other Initiatives

This retrospective review follows previous reviews of the Foundation's tobacco[1] and end-of-life programs.[2] This section provides a brief overview and discussion of the three reviews and possible reasons for what may be perceived differences in the outcomes found and conclusions drawn. This is not meant to be a rigorous and detailed analysis and comparison of the three reviews, but rather an attempt to gain insights about possible reasons for differences in outcomes and conclusions.

This review includes a very broad set of 80 national programs that ranged from "directly related" to the intent of the 1991 chronic care priority to those that were "less directly related" to the priority. For this discussion, the analytic focus is on the 23 programs that were directly related to the chronic care priority.

"Directly Related" Chronic Illness Programs. Between 1972 and 2010, the Foundation funded 23 national programs, and a total of 852 individual grants, that were directly related to the 1991 priority (Chronic Care Group 1). Resources allocated to these programs over this period totaled $280 million; $84 million was paid out between 1978 and 1990 (before the establishment of the chronic care priority), with $196 million paid out between 1991 and 2010.

Tobacco Programs. The tobacco programs were a direct result of RWJF's 1991 priority to "promote health and prevent disease by reducing substance abuse," which was established alongside the chronic care priority. As described in the tobacco retrospective, after a somewhat disorganized start, through the recruitment of new leadership for this effort and intensive staff analysis, a coordinated and comprehensive strategy was developed and implemented, with components ranging from research to access to smoking-cessation programs, to advocacy for policy change to raise tobacco taxes and enact clean air laws and communications. According to the tobacco retrospective, between 1991 and 2009 the Foundation's tobacco-related grants totaled approximately $700 million, with most of this amount allocated after the development of the comprehensive strategy.

End-of-Life Programs. A subset of chronic care programs, the Foundation's end-of-life efforts might be seen as the exception that proved the rule. Among the broad and generally fairly diffuse set of chronic care programs, end-of-life funding was much more narrowly targeted on specific aspects of chronic illness and the care system. As described in the end-of-life retrospective, the perceived "failure" of SUPPORT, a major Foundation program that attempted to change end-of-life care, and the resulting disappointment among Foundation staff, may have contributed to and energized a strategic focus on end-of-life issues. The resulting efforts were particularly important to the creation of the academic and clinical fields of end-of-life care. Funding for the six end-of-life national programs totaled $162 million, the large majority of which was granted between 1995 and 2008.

Discussion. These brief descriptions of the initiatives highlight several important differences between the 23 chronic care programs and the tobacco and end-of-life funding priorities, including the degree to which funding in each priority area focused on developing and implementing strategies, the coordination of each initiative's components, and the amount and concentration of funding.

A significant difference between the chronic care programs and the two other initiatives were the latter's much more intensive efforts to develop comprehensive intervention strategies that ranged from research to interventions based on the evidence gathered in the research to educational and policy change advocacy (in the case of tobacco) efforts to change behavior. In comparison, with certain important exceptions, the chronic care strategies tended to be program-specific, with little reference to other programs, and rarely any follow-up programs to build on the successes and lessons learned from the previous work.

Another difference was the choice of the major target for each initiative. The chronic care priority aimed to "to improve the way services are organized and provided to people with chronic health conditions," perhaps an overly ambitious and wide-ranging goal, which may have discouraged comprehensive strategy development simply because of its breadth, not to mention the many professional, political, and social obstacles to changing the health care system. The tobacco and end-of-life initiatives, in contrast, focused more on behavioral change—the tobacco initiative on changes in consumer behavior in response to policy change, and the end-of-life initiative on changes in the behaviors of providers and consumers regarding their choice and use of end-of-life services.

Finally, over comparable periods of time, total funding was significantly higher and more concentrated for the tobacco and end-of-life initiatives compared with the chronic care initiative. The total resources devoted to the tobacco initiative was approximately three times that of the 23 chronic care programs, while funding for the six end-of-life programs was approximately equal to that of the 23 much more diverse chronic care programs.

> In comparison, with certain important exceptions, the chronic care strategies tended to be program-specific, with little reference to other programs, and rarely any follow-up programs to build on the successes and lessons learned from the previous work.

Some important exceptions to the differences noted above among chronic care programs were the *Improving Chronic Illness Care* program and the sets of diabetes and asthma-related programs. *Improving Chronic Illness Care* was very successful in developing the intellectual framework for comprehensive care of persons with chronic illness, though less successful in implementing this framework and actually changing systems of care (per the chronic care priority). Perhaps this program would have had more success in changing systems had it been part of a broader comprehensive strategy with a set of coordinated programs. It should be noted, however, that the spread of the model continues: the Patient-Centered Medical Home model developed by the American Academy of Family Physicians and endorsed by some 22 physician professional organizations integrates the Chronic Care Model with additional primary care expectations such as access, coordination of care and continuity. Nevertheless, the total funding for *Improving Chronic Illness Care* and associated programs was less than $30 million, compared, for example, the $162 million devoted to changing end-of-life care.

For both the diabetes-related and asthma-related initiatives there were efforts to develop and implement coordinated and complementary strategies and programs. Total funding, however, for the diabetes and asthma programs were $14 million and $26 million respectively, probably significantly less than comprehensive strategies in these areas required, and, importantly, there was little follow-up to the initial implementation of these strategies.

Thus, compared with the chronic care initiative, the tobacco and end-of-life initiatives had much greater strategic focus, significantly higher and more concentrated funding, and consistent strategic building on program successes.

Time Line of RWJF's National Programs According to Grantmaking Theme and Chronic Care Group, 1979–2010

Groups as related to the
intent of the 1991 initiative:

- **Group 1:** Definitely Related
- **Group 2:** Closely Related
- **Group 3:** Distantly Related

RWJF Leadership	David E. Rogers (1972–1987)	Leighton E. Cluff (1985–1990)	Steven A. Schroeder (1990–2002)	Risa Lavizzo-Mourey (2002–present)

1991
RWJF Makes Chronic
Care a Priority

1979 · 1985 · 1990 · 1995 · 2000 · 2005 · 2010

Theme I
Management of Chronic Conditions

- Chronic Disease Care Prog.
- R&D Program to Improve Patient Functional Status
- Health Care for the Homeless Program
- AIDS Health Services Program
- AIDS Prevention and Services Projects
- Building Health Systems for People with Chronic Illnesses
- Chronic Care Initiatives in HMOs
- Improving Chronic Illness Care
- Partnership for Solutions
- Diabetes Initiative
- New Health Partnerships
- Prescription for Health

Theme II
Children & Asthma

- Coordinated Care for Chil. with Comm. Disorders
- Allies Against Asthma
- Improving Asthma Care for Children
- Managing Pediatric Asthma

Theme III
Quality of Care

- R&D to Improve LT and Amb. Care Quality
- Pursuing Perfection
- Rewarding Results
- Aligning Forces for Quality
- Developing Payment-Reform Strategies for High-Value Care

Theme IV
End-of-Life Care

- Care of Critically Ill Hospitalized Adults (SUPPORT)
- Promoting Excellence in End-of-Life Care
- Comm.-State Partnership to Improve End-of-Life Care
- Targeted End-of-Life Projects Initiative
- Center to Advance Palliative Care
- Caring Connections

1991
RWJF Makes Chronic
Care a Priority

Timeline years: 1979 — 1985 — 1990 — 1995 — 2000 — 2005 — 2010

Theme V
Elderly & Long-Term Care

- Program for the Health-Impaired Elderly
- Hospital Initiatives in Long-Term Care
- Social HMO
- On Lok Approach to Care for the Elderly
- Interfaith Volunteer Caregivers Program/Faith in Action
- Supportive Services Program for Older Persons
- Dementia Care and Respite Services
- Life-Care-at-Home Communities Demonstration
- Supportive Services Program in Senior Housing
- Program to Promote Long-Term-Care Insurance for the Elderly
- Partners in Caregiving: The Dementia Services Program
- No Place Like Home
- Coming Home: Affordable Assisted Living
- Statewide System of Care for Chronically Ill Elderly in MA
- State Initiatives in LT Care
- Home Care Research Initiative
- Better Jobs Better Care
- Green House Initiative

Theme VI
Disabilities

- Dental Training for Care of the Handicapped
- Improving Service Systems for People with Disabilities
- Funding Part. for People with Disabilities
- Independent Choices
- Cash & Counseling
- Self-Deter. for Persons with Devel.

Theme VII
Medicaid/Medicare

- Medicaid Managed Care Program
- Medicare/Medicaid Integration Program

Theme VIII
Mental Health

- Program on Chronic Mental Illness
- Mental Health Services Develop. Program
- Mental Health Services Program for Youth
- Replication of the Fnd's Programs on Mental Illness
- Depression in Primary Care
- Caring Across Communities
- National Demonstration of Early Detection, Intervention, and Prevention of Psychosis in Adoles. and Young Adults
- Disparities Depression Initiative

Theme IX
Other

- Community Programs for Affordable Health Care
- Community Care Funding Partners Program
- Service Credit Banking for Elderly
- Local Funding Partnerships
- Service Credit Banking in Managed Care
- Health of the Public: An Academic Challenge
- Old Disease: TB in the 1990s
- Community Partnerships for Older Adults
- Hablamos Juntos: Improv. Patient-Provider Commun. for Latinos
- Active Living Resource Center
- Dartmouth Atlas Project
- Org. Approach to Identifying and Improving Care for Patients with Low Literacy and Chronic Disease

Appendix 3 (continued)

Descriptions of Chronic Care Programs

This appendix includes descriptions of programs in chronic care Groups 1 and 2 according to the themes and groups shown in the Time Line on the previous pages, with links to expanded descriptions on the Foundation's website and to program websites. Programs classified in Group 3 are listed with links to descriptive material.

THEME I: MANAGEMENT OF CHRONIC CONDITIONS

GROUP 1 (DEFINITELY RELATED)

Chronic Disease Care Program (1980–1984)

One of the earliest chronic care-related programs funded by the Foundation, this program built upon strong evidence that nurses could help doctors improve counseling, education, and monitoring of patients with chronic diseases so that patients might better follow a plan of care and reduce complications of their illness. The *Chronic Disease Care Program* sought to reduce the need for hospitalization or institutional care by helping patients follow a plan of management for their condition in order to improve functional effectiveness. The program also helped to support the development of services to help chronically ill patients follow a plan of management by hospitals and their medical staffs.

Michael H. Alderman, MD, Cornell University Medical College, was program director and an advisory committee was selected to assist RWJF in evaluating proposals and monitoring the program. Based upon the recommendations made by the advisory committee, eight institutions were awarded grants in January 1980.

The grantees were located in multiple health care settings, which required the development of different services appropriate to their particular circumstances. For example, programs were located in an acute general hospital, an ambulatory care clinic of a hospital and medical school consortium, a community hospital with a strong rehabilitation center, and a hospital with a very large salaried physician group practice.

Building Health Systems for People with Chronic Illnesses (1992–2002)

This program provided more than $14 million to 32 projects that included a broad range of initiatives that addressed the full spectrum of medical, mental health, and supportive services needs for people with disabilities and chronic health conditions. This program was intended to address the deficiencies in the health care system that are faced by this population, which generally results in fragmented, unresponsive, or inappropriate care. These barriers to care contribute significantly to the high cost of care for people with chronic conditions.

In the early 1990s, approximately 99 million Americans had some sort of chronic condition and were receiving inadequate and costly care. RWJF saw the *Building Health Systems* program as a vehicle to quickly generate innovative ideas in the field of chronic care. This program was established at the same time the Foundation adopted improving chronic care as one of its goal areas. The program's work was informed and guided by the 1990 passage of the federal Americans with Disabilities Act, which emphasized consumer involvement and self-determination for people with disabilities.

F. Marc LaForce, MD, was the program director for *Building Health Systems*. The national program office was initially established in 1992 at Genesee Hospital and the University of Rochester School of Medicine and Dentistry. In 1995, the Foundation moved the program funds to the Center for Health Care Strategies, which was managing another Foundation program at the time. Administrative responsibilities were moved back to RWJF in 2002; however, the Center for Health Care Strategies continues to maintain information about the projects on its website.

A national advisory committee was established for the program in 1992. The members were selected to represent the range of issues involved in the program, including those concerning children, people with disabilities, mental health, financing, and care coordination. The committee met during the annual conferences, and during each of the five funding rounds to review proposals and select grantees. The committee also assisted in site visits both as the grantees were selected and once the projects got under way.

The program was designed with a holistic view of the health care system and encouraged the submission of diverse investigator-initiated proposals focused primarily on overcoming the fragmentation, financing barriers, and episodic care that is characteristic of care for people with chronic conditions. Community-based or social health models of caring were encouraged and priority was given to programs that were comprehensive, were not disease-specific, and were rooted in the community. Over the course of the program, interventions that linked housing, informal caregiving, and employment for people with disabilities also was included.

The vision of the program director was to support projects that attempted to integrate care delivery and financing, and advance the movement away from an acute care focus toward a social health model of care for people with chronic conditions. All of the projects targeted one or more of the following population groups: people with physical or developmental disabilities; people with severe, persistent mental illness; children with special health care needs; and frail elderly individuals.

Results: The program aimed to overcome barriers to employment for people with disabilities. The results of the program included the development of models of care in five areas:

- Self-determination for people with developmental disabilities; integrating medical, social, and long-term care services for elders and people with disabilities

- Arrangement of family supports for children with special health care needs and their families that move care to the community provider level

- Blending supportive housing with health care; integrate health and social services for the frail elderly

- Helping people with disabilities leave nursing homes and re-enter the community

- Helping people with disabilities overcome barriers to employment

The grants made through *Building Health Systems for People with Chronic Illnesses* supported a variety of worthwhile, though very dispersed and uncoordinated, efforts to improve services for people with chronic illness. There is little evidence that any of the funded grants produced lasting changes in systems of care.

Chronic Care Initiatives in HMOs (1993–1997)

This was a national program charged with identifying, demonstrating, evaluating, and disseminating innovations in health care of chronically ill people enrolled in managed care organizations. The Foundation provided $5.6 million for this program, with a national program office directed by Peter Fox at the American Association of Health Plans. Ultimately, 18 projects were funded.

The intent of this *Chronic Care Initiatives in HMOs* was to provide HMO managers, medical directors, providers, and public and private payers with research and practice data. This data would help to guide them in financing and delivering chronic care services by fostering and evaluating innovations in the way people with chronic illnesses receive care in this type of system. Priorities for projects funded under this program included: improving the methods HMOs use to identify high-risk chronically ill people for special interventions that prevent deterioration; understanding the impact of case management in the HMO setting; and reorganizing primary care in both the nursing home and ambulatory settings to better meet the needs of chronically ill patients.

Planning grants and follow-up grants were funded. The planning grants were designed to develop research protocols and to stimulate development of innovations in the delivery of services. The follow-up grants supported evaluations and demonstrations of innovative approaches to the provision of health care services to chronically ill members of HMOs.

Results: Several positive results from this program may have significant benefits for the future management of chronic illness in managed care settings.

- Performance measures were developed by the National Committee for Quality Assurance that assessed how well a managed care organization cares for chronically ill enrollees

- A screening tool was developed that reliably identifies senior enrollees at high risk of frequent hospitalization

- A cooperative health care clinic expanded regionally, improving both patient and physician satisfaction, and providing primary managed care within specialized chronic care clinics

- Recommendations, opportunities, and challenges in care management practices for chronically ill older patients were developed

With one notable exception, there was little evidence, however, that this program, or its grants, had a significant impact beyond the life of the program on the actual care provided to persons with chronic conditions. The exception is the funding provided by this program to Edward Wagner, MD, to develop what became the initial foundations of the Chronic Care Model, described next.

Improving Chronic Illness Care (1997–2010)

The Chronic Care Model was developed by Edward Wagner, MD, an internist and director of the MacColl Institute for Healthcare Innovation at the Center for Health Studies, Group Health Cooperative in Seattle. *Improving Chronic Illness Care* (ICIC) sought to help health care organizations redesign and improve their care of people with chronic illnesses through the adoption of the Chronic Care Model. The Foundation authorized up to $25 million dollars to support ICIC.

Wagner first came to the Foundation's attention in 1992 as a grantee of the program *Chronic Care Initiatives in HMOs*. During this project he identified a number of issues, including importantly that the health care system was structured for acute care rather than the management of long-term, chronic conditions. Among the issues he noted were that the typical primary care offices are designed to respond to acute illness and do not have systems in place to care for chronically ill patients. Physicians are often too busy to educate and support chronically ill patients to the degree necessary to keep them healthy. He also found that chronically ill patients were not receiving enough education about their conditions nor were they given the tools they need for self-management once they left the doctor's office.

Based on these findings and his many years of providing care to people with chronic conditions, Wagner developed the Chronic Care Model. The goal of the Chronic Care Model is to replace the traditional physician-centric office structure with one that supports clinical teamwork in collaboration with the patient. Under this model, physicians, nurses, case managers, dieticians, and patient educators collectively share responsibility for the patient's well-being, with the support of administrative staff and relevant, useful technology.

The Chronic Care Model defines six elements whose coordination is necessary for high-quality disease management:

- Doctors' offices and clinics should identify existing community resources and programs, and encourage patients to participate in them.

- Health care organizations must make excellence a priority and pursue it visibly. This includes support by top management, open communication on error and failings, and strategies for improvement.

- Clinicians should work collaboratively with their chronically ill patients, and encourage their participation in setting goals and fine-tuning treatment.

- Clinical staffs need defined roles if they are to move from a one-on-one doctor/patient relationship to teamwork. Follow-up with patients is essential so they feel supported in self-management efforts outside the medical office.

- Clinicians must have explicit guidelines in order for them to link their treatment to the research evidence, whether the question is scientific (drug doses) or psychosocial (how best to motivate overweight diabetics to diet).

- The use of computerized clinical information systems can efficiently deliver disease management information about the patients, including care guidelines, test results, and pop-up reminders about individual patients. They also enable the clinical team to look at cohorts within their practice, such as all patients with diabetes, and measure their performance against quality benchmarks.

The Chronic Care Model is based on the idea that by integrating these elements into primary care practice, health care organizations will be better able to manage clinical responsibilities while helping patients develop the tools they need for self-management, thus becoming active participants in their own care. Instituting this model results in healthier patients, lower costs, and clinicians motivated by evidence of a job well done.

The goal of the ICIC program was to improve the health of chronically ill patients by helping large numbers of health plans and provider groups, especially those that serve low-income populations, improve their care of those with chronic illness. The idea was to marry medical science with redesigned health care delivery systems so that chronically ill patients in any clinical setting can receive a prompt diagnosis and health care that helps them manage their condition while avoiding debilitating and expensive complications.

The final design for ICIC included three major components:

- A grant program for research on system barriers to state-of-the-art chronic disease care. These included studies of how to integrate community resources into clinical practice, adapt disease-management tools to small physician practices, use Web-TV technology to teach self-management techniques to isolated rural patients, and enhance the flow of medical information as patients move from one health care setting to another.

- Real-world tests of the Chronic Care Model in a range of clinical practice settings to teach grantees how to re-engineer their work environment. ICIC teamed up with the Institute for Healthcare Improvement to run training programs called the Breakthrough Series, which included national meetings, group coaching, and feedback for clinical leadership teams designated by their health care organizations. Their assignment was to implement the Chronic Care Model in their workplaces, but also to stay in touch with the other teams as part of an idea-sharing collaborative. As of January 2006, more than 1,300 health care organizations had participated in the Breakthrough Series Collaborative.

- Flexibility in the implementation of the Chronic Care Model. While the Chronic Care Model is relatively prescriptive, dictating criteria and processes for changing medical office design and practice, ICIC presented it as a flexible tool, designed for adaptation to a variety of primary care settings. For example, grantees were encouraged to modify the recommended

form for interviewing new patients. The only condition was that these modifications had to be scientifically tested to document better results. This opened the door to innovation at every level of ICIC, creating the same dynamic collaboration between the national program office and its grantees that the Chronic Care Model promoted for patients and the health care team.

Results:

- ICIC's clinical improvement program engaged dozens of practices and health systems in Breakthrough Series Collaboratives around the country.[3] These collaboratives collectively involved more than 1,500 different practice organizations–including a sizable percentage of the country's community health centers–37 academic health centers, and large organizations such as New York Health and Hospitals Corporation.

- The targeted research grants program funded 19 research projects that looked at major knowledge gaps and barriers in the Chronic Care Model and how it was being implemented.

- ICIC staff published more than 100 articles in academic publications and made some 350 presentations (in addition to those done as part of Breakthrough Series Collaboratives) to academic and practitioner audiences.

- The ICIC website grew into a vital hub for resources, information, and communication for the chronic illness care field. Historical ICIC data show a six-fold increase in traffic over the lifespan of the website.

In a 2009 *Health Affairs* article, Colman et al.[4] concluded that:

- Practices redesigned in accord with the Chronic Care Model generally improve the quality of care and the outcomes for patients with various chronic illnesses. This finding appears to be consistent in both U.S. and international settings.

- The combination of the effort required by busy practices, unsupportive reimbursement, and an uncertain business case have limited widespread implementation of the Chronic Care Model except by very large organizations.

According to ICIC and RWJF staff, the Chronic Care Model has been embedded into a number of health system reform and improvement efforts, including:

- The Patient-Centered Medical Home–a model developed by the American Academy of Family Physicians and endorsed by some 22 physician professional organizations–which integrates the Chronic Care Model with additional primary care expectations such as access, coordination of care, and continuity

- National health care reform legislation (the Affordable Care Act), with its emphasis on evidence-based, patient-centered, and population-based care systems

- The National Committee for Quality Assurance's accreditation standards and performance indicators and The Joint Commission on Accreditation of Healthcare Organizations' (now called The Joint Commission) certification for chronic disease programs

The results of this program demonstrated that the Chronic Care Model has become widely accepted and endorsed as the guide for chronic illness care improvement. It has been integrated in accreditation, measurement, financial incentives, quality improvement, and educational programs across the country.

The influences of the Chronic Care Model cited by interviewees ranged from "changing the way people think about" the medical care provided to persons with chronic illness to the inclusion of "medical homes" in the Affordable Care Act. Yet even *Improving Chronic Illness Care* had difficulty extending the Chronic Care Model beyond a highly organized setting, such as a group practice HMO to the broader community of medical practices. These are not (yet) capable of implementing key requirements of the Chronic Care Model, such as the need to integrate medical and social services and to have clinical information systems that include information on individual patients and populations of patients. As one interviewee explained, they had successfully implemented most of the elements of the Chronic Care Model in their clinic, but the model was difficult to implement in most solo and small group practices, and impossible "across the street" in the teaching setting that was associated with the clinic.

Partnership for Solutions: Better Lives for People with Chronic Conditions (1999–2004)

This program conducted original research and identified existing research that clarified the nature of the problem and communicated those findings to policy-makers, business leaders, health professionals, advocates, and others. The program also identified promising solutions to the problems faced by people with chronic health conditions. The national program office was located at Johns Hopkins University Bloomberg School of Public Health in Baltimore, under the direction of Gerard Anderson, PhD.

Partnership for Solutions was designed to gather and analyze data about chronic illness in the United States. Its goal was to raise the profile of chronic illness so that policy-makers, providers, and the public could come together to craft workable changes to the way the health care system treats the chronically ill. It was to be an integrated research and communications effort to build awareness of the growing numbers of Americans with one or more chronic diseases and to stimulate new methods to provide them additional care, support, and help. A range of topics about caring for chronically ill persons were examined in this program, including the characteristics of people with chronic conditions, what they need, and how best to deliver and pay for their health care. To accomplish the goals of this program, two highly integrated and interactive approaches were used: 1) strategic research and analysis on topics related to the problems and solutions of those with chronic conditions in the 21st century; and 2) communications and social marketing tools used to define the problems, shape the research agenda, identify strategies for change, and target key audiences.

The program began with a planning period to flesh out the program's goals and agenda, during which Johns Hopkins researchers analyzed five chronic conditions, and identified the issues common to patients with each condition. The five chronic conditions were; Alzheimer disease, frailty in the elderly, diabetes, asthma, and severe mental illness. Seven advocacy, consumer, and provider organizations that deal with these five conditions were invited to participate in the program, and a communications firm was engaged to provide guidance to the program's dissemination efforts. These partner organizations agreed to regularly survey their members and conduct workshops to learn more about the issues faced by those with chronic illness and to work with the Johns Hopkins researchers in communicating key research findings.

Program staff developed several key research questions:

- What types of benefits do large corporations offer for people with chronic conditions; which benefits packages are models for both the private and public sectors?

- What is the impact of private sector insurance benefits on health care and productivity for those with chronic conditions?

- How does the way in which doctors and hospitals are paid affect the quality of care for people with chronic conditions?

- Are there other ways to pay for care and support not covered by private insurance or public health coverage programs?

Results: Partnership for Solutions, and subsequent efforts based on this program and funded by the Foundation, have produced widely used and cited analyses and information about the state of chronic illness and chronic illness care in the United States. The program's research and analyses characterizing the nature, growing size, and impact of chronic illness in the United States was disseminated through more than 35 articles in peer-reviewed journals; more than 30 reports, fact sheets, and issue briefs; a chartbook of key statistics; 25 workshops with partners and other policy organizations; and an estimated 500 presentations. Policy-makers in public, private, and nonprofit organizations used the program's research findings to inform their efforts to improve care for people with chronic conditions.

Diabetes Initiative (2002–2009)

The Diabetes Initiative included two related national programs: *Advancing Diabetes Self-Management* and *Building Community Supports for Diabetes Care*. The national program office for both programs was located at Washington University in St. Louis, under the directorship of Edwin B. Fisher, PhD, director of the Division of Health Behavior Research and professor of psychology, medicine, and pediatrics.

Diabetes is a group of diseases in which defects in insulin production, insulin action, or both cause high levels of blood glucose. Diabetes can result in serious complications, including blindness, kidney damage, cardiovascular disease, and the necessity of lower-limb amputations. By controlling blood glucose, blood pressure, and blood lipids such as cholesterol, people with diabetes can reduce their risk of complications. Although a wide array of medications can help with the clinical control of diabetes, much of the burden of diabetes care and prevention of complications lies with patients and their families through self-management. To succeed, people with diabetes need effective self-management education programs that offer practical skills to sustain healthy behaviors for a lifetime.

Advancing Diabetes Self-Management included six project sites and was designed to demonstrate that effective, multi-component diabetes self-management programs can be delivered in primary care settings and can significantly improve patient outcomes. *Building Community Supports for Diabetes Care* included eight project sites whose goal was to extend support for diabetes management beyond the clinical setting into the community through clinic and community partnerships.

The national program staff offered a wide array of technical assistance through a collaborative learning network that emphasized collaboration through peer-to-peer learning and synergy among project staff, program staff, and advisers. Assessment of Primary Care Resources and Supports for Chronic Disease Self-Management was a tool for primary care sites to assess their capacity for self-management and guide quality improvement. Reports, handbooks, tools, articles, and other publications were produced, a website was developed and maintained, and presentations were made at regional, national, and international conferences.

The projects created models of providing care for patients with diabetes and supporting their self management, which integrated clinical care across a variety of settings and with a range of providers, and included support groups, linkages to community resources, skill-building and exercise classes, social marketing, and educational initiatives. Community health workers were incorporated as key components of patient self-management support in many sites. These workers shared the environment and language of the patients they served and were trained to provide advocacy, support, and education. Close working partnerships with other clinical sites, community organizations, churches, and government agencies were established to expand access to interventions and supports that help people manage their diabetes.

Results: The program demonstrated that diabetes self-management programs and services can be implemented in a variety of clinical and community settings. The Resources and Supports for Self-Management model provided a flexible framework for the project staff when designing their clinical approaches. Key components of this model include individualized assessment, collaborative goal setting, development of key skills, ongoing follow-up and support, community resources, and continuity of quality clinical care. The results of the Diabetes Initiative were similar to several of the programs described above, that is, the grants funded by the program produced a number of useful products, but there was little or no follow-through to continue these efforts after funding for the program ended.

GROUP 2 (CLOSELY RELATED)

Research and Development Program to Improve Patient Functional Status (1981–1991)

The goal of this program was the development of new approaches to measuring and improving the functional status of people at all ages with chronic conditions. This was an early effort to call attention to the importance of functional outcomes, in addition to establishing diagnoses or measuring mortality, when addressing the complexities of managing chronic conditions. A range of projects was supported, from pilot studies to full-scale clinical trials.

Results:

- The development of improved diagnostic instruments

- The diagnosis and appropriate management of somatization disorders

- The sensitivity and specificity of markers of psychosocial stress in pregnant urban women

- The value of increased social supports in improving the health and functional status of people in high-risk situations, such as following hip fractures

Despite challenges, this program was generally successful in meeting its goals.

New Health Partnerships: Improving Care by Engaging Patients (2005–2008)

This program explored whether primary care centers could deliver comprehensive patient and family-centered self-management support to patients with chronic conditions. The program began with a face-to-face collaborative learning community called Quality Allies (2005–2007). The second phase of this program was a virtual community called *New Health Partnerships* (2007–2008), which was designed to foster the spread of self-management support by enabling providers to participate in their patients' care without having to spend the time and money required in a face-to-face learning community. *New Health Partnership*'s 16-month virtual learning community provided a one-stop shop for expert advice, evidence-based research, care planning, and patient education tools to support providers in implementing self-management support.

GROUP 3 (DISTANTLY RELATED)

From the early 1980s to the mid 1990s, three programs were developed in this area, one for the homeless and two for people living with AIDS: *Health Care for the Homeless Program* (1982–1991); *AIDS Health Services Program* (1985–1992); and, *AIDS Prevention and Service Projects* (1986–1994). Starting in 2002, *Prescription for Health: Promoting Healthy Behaviors in Primary Care Research Networks* tested the use of evidence-based models and innovative tools in primary care to counsel patients to change their unhealthy behaviors. The program focused on four leading behaviors associated with premature death: smoking, risky drinking, unhealthy diet, and physical inactivity.

THEME II: CHILDREN AND ASTHMA

Asthma is a chronic inflammatory disease of the airways characterized by recurrent episodes of breathlessness, wheezing, coughing, tightness of the chest, and other breathing difficulties. Asthma affects all populations but has a disproportionate impact on economically disadvantaged, urban, and minority groups. The disease takes a heavy toll on young patients and their families. Asthma has traditionally been a leading cause of school absenteeism, and accounted for an estimated 14 million school absence days in 1996, up from 6.6 million in 1980. Pediatric asthma is responsible for billions of dollars in health care costs and continues to be responsible for hundreds of thousands of hospitalizations and emergency department visits a year.

The number of Americans, particularly children, with asthma grew dramatically in the 1990s. According to the Centers for Disease Control and Prevention between 1980 and 1995, the prevalence rate of asthma among those under 17 more than doubled, increasing from an estimated 3.6 percent to 7.5 percent. As the prevalence rate rose, so did the mortality rate, which increased almost threefold between 1979 and 1996, from 93 to 266. By 2001, more than 20 million Americans were reported as having asthma, about a third of them children.

GROUP 1 (DEFINITELY RELATED)

In 1999 RWJF initiated funding of three asthma-related programs. These programs, along with the Diabetes Initiative, were part of a programmatic shift at RWJF starting in the late 1990s toward targeting quality of care for specific chronic diseases. This shift occurred, in part, because of enthusiasm generated by the development of the Chronic Care Model and the possibility of applying this model to achieve improved quality of care for persons with specific conditions. The shift was also, however, an implicit acknowledgment of the difficulty experienced by the Foundation's programs in the 1990s to achieve comprehensive changes in the health care system that would address the needs of persons with chronic conditions, especially those with multiple conditions. It was felt that focusing on specific conditions would improve the chances of achieving useful improvements in care.

The asthma-related programs were designed as a group to address different aspects of asthma care: a community-coalition approach (*Allies Against Asthma*), demonstration sites to improve care of children whose care was funded by the State Children's Health Insurance Program (*Improving Asthma Care for Children*), and improving the emergency care of asthma patients (*Managing Pediatric Asthma*). While each of the three programs produced useful information and resulted in improved care for specific groups of persons with asthma, the goal of a coordinated and continuing set of programs was never achieved. The coordination was, in general, limited to yearly meetings of grantees to share ideas and learn from each other. Interviewees reported that there was relatively little interaction among either programs or grantees beyond these yearly meetings.

There was little follow-up by the Foundation to the achievements of these programs. *Managing Pediatric Asthma*, for example, was designed to develop and test care models in hospital emergency departments, with the expectation that the successful models would be disseminated in a subsequent program to be funded by RWJF; no follow-up funding was provided, however.

Of note, the diabetes and asthma initiatives were among the most "strategic" of the chronic care initiatives funded during the 1990s and 2000s. There was an explicit attempt to develop and fund coordinated efforts to address multiple, though discrete, parts of the jigsaw puzzle of chronic illness care. Ultimately, little synergism among programs was achieved, however, and the Foundation chose not to continue funding of the diabetes and asthma initiatives beyond the initial programs. The leadership transition at RWJF in 2003, with the development of new priorities, as well as overall funding reductions coincident with this transition, may have had an important impact on the decision to not renew these initiatives. In addition, some of the program staff responsible for these programs at RWJF also left the Foundation before the programs ended, so these programs lacked champions who might have successfully sought continued funding.

Allies Against Asthma: A Program to Combine Clinical and Public Health Approaches to Chronic Illness (1999–2009)

This program supported the efforts of seven community-based coalitions to improve the management of pediatric asthma in their areas. The national program office was located at the University of Michigan in Ann Arbor under the direction of Noreen M. Clark, PhD. In addition to overseeing and assisting the coalitions, Clark and her program staff were responsible for evaluating the impact of the coalitions and their interventions. A 15-member national advisory committee was established to help select the program grantees, provide technical assistance to the coalitions, and support the national program staff in managing and evaluating the program.

There were seven coalitions located throughout the United States, including one in San Juan, Puerto Rico. Coalition members included health care providers, government agencies (including health departments), schools, and nonprofit organizations, as well as parents and caregivers. The coalitions implemented comprehensive asthma management strategies in low-income neighborhoods to improve the medical care, education, and support of asthmatic children and their families who were dependent on publicly financed care and safety-net providers. It also aimed to stimulate environmental and other policy initiatives to increase a community's capacity to control the disease.

The program had three primary objectives:

- Reduce hospital admissions, emergency room visits, and missed school days

- Enhance the quality of life of children with asthma

- Develop a sustainable strategy for asthma management in the community

Results: Key findings from the program showed that the seven coalitions made or contributed to a total of 90 changes in pediatric asthma-related policies and systems, ranging from improved practices within single health care institutions to revisions of citywide policies and state laws. Parent surveys showed marked differences between communities that were targeted by the coalitions for intervention and the comparison communities that were not. The results of the surveys suggested that children in the intervention neighborhoods experienced a greater reduction in recent asthma symptoms than did children in the comparison neighborhoods. Parents of children with asthma in the intervention neighborhoods showed significant improvement on two quality-of-life survey questions: how often did they feel helpless or frightened when their child experienced breathlessness or other asthma symptoms, and how often did they feel angry that their child had asthma.

Improving Asthma Care for Children (1999–2009)

This program tested new approaches to managing asthma in children receiving care through Medicaid managed care. The program funded demonstrations of innovative asthma management practices in five Medicaid managed care organizations located in New York (3), California (1), and Missouri (1). The Center for Health Care Strategies managed the program and provided technical assistance to the project staff, under the co-directorship of Richard J. Baron, MD, and Karen L. Brodsky, MHS (1999–2002), and Patricia J. Barta, MPH (2002–2005). A national advisory committee was established to help select grantees and guide the project.

Grants for *Improving Asthma Care for Children* went to support formal collaborations of managed care organizations with other providers of asthma care, such as school-based health centers, child-care agencies, and federally qualified health centers. Grantees were expected to develop and demonstrate innovative models of pediatric asthma care for a managed care population of at least 20,000 Medicaid or SCHIP enrollees. The goals of the projects were to:

- Improve managed care clinical and administrative practices, and improve coordination among providers of asthma services

- Develop innovative clinical service delivery models

- Improve patient education and self-management strategies

- Implement community-targeted education campaigns about environmental asthma triggers and their abatement

- Evaluate the impact of the innovation undertaken

Results: The demonstration sites achieved varying levels of success, but all five reported significant improvement in at least one area of childhood asthma management. Collectively, the groups demonstrated that Medicaid managed care organizations can develop and implement interventions that have a positive impact on the heath care of children with asthma while also controlling the cost of asthma care. The grantee organizations integrated a number of their projects' administrative and policy changes and clinical care delivery improvements into their routine practices and procedures.

Managing Pediatric Asthma: Emergency Department Demonstration Program (1998–2005)

This program developed and tested emergency department-based systems to improve pediatric asthma care in high-risk populations. The American Academy of Allergy, Asthma & Immunology (AAAAI) in Milwaukee managed the program and provided technical assistance to the project.

When an asthmatic child has difficulty breathing, particularly when physicians' offices are closed at night and on weekends, the hospital emergency department (ED) is a common source of treatment. For families without insurance coverage, the ED may be their only option. In 2002, there were more than 727,000 ED visits by children because of asthma attacks.

The Foundation's program staff viewed the hospital ED as a potential resource in chronic asthma management, extending beyond the traditional role of the ED as providing episodic treatment for acute asthma attacks. The Foundation program staff reasoned that ED physicians see large numbers of children with asthma, typically when an attack is under way. This program wanted to test whether this interaction offered a "teachable moment" that the staff could exploit to make a lasting impact on the health of the pediatric asthma patient. The projects funded under this program were intended to implement and evaluate:

- ED-based interventions to improve the delivery of clinical care to children with asthma

- Patient, family, and caregiver education in asthma management

- Surveillance systems to track pediatric asthma patients and measure the impact of the interventions

Results: Although outcomes were not uniform, the projects collectively demonstrated that EDs can deliver effective asthma education and management programs to pediatric asthma patients and their families. They found that children with the mildest chronic asthma severity classification constituted an unexpectedly large proportion of emergency department pediatric asthma patients. The projects also demonstrated that ED-based patient tracking systems can produce data to enhance understanding of the local pediatric asthma population, and inform clinical and educational interventions.

GROUP 2 (CLOSELY RELATED)

No programs

GROUP 3 (DISTANTLY RELATED)

Program of Coordinated Care for Children with Communicative Disorders (1984–1991)

THEME III: QUALITY OF CARE

GROUP 1 (DEFINITELY RELATED)

No programs

GROUP 2 (CLOSELY RELATED)

Research and Demonstrations to Improve Long-Term and Ambulatory Care Quality (1992–1997)

This program sought to stimulate research, demonstration, and evaluation projects to develop, implement, and assess new methods for measuring and improving the quality of patient care in long-term and ambulatory care settings. However, despite a large number of letters of intent in response to the call for proposals, few were "imaginative and well-thought-out. … It appears that the state of the art of research in quality assurance for ambulatory care or long-term care is not advanced enough to support this type of project," wrote Jack D. McCue, MD, Chair of the Berkshire Medical Center and program director.[5] Eight projects were funded.

Pursuing Perfection: Raising the Bar for Health Care Performance (2000–2008)

This program was intended to demonstrate to the broader provider community that ideal care is attainable. This program supported efforts by seven health care organizations with the goal of dramatically improving patient outcomes by pursuing perfection in all of their major care processes. The sites funded for this program included four hospitals and three predominantly outpatient organizations, and each one implemented a series of projects aimed at redesigning condition-specific processes of care and units of operation. The goal was for these sites to attain "organization transformation," which would spread improvement and build capacity to the point that the organization was providing ideal care to all patients. At the time, this program was RWJF's most ambitious quality improvement effort. The results of this program showed that most of the seven grantee organizations made "tremendous progress" in improving the quality of their care, and transitioned to national leaders in health care improvement.

GROUP 3 (DISTANTLY RELATED)

Rewarding Results: Aligning Incentives with High-Quality Health Care (2002–2009)

This is a national program of RWJF and California HealthCare Foundation that tests the use of financial incentives to improve the quality of health care. The program supports seven projects across the nation that implements systems designed to measure the performance of health care providers and adjust their compensation based on performance scores.

Aligning Forces for Quality: The Regional Market Project (2005–active)

This program was launched with the premise that no single person, group, or profession can improve health and health care throughout a community without the support of others. It seeks to drive quality improvement by aligning key players in local communities.

Strengthening the Consumer-Purchaser Disclosure Project to Ensure a Performance-Based Health Care System (2010–2011)

RWJF provided funding to the Consumer-Purchaser Disclosure Project of the Pacific Business Group on Health (PBGH). According to PBGH, this project consists of "a group of leading employer, consumer, and labor organizations working toward a common goal to ensure that all Americans have access to publicly reported health care performance information. Our shared vision is that with this information, Americans will be better able to select hospitals, physicians, and treatments based on nationally standardized measures for clinical quality, consumer experience, equity, and efficiency."

THEME IV: END-OF-LIFE CARE

For a description and discussion of the Foundation's end-of-life programs, please see the review of these programs by Patricia Patrizi and colleagues, *Improving Care at the End of Life: How the Robert Wood Johnson Foundation and Its Grantees Built the Field*.

THEME V: ELDERLY AND LONG-TERM CARE

GROUP 1 (DEFINITELY RELATED)

Program for the Health-Impaired Elderly (1979–1988)

This program aimed to establish coordinated systems of care among the many agencies and institutions in the community concerned with health-impaired seniors. It provided five-year grants to eight geographic regions to support the formation of new public/private groups responsible for establishing coherent and coordinated systems of care for the elderly and to ensure they were matched with the appropriate resources.

The key objective of the *Program for the Health-Impaired Elderly* was to create and maintain a decision-making structure that would have both the capacity and the authority to develop policy that would link the elderly with appropriate service providers, thus helping seniors into a coordinated system of care. This program also aimed to promote the optimal allocation and use of resources to meet the needs of individual seniors in a defined community. The major effort of the program was the reorganization of the way in which groups of providers delivered services to seniors within the complex long-term care environment, which included a mix of formal/informal resources, private/public support, health/social services, and institutional/home care.

Results: An evaluation report stated that each of the projects had made substantial progress in the achievement of their goals and objectives, and were moving into a fully operational phase. One of its findings was that the successful decision-making structures in all of the projects included the primary providers who were able to fully participate in the project. There was also a formalization of agreements between participating agencies in order to establish a uniform process for determining the needs of individual seniors. Once the assessment was made, the information could be used cooperatively on behalf of these seniors, as well as to prioritize system

resources on this basis. Even with agency agreements in place, non-agency or informally organized services remained the primary intervention. The other important feature of this program was that while each individual project employed different strategies, they all emphasized the considerable value of the natural support system of the senior, which includes family, friends, and neighbors.

Hospital Initiatives in Long-Term Care (1980–1989)

This program was designed to help hospitals become more involved in long-term care by enabling and supporting them in the development of comprehensive programs that integrated institutional and community-based services to meet the health care needs of a high-risk elderly population. A case management approach was emphasized to help hospitals participate ad potentially take a leadership role in community-based long-term-care services. A major goal of the program was to make discharge planning more effective for chronically disabled older patients when they returned to the community.

Results: A major challenge for this program was getting the full involvement of the administrative and leadership staff, and the integration of the infrastructure of the hospitals involved. One issue was the large differences between the hospitals, which included community, large urban, and rural hospitals. As a result, there was considerable variation in the ways the programs developed, and it was difficult to have comparability or coordination between the different sites.

On Lok Approach to Care for the Elderly (1983–1994)

This program was based on the On Lok model of providing long-term care to the frail elderly to enable them to continue living at home, which was developed in San Francisco in the 1970s. The core features of the On Lok model are:

- Medical day care as the basis of first-line health surveillance, treatment, and therapy

- Ready access to the full spectrum of other needed services

- Central responsibility for the ordering and management of all services by a primary care clinical team

- Online computer-based tracking of patients' clinical and functional status, utilization, and costs

Since most of the clients are dually eligible for Medicare and Medicaid, this model provides a very attractive alternative to nursing home care. The key questions were whether it could be replicated in other locations and extended to other populations.

In 1983 RWJF awarded $228,930 plus a $350,000 line of credit to enable On Lok to negotiate capitated financing under Medicaid and Medicare. In 1987 the Foundation extended its involvement by supporting a replication of the model at six sites. The Foundation awarded money to the sites directly and for technical assistance, however the sites were also expected to find additional funding of at least $300,000 from other sources.

Results: The Foundation's support facilitated On Lok's transition to a capitated system and demonstrated that the model could be replicated in a variety of settings, despite the fact that the replication process encountered a number of difficulties. One problem was that the process of obtaining waivers was longer and more arduous than anticipated, and the first waiver awards were

made almost four years after the replication sites were selected, which created financial difficulties for the sites. Negotiating reasonable reimbursement levels with the states was difficult in several cases. It was also problematic to define the central components of the On Lok model with the need to allow for innovation and autonomy, and the flexibility to adapt to local conditions at the individual sites.

Program to Promote Long-Term-Care Insurance for the Elderly (1988–2006)

This program aimed to protect elderly persons against impoverishment caused by the costs of long-term care by offering high-quality insurance protection for both nursing home and home-based care. The program was charged with providing states with resources to plan and implement partnership programs in order to join private, long-term-care insurance with Medicaid to fulfill the aims of the program. Consumers who purchased such policies would be insured for long-term care up to a pre-set dollar amount through the private insurer. Once the private insurance was exhausted, those subscribers could continue their long-term care under Medicaid without spending their assets, as is usually required to meet the criteria for Medicaid eligibility. The national program office was located at University of Maryland Center on Aging under the directorship of Mark R. Meiners, PhD.

The program had five main goals:

- Help seniors avoid impoverishment by guaranteeing asset protection

- Ensure access to quality long-term care

- Ensure coverage of a full range of home and community-based services

- The development of a case management infrastructure in which the primary care physician bears some financial risk in order to prevent excessive or inappropriate utilization

- The assurance of equity and affordability in the long-term-care insurance program for lower-income individuals

In the mid-1980s insurance companies began marketing long-term-care insurance as costs began to rise and many people ended up in poverty because they had to spend down their assets in order to be eligible for Medicaid. In 2000, Medicaid's proportion of state budgets exceeded 20 percent, and it was spending more than two-thirds of its funding on nursing home care despite the fact that the elderly and disabled represented just one-third of Medicaid recipients. Concerns about long-term care continued to increase as more people were living longer and the costs continued to increase.

The program attempted to minimize the likelihood that seniors would have to spend down their assets in order to qualify for financial aid for long-term care. The spending down of assets results in the public sector bearing much of the cost, so this program works to also save public funds. At the time this program was authorized, less than 1 percent of seniors had long-term-care insurance. The problem is compounded by elderly consumers not being aware of or denying the need for long-term-care coverage; by elderly individuals often mistakenly believing that Medicare pays for long-term-care costs; and by the reluctance of the public sector, particularly the federal government, to address any major new initiatives that could increase its budget.

Results: Four states were able to implement partnerships: California, Connecticut, New York, and Indiana. By the year 2000, a total of 104,000 applications had been taken and more than 95,000 policies had been sold in the four program states. More than 25,000 new applications were received for partnership policies in 1999. Program redesigns in Connecticut, Indiana, and California have produced increases in applications received ranging from 324 percent to 540 percent, compared to similar time periods prior to those adjustments. In New York, where total sales have been the largest in number, updates to its program model were being explored to further program goals. Program staff found that state regulations that were developed for partnership products represented a more restrictive regulatory model than previously existed in the states for long-term-care-insurance policies. The regulations specify that policies are standardized and of high quality; however, the tighter regulations also restrict the options of insurers if they want to make innovative changes.

The Omnibus Budget Reconciliation Act (OBRA) of 1993 contained language with direct impact on the expansion of partnerships for long-term care to other states. The act recognized the four initial states that implemented the program—Connecticut, California, Indiana, and New York—plus a future program in Iowa and a modified program in Massachusetts. These six states were allowed to operate their partnerships as planned because their state plan amendments had been approved by the Department of Health and Human Services before OBRA 1993 went into effect. The remaining states were prohibited from doing so. The four initial states continue to offer the specially tailored long-term-care insurance policies. The partnership programs estimated to have saved the four states $8 million to $10 million in health care bills, allowing them to be more assertive in prodding people to get long-term-care insurance because the policies are more affordable.

In February of 2006, President George W. Bush signed the Deficit Reduction Act of 2005 that allowed the long-term-care insurance partnership model to be used in all 50 states. Besides increasing the incentives to purchase long-term-care insurance, the bill made it harder for seniors to give away money and property before asking Medicaid to pick up their nursing home tabs. Policies in these new programs must meet specific criteria, including federal tax qualification, identified consumer protections, and inflation protection provisions. According to the AARP Public Policy Institute, by April 2006 some 21 states had enacted authorizing legislation (Arkansas, Colorado, Florida, Georgia, Hawaii, Idaho, Illinois, Iowa, Maryland, Massachusetts, Michigan, Missouri, Montana, Nebraska, North Dakota, Ohio, Oklahoma, Pennsylvania, Rhode Island, Virginia, and Washington).

Partners in Caregiving: The Dementia Services Program (1991–2003)

This program was developed by RWJF and the Wake Forest University School of Medicine to build on the success of their previous collaboration, the *Dementia Care and Respite Services Program* (1986–1994). That program demonstrated that adult day centers could provide needed services for a wide range of people with dementia, while remaining financially viable. The national program office was located at Wake University under the directorship of Burton V. Reifler, MD, MPH.

To extend the work of the demonstration program, 50 sites were funded nationwide to address three questions:

- Could the lessons learned be applied at adult day centers more quickly and economically, and with similar success?

- Was the adult day center model appropriate for people with other chronic disabling conditions, such as multiple sclerosis?

- Could the same results be achieved through technical assistance only or was funding a requisite to the success of an individual adult day center?

To address the last question, the 50 program sites were split into two groups; 25 sites received funding (typically under $100,000) and limited technical assistance, and the other 25 sites received a broad spectrum of technical assistance, with little or no direct RWJF funding.

Dementia is the loss of intellectual abilities, such as thinking, remembering, and reasoning to such a severe degree that it interferes with a person's ability to function on a daily basis. Dementia itself is not a disease, but describes a group of symptoms. The most common disease resulting in dementia is Alzheimer disease, which affects approximately 4 million American adults. Alzheimer progressively destroys one's memory, judgment, and ability to communicate, often with profound changes in personality, mood, and behavior, eventually resulting in the inability to care for oneself.

Since most people who suffer from a chronic, debilitating illness prefer to remain in their own home or in the home of a family member or friend, adult day centers offer a positive alternative to nursing homes. Adult day care provides a structured, comprehensive program in a protective setting that allow chronically ill people to continue living at home or with their family by providing services during business hours, when many family members are unable to look after their loved ones. There are two forms of this kind of service, the medical model and the social model. Adult day care sites in the *Partners in Caregiving* program were based on the social model.

Financing is a problem for adult day centers since they must piece together federal, state, and local funds from a variety of sources including Medicaid, social service block grants, the Older Americans Act, local Veterans Affairs (VA) medical centers, the Department of Agriculture's food reimbursement program, state general fund dollars, and philanthropies. Adult day centers cannot receive funds from Medicaid, Medicare, or the VA if medical services are not provided. Even if medical services are provided, Medicaid and VA funds are not available in all states. Increasingly, private insurance policies are covering home-based and community-based care, but this remains an extremely small source of revenues. The final source of revenue is through individual payment from participants or their families.

In this program, many different service models were developed. Some centers served a variety of people, such as the cognitively impaired and the physically challenged and developed separate programs to run under one roof. Other sites integrated people with different conditions, such as people with Alzheimer disease or other form of dementia, mental retardation, chronic mental illness, and the frail elderly into one program. Some sites served a single population, such as those with early-stage Alzheimer disease or individuals with multiple sclerosis. The program funded or provided technical assistance to adult day centers in a variety of sizes and settings, and

included nursing homes, hospitals, mental health facilities, and free-standing adult day care centers. Some of the centers were large and served upward of 80 people a day while others were small and limited their capacity to 15–20 people a day.

To test whether programs could improve and sustain operations under different financial conditions, some sites received smaller grants (up to $100,000 for expansion sites and up to $250,000 for start-up centers) for periods of two or three years. To encourage sustainability, each $2 of Foundation funds had to be matched by $1 in local funds. While all sites applied for grants, only half of the 50 participating sites received funds. The funded sites also received limited technical assistance from the national program office in the form of site visits and annual program meetings. The other 25 sites received no funding, but were provided with intensive technical assistance in addition to site visits and annual program meetings, which included special training workshops and resource materials, consultant services, visits to model day centers, access to a toll-free help line at the national program office, and hands-on assistance.

Results: This program showed that the lessons learned under the demonstration program could be applied swiftly and effectively. Adult day centers were shown to effectively serve people with other chronic conditions. Technical assistance was found to be just as effective as funding in helping adult day centers replicate models of care, and become financially viable at the same time. Improvements were seen in revenue-gathering and financial performance. Sites extended hours so they were open from 8 a.m. to 6 p.m., allowing more working families to use their services for their elderly relative; they also began offering services such as shampoos or pedicures on a fee basis. At the end of the *Partners in Caregiving Program*, sites were meeting an average of 83 percent of their cash expenses through net operating revenue.

State Initiatives in Financing Long-Term Care (1994–1998)

This program promoted the development of state reform of long-term-care financing and delivery systems and development of strategies to broaden access to long-term-care coverage. While authorized for $3.6 million, funding totaled $917, 019 for five planning sites.

GROUP 2 (CLOSELY RELATED)

Interfaith Volunteer Caregivers Program/Faith in Action (1984–current)

More than 1,700 projects across the country received small grants to support interfaith volunteer caregiving through two national programs. The projects brought together coalitions of religious congregations, and social service and other organizations to engage and organize volunteers to provide services to people in need, especially those who were frail, elderly, and homebound. The program was divided into these phases, the *Interfaith Volunteer Caregivers Program* (the demonstration), the replication, and *Faith in Action* (the attempt to take it to national scale).

The demonstration sought to test the idea that interfaith coalitions could mobilize and organize volunteers to provide services such as visiting, transportation, help with light housekeeping, and other services to people in need. An evaluation found that, despite some difficulties in sustaining activities at some sites, these programs have helped hundreds of thousands of people.

Coming Home: Affordable Assisted Living (1992–2007)

This program was created in partnership with NCB Capital Impact (formerly NCB Development Corp.) to develop affordable assisted-living models, with a focus on smaller, rural communities, and low-income seniors. Affordable assisted living typically refers to licensed residential projects that provide apartment-style housing, together with supportive services to older residents, such as help with personal care, meals, housekeeping, and medication management. At least 25 percent of the seniors living in this housing are financially eligible for state Medicaid programs. This program demonstrated that assisted living can be created as a viable alternative to institutional long-term care for people with low incomes. As of September 2008, there were 50 completed projects with 1,909 units of affordable assisted living located in 13 states.

Statewide System of Care for Chronically Ill Elderly in Massachusetts (1993–1996)

This program was modeled on the PACE program and included six sites in Massachusetts. The Program of All-Inclusive Care for the Elderly (PACE) was developed in the early 1970s by On Lok Senior Health Services in San Francisco. The PACE model is characterized by a focus on the significantly impaired, frail elderly, team-managed care that integrates a comprehensive package of acute and long-term health services in both inpatient and outpatient settings, and capitated financing from Medicare and Medicaid. This model provides team-managed care that integrates acute and long-term health services in both inpatient and outpatient settings for seriously impaired elderly people. The six sites in Massachusetts were under the state's Elder Service Plans. These plans provide comprehensive medical and social services to frail elders so that they can live in their communities instead of in nursing homes. A team of health professionals does an assessment of each elder's needs, and develops a plan of total care. Services are usually provided in an adult day health center, but may be given in the elder's home or other facility.

Home Care Research Initiative (1994–2002)

This program supported primary research projects to improve knowledge about home care health policy and practice. Home and community-based services—which range from skilled nursing and physical therapy to help with daily activities such as bathing and dressing—are vital to many people with chronic illness or disability. By 1995, these services had become the fastest-growing component of U.S. health care spending, and demand for home care was increasing while, financial and political forces were pushing for spending cuts. This program substantially contributed to current knowledge about spending on home and community-based services and options for expanding managed long-term care and assisted living. The program funded research projects that helped to address gaps in knowledge, synthesized existing research, and developed consensus on home and community-based service goals and successes. It advanced new concepts and paradigms by commissioning 26 papers (20 of which were completed) to inform policy-makers, practitioners, and researchers. Program staff worked with policy-makers and long-term-care opinion leaders to identify relevant long-term-care research issues, and understand how to communicate research results in ways that are responsive to their needs. As a result, state policy-makers increased their awareness of the value and importance of research.

Better Jobs Better Care: Building a Strong Long-Term-Care Workforce (2002–2009)

In partnership with the Atlantic Philanthropies, *Better Jobs Better Care* was a research and demonstration program that aimed to reduce vacancy and turnover rates among nursing assistants, home health aides, and personal care attendants who provide direct care; and to improve the quality of care provided to older adults by supporting changes in long-term-care policy and provider practices. The program tested new approaches to providing a more stable and qualified long-term-care staff through demonstration grants to coalitions in five states and applied research grants to eight teams across the country. This program was built around two simple but powerful concepts; quality long-term care depends on the availability of a stable, competent, and committed workforce; unless employers can offer direct-care workers improved working conditions, better training, and quality jobs, the epidemic of high turnover and vacancy rates will continue. The finding of an evaluation suggested that the program did not meet its goals, that there was no evidence that the implemented changes improved the workers' jobs. Surveys conducted at the beginning and end of the program showed job satisfaction declined slightly, while likelihood of leaving the job increased slightly.

Green House Initiative (2002 to present)

This program, which began in 2002, supported a group home alternative to the traditional nursing home. Instead of a large facility with many elderly residents, a Green House has only 6–10 residents; each individual has a private bedroom and bathroom; each home has a central area for cooking, eating, and gathering. In this environment, nursing assistants play a much broader role in the care of patients. Green Houses are designed to return control, dignity, and a sense of well-being to the residents and care staff.

The national program that developed from the pilot project is run by NCB Capital Impact, which ran the *Coming Home* program. The program's goal is to:

- Increase the Green House adoption rates from 25 homes per year to 125 through intensive financing, marketing, and policy activities

- Develop a series of program evaluations

- Use the Green House Initiative as the catalyst for transforming institutional care at skilled nursing homes

Supportive Services Program for Older Persons (1985–1993)

The goal of this program was to promote the expansion of nontraditional health and health-related services to the elderly, and to demonstrate that a private market for such services could be developed. The basis for the program was knowledge that many seniors have service needs that were being neglected and were critical for independent living at home, such as housekeeping, shopping, and respite care. The program was intended to provide four-year start-up funding grants to nonprofit home health agencies to develop and market that broader range of services and to demonstrate new methods of organizing and financing them. By the end of the demonstration, it was clear to the directors, evaluators, and RWJF staff that the program had not met the original expectations. Important lessons were learned, including that these kinds of services need a large volume of customers to support administration, and supervision to ensure quality service.

Supportive Services Program in Senior Housing (1988–1995)

This program was an outgrowth of the *Supportive Services Program for Older Persons*, and had the same general objective of improving services to allow seniors to remain living independently in their community. This program differed in that it was directed at subsidized housing projects. Three-year grants were awarded in November 1988 to l0 state housing finance agencies. The program was seen by housing owners and managers as being beneficial in the long run since by improving functional status and health, tenant turnover and the associated costs were reduced and management–resident relationships were improved. Service coordination was seen as a key element and was strongly consumer-oriented. Working closely with resident groups ensured that the available services were what the residents really wanted.

Life-Care-at-Home Communities Demonstration (1987–1994)

This program was designed to study the financial planning of continuing care retirement communities (CCRC's), particularly regarding health care services. CCRC's had been instituted in a number of areas around the country and were viewed as an important innovation in providing support and necessary services to allow seniors to continue living independently. It became immediately apparent, however, that CCRC's were only an affordable option for wealthy people due to the sizable entry fees and monthly payments. Therefore, the major purpose of the program was to make CCRC's more affordable for seniors primarily by eliminating the necessity for large capital outlays for building new housing and service facilities, which were the basis for the large CCRC entry fees. To lower costs further, the community-based concept would have the capacity for a much larger enrollment, thus expanding liability to a much larger population base.

No Place Like Home: Providing Supportive Services in Senior Housing (1992–1996)

This program sought to develop innovative approaches to financing and delivering supportive services to older people who live in private, publicly subsidized housing for elderly. It provided small grants to 11 sites. Total funding was $174,444.

GROUP 3 (DISTANTLY RELATED)

Social Health Maintenance Organization (1983–1986)

This program sought to simultaneously reduce costs and improve the quality of care for the elderly by combining the services of the fragmented health and long-term-care systems into a single social HMO entity. It was authorized at up to $1 million, but only one site was funded at $389,520.

THEME VI: DISABILITIES

GROUP 1 (DEFINITELY RELATED)

Improving Service Systems for People with Disabilities (1989–1998)

This program sought to strengthen the capacity of community-based agencies run by and for people with physical disabilities to create comprehensive systems of services for this population. The program was the largest single commitment of private funds ever provided to benefit people with disabilities. It was managed by Lex Frieden at the Institute for Rehabilitation and Research and funded 12 sites in 10 states with planning grants: Ability Center of Greater Toledo (Ohio), Ability Resources (Okla.), Adaptive Living Program for Handicapped Americans (Maine), Ann Arbor Center for Independent Living (Mich.), Atlantis Community (Colo.), Center for Independence of the Disabled in New York, Center for Living & Working (Mass.), Montana Independent Living Program, Resources for Independent Living (Calif.), Southeastern Minnesota Center for Independent Living, Summit Independent Living Center (Mont.), and Stavros Center for Independent Living (Mass). All but Resources for Independent Living received implementation grants. The program was evaluated by A.E. Benjamin at the University of California, Los Angeles, David Geffen School of Medicine.

Funding Partnership for People with Disabilities (1990–1996)

RWJF agreed to participate with 18 other private grantmakers in funding this program with the goal of fostering the integration of people with disabilities into all aspects of American life. The Dole Foundation for Employment of People with Disabilities was the lead funding partner and directed the program. The Foundation funded proposals in the $25,000 to $50,000 range, not to exceed a total of $200,000 for efforts to address the health and related supportive service needs of this population group. Each applicant had to represent a collaboration among consumer groups, service providers, educational and vocational institutions, and/or government agencies. Four sites received funding: Drexel University, Philadelphia; St. Joseph Rehabilitation Hospital and Outpatient Center, Albuquerque; Theda Clark Memorial Hospital, Neenah, Wis.; and Vermont Center for Independent Living, Montpelier, Vt.

Independent Choices: Enhancing Consumer Direction for People with Disabilities (1994–2002)

This program was designed to foster the development of consumer-directed home and community-based services for people of all ages with chronic disabilities. This program supported four research and nine demonstration projects, and was managed by the National Council on the Aging in Washington.

In 1995, approximately 17 percent of Americans had a disability, and 30 percent of these people needed some type of supportive services, such as assistance with bathing or walking. Advances in medical technology allow people to live longer and as they age, their needs increase, as do the expenditures for long-term-care services, including those paid for by Medicaid. In response, state and federal policy-makers began to seek ways to meet the increasing demand for these services, and began to look at the concept of "consumer-directed health care," as one strategy to more efficiently distribute these limited resources, and to see if this strategy could improve the lives of a greater number of individuals with disabilities. Consumer-directed health

care requires consumers to be informed in order to assess their own health care needs, determine how and by whom their needs will be met, and monitor the quality of services they receive.

This program supported both demonstration and research projects. The demonstration projects applied and tested new approaches to providing consumer-directed services. These projects ranged from introducing consumer choice in Ohio's Medicaid waiver program for older adults to developing and implementing a "rapid response" program to address unmet service needs of home care clients in Alameda County, Calif. The research projects were chosen to expand knowledge about what consumers prefer in managing their own health and personal services and whether different groups of consumers have different preferences. These projects ranged from exploring how cognitively impaired adults and their caregivers in New York City and the San Francisco Bay area make decisions about services to examining the role of racial and ethnic group preferences among older Boston residents in consumer-directed services.

Results: The demonstration projects showed that tangible progress was made at the state level in planning for and designing options for older users of personal assistance services, such as personal care (help with activities of daily living such as eating, dressing and toileting) and homemaker or chore services. The program designed and implemented an emergency back-up service, which offered emergency and short-notice personal assistance services (e.g., help with meal preparation, toileting, bathing and grooming, and light housekeeping). Training materials were also developed for staff and consumers of a consumer direction program in Minnesota.

The research projects studied consumer direction for older people with Alzheimer disease and older people living in assisted living and nursing homes. They showed that it is possible to make professional judgments in line with consumer preferences based on the consumer's perspectives on care preference. Research also showed that addressing consumer preferences may have important implications for the quality of care and satisfaction with care. The research compared outcomes for physically and cognitively impaired people in a consumer-driven personal assistance program to those of people receiving agency-directed services.

The program had three key outcomes. First, the program was generally successful in achieving its goals. It stimulated innovative activity in the field and attempted to tackle important issues in a serious and focused way. Second, the program partially contributed to bringing the concept of consumer direction in the field of aging into the mainstream consciousness. It also broadened the number of actors and sites where consumer-directed projects are being planned and implemented. Finally, it played a modest role in shifting attention from the ideology of consumer direction to the technical challenges of designing programs.

Self-Determination for Persons with Developmental Disabilities (1995–2001)

This program helped 18 states implement a more cost-effective system for serving persons with developmental disabilities while simultaneously giving those persons and their families more choice in determining the services they receive. The program sought to build on the principles of the Monadnock self-determination project (a program originally funded under RWJF's *Building Health Systems for People with Chronic Illnesses* program) by providing grants for similar self-determination efforts to state agencies that oversee the delivery of services to people with developmental disabilities.

In the mid-1990s, state programs serving individuals with developmental disabilities faced three serious problems: rapidly rising costs for services; insufficient resources to serve everyone who needed help; and fixed sets of services that gave individuals and their families little control over what, when, or how services were provided. The University of New Hampshire Institute on Disability served as the national program office, and managed the project selection process and provided technical assistance to the federal and state policy-makers.

The federal Administration on Developmental Disabilities estimated that in the mid-1990s, there were nearly 4 million Americans with developmental disabilities, which include severe, chronic disabilities attributable to mental or physical impairments that occur before age 22 and are likely to continue indefinitely. The vast majority of developmentally disabled people live with their families, who provide financial and other support. Those who cannot live with their families may become eligible for benefits under Medicaid. Although people with developmental disabilities made up less than 1 percent of those eligible for Medicaid, the cost of long-term care was approximately 10 percent of 1994's total Medicaid expenditures, and states spent an estimated $5 billion on other programs to serve this population.

Over the past decades, there has been a shift for people with developmental disabilities from living in large institutions to group homes. While states cover these costs, they also provide a variety of services and supports to people with developmental disabilities who live in the community, including case management, personal care services, homemaker/home health aide services, adult day care, transportation, and home and vehicle modifications. While the shift away from large institutions, and the wider use of Medicaid waivers, has led to greater flexibility in living arrangements and service delivery, three serious problems plagued developmental disability programs in the mid-1990s: 1) the rapidly rising cost of both medical care and other funded services was putting a severe strain on state Medicaid budgets, prompting governors and legislatures to look for cost savings; 2) while de-institutionalization and Medicaid waivers allowed states to serve more people, many states did not have the resources to meet the long-term-care needs of everyone who sought public help, and often had long waiting lists; 3) individuals with developmental disabilities (and their families) often had little control over where the disabled persons lived, which services they received, and who provided them. With the help of people with developmental disabilities and their families, states began to realize they had established community-based service delivery infrastructures that were costly and ineffective in providing support that helps people be as independent as possible.

Using the Monadnock project as a template, this program used four elements from that project, even though the implementation would be different in each state due to their own philosophies and infrastructures.

- The first element was person-centered planning, where individuals have a say in their service plan, are able to define their needs, learn about the services, providers, and options available, and receive assistance in planning the services and supports that answer those needs. The individual could designate family and friends, which was dubbed a "circle of support" to help in decision-making.

- The second element was to use independent support brokers instead of case workers. This provided independent professionals (brokers) who helped individuals and their families identify their needs, and find services and providers who could meet those needs.

- The third element was the individual budgets which were allocated from a pool of money that the individual could then use to pay for the services and supports he/she chose. The size of the individual budget was usually based either on what the individual had needed in the past or on what people with similar disabilities or needs generally received.

- The final element was the use of fiscal intermediaries, which could be designated to act as a business agent, purchasing services, managing wages, taxes, fringe benefits, as well as handling accounting and compliance with labor and tax regulations.

This program also established two main objectives for participating states. The first was regarding state policy reform and included changing quality assurance and financial monitoring requirements to be consistent with self-determination principles; enlisting legislative and executive branch support; redirecting the use of non-Medicaid funding to further program goals; and helping to identify necessary federal policy changes. The second objective was the implementation of pilot programs in at least two geographic areas in the state that would give developmentally disabled persons greater control over the services they receive.

Results: Two different evaluations were conducted. One evaluated the effect of the program on individuals and reported a shift in decision-making from professionals to individuals with disabilities, and improvement in some but not all quality-of-life indicators. The other evaluation examined institutional changes in the project states, and found that flexibility, a system-wide approach, and the availability of direct support workers were critical factors in the success of self-determination initiatives.

GROUP 2 (CLOSELY RELATED)

Cash & Counseling (1994–current)

This program conducted on-site research at sites that had implemented or experimented with a cash-and-counseling program or similar approach. In cash-and-counseling programs, the government provides regular cash allowances to disabled individuals as well as counseling about available services. The research concluded that the cash-and-counseling model can provide consumers and policy-makers options for long-term care and are worthy of greater experimentation in the United States.

Based on these findings, the program sought to expand this model of consumer-directed supportive services to more states, allowing thousands more older adults and people with disabilities to have choice and control over the care they receive. *Cash & Counseling* addresses the frustration of Medicaid consumers and their extended families with home care service, the inflexibility of Medicaid, unavailability of aide, and high turnover in their communities—and the resulting stress it creates. *Cash & Counseling* is a voluntary and market-based solution that helps the elderly population plan and budget the services they want and require. It counsels consumers with budget planning and paperwork; and program flexibility allows consumers to choose the services they really want (e.g., bathing, grooming, cooking, housekeeping). Most importantly, it gives elders the ability to hire their own personal care aids rather than be dependent on the social worker assigned to them. *Cash & Counseling* brings flexibility, choice, independence, and control of daily chores in the hands of elderly people, allowing them to transcend an often complicated and frustrating system.

GROUP 3 (DISTANTLY RELATED)

Dental Training for Care of the Handicapped (1979–1982)

This $4.7 million program sought to increase the number of community dentists prepared to care for the physically and mentally handicapped by training dentists with the appropriate skills and attitudes necessary to care for handicapped children and adults. It funded 16 sites around the country.

THEME VII: MEDICAID/MEDICARE

GROUP 1 (DEFINITELY RELATED)

No programs

GROUP 2 (CLOSELY RELATED)

Medicaid Managed Care Program (1995–2004)

This program helped state governments, health plans, and consumers improve their use of managed care. The program also promoted the delivery of high-quality health services for low-income persons and persons with special health care needs, and sought to take advantage of Medicaid's movement to managed care as a way to develop improvements in the way care had been delivered to this population. The Foundation's staff felt that managed care represented an opportunity to both reduce the cost and improve the quality of health services delivered to low-income Americans.

Results: Overall, the program reached large sectors of its intended audiences with products that were well regarded, and the program has led to concrete changes in the way some states and health plans deliver Medicaid managed care.

Medicare/Medicaid Integration Program (1997–2006)

This program helped states integrate or move toward integration of acute care and long-term care for low-income individuals who are eligible for both Medicare and Medicaid, and who are enrolled in Medicare and Medicaid managed care. These people are termed dual eligibles, and they have historically had many problems obtaining adequate health care in the fragmented U.S. health care system. The growth of managed care in the 1990s seemed to present an opportunity to provide integrated acute and long-term care to dual eligibles.

Results: Three approaches for managing the care of dual eligibles emerged during the program; full integration, partial integration, and managed fee-for-service. Staff of the program helped states integrate their Medicare and Medicaid data through advisory meetings with state project staffs, the use of consultants, a data users group, and two technical assistance reports on data collection, use and integration. The program also helped build support for Medicare/Medicaid integration among staff at the federal Centers for Medicare & Medicaid Services and in state governments.

GROUP 3 (DISTANTLY RELATED)

No programs

THEME VIII: MENTAL HEALTH

GROUP 1 (DEFINITELY RELATED)

Program on Chronic Mental Illness (1984–1994)

This program promoted independent living for people with severe, and often disabling, chronic mental illness by establishing comprehensive, community-based systems of care and rehabilitation, including expanded housing options. The program was designed to demonstrate the benefits of centralizing responsibility and authority for the care and treatment of adults with severe mental illness. The complex problems of this population demand a wide array of services from both the mental health system, and the broader health and human services system. The program focused on systems integration through the creation of local mental health authorities, which were governmental and quasi-governmental entities designed to centralize administrative, fiscal, and clinical responsibility for adults with chronic mental illness. It was believed that these would reduce fragmentation, introduce a community support system, improve the continuity of care, and promote improved clinical and social outcomes for individuals and their families.

RWJF provided $29 million in grants and loans to nine cities in the United States: Austin, Texas; Baltimore; Charlotte, N.C.; Cincinnati, Columbus, and Toledo, Ohio; Denver; Honolulu; and Philadelphia. Additionally, the Department of Housing and Urban Development (HUD) provided each city with 125 Section 8 certificates to subsidize rents for individuals with severe and persistent mental illness so that they could afford safe housing. A national program office, run by Miles Shore and Martin Cohen at Harvard Medical School provided the grantees with technical assistance in setting up a local mental health authority and developing housing in their cities.

The local mental health authorities were often part of city or county government, or were sometimes private organizations with a board of directors appointed by a government agency. They mostly planned mental health care delivery at each site, allocated resources, and provided clinical oversight; however some also provided mental health services directly. Each authority also created a housing development agency to help create housing opportunities for clients using the Section 8 rent certificates from HUD. They assumed responsibility for the care of adults with mental illness, particularly for individuals with chronic mental illness, while maintaining accountability for integrating the system of care to promote continuity of care and meet the complex needs of the target population.

The *Program on Chronic Mental Illness* was a demonstration of systems change, and was not intended to provide specific clinical and social services. It was expected, however, that state-of-the-art mental health services would be available at each of the sites. The program operated under the logic that poor outcomes for those with severe mental illness were due to a lack of coordinated services. A better integrated system of care with a local mental health authority at the center, would lead to more continuity of care, to greater availability of care, and ultimately to better outcomes for people with severe mental illness and their families. This was the systems integration hypothesis that the *Program on Chronic Mental Illness* was designed to demonstrate.

Results: An evaluation of the program concluded that local mental health authorities were feasible and desirable structures for centralizing administrative, fiscal, and clinical responsibility in large cities. A problem was that the authorities were slow to be created and required technical

assistance, even more than financial resources, to establish and strengthen them. The authorities took many forms, adapting the basic concept to local conditions with positive results. The *Program on Chronic Mental Illness* demonstrated the feasibility and the utility of local mental health authorities in promoting the integration of service systems. The program also demonstrated that integration could have a positive impact on continuity of care, family burden, and housing status for individuals with severe mental illness.

Depression in Primary Care: Linking Clinical and System Strategies (1999–2006)

This program was designed to assist health care organizations in integrating elements of the Chronic Care Model into their practice in order to recognize and treat depression, as well as to develop financial incentives to support that use. The program was funded in response to a 1998 Foundation-funded study showing that most health care practices face financial and organizational barriers to screening and treating patients for depression. The national program office was located at the Department of Psychiatry at the University of Pittsburgh, directed by Harold Pincus, MD, who had done previous work on this issue.

When seeking treatment for depression, people often turn to their primary care providers, yet while effective models for recognizing and treating depression have been developed, depression still goes largely unrecognized and untreated by primary care providers. In 1998, a Foundation-funded study suggested that most primary care practices face several barriers to treating patients with depression. These barriers include: inadequate training of physicians; problems with the billing and organizational structure of the health care setting that inhibit coordinated care; lack of access to high-quality care; and lack of data on the costs and benefits of treating depression in primary care.

There were three elements to the *Depression in Primary Care* program; the first element attempted to re-align incentives by forming partnerships among health care practices, health plans, and purchasers, such as employers and academic institutions to test the feasibility and effectiveness of applying the Chronic Care Model to depression care, and to combine that with economic incentives and organizational systems to sustain that treatment. To accomplish this, the sites:

- Encouraged physicians to use a screening tool for depression with their patients, especially those at high risk for depression

- Chose evidence-based guidelines for treating depression

- Created training manuals for use by primary care providers in implementing the guidelines

- Hired care managers, or relied on existing employees, who provided care management services in a variety of formats (e.g., telephone calls, face-to-face meetings, email) to help patients and families better understand and manage their illness, and who also coordinated care between primary care providers and mental health specialists

- Developed mechanisms, such as a disease registry to track patients with depression, to ensure that they received the care they needed

- Provided booklets, videos and peer support groups, and suggested community resources, to help patients become more involved in their own care

- Developed approaches to overcome economic disincentives for implementing the clinical model among primary care groups, behavioral health clinical groups, health plans, and purchasers
- Tested specific mechanisms for enhancing reimbursement for elements of the Chronic Care Model
- Worked with health plans and other payers to analyze the costs and benefits of improving depression care, and to develop strategies for sustaining reimbursement for such care

The second element documented the clinical value and economic payoff of improving depression care for patients, health practices, health plans, and employers. Following a call for proposals, the program funded 26 research projects. In 12 of them, researchers evaluated models that combined clinical and economic strategies for treating depression in primary care settings, or assessed barriers to such care and devised strategies for overcoming them. Topics included finding and treating depressed students through school-based health centers, creating employer demand for improved depression care, and developing payment methods to reward physicians for high-quality depression care. In the remaining 14 projects, researchers evaluated the impact of policy changes designed to encourage the screening and treating of patients for depression in primary care settings. The researchers assessed the validity of systems that measured the quality of depression care, identified tactics by health plans that improved outcomes of depression care, and demonstrated the effect on employee productivity of a program that integrated primary care for employees with depression.

The third element developed the abilities of talented early-career primary care physicians to provide leadership in treating depression as a chronic illness. The program funded four leaders who worked with senior mentors, took courses to gain skills in research and evaluation, and pursued research projects with their mentors. Three out of four of the leaders received National Institutes of Health career development awards that have allowed them to continue their work in this area.

Results: Numerous primary care practices adopted the Chronic Care Model for treating depression. The model included screening for depression, providing resources to providers and patients, and creating chronic illness registries to track their progress. Some elements of economic models were integrated into the operations of several sites and other collaborations; however, the majority of sites were unable to sustain new payment methods to pay for such care.

This program helped to close the divide between physical and behavioral health among clinicians, health plans, employers, and researchers, and continues to provide researchers and policy-makers with important information that can be used to inform changes in policy and practice as it relates to better integration of behavioral health and primary care. A core message from this program was to eliminate duality of thinking between mental and general health, and between clinical and economic systems. The program also made major advances in providing an evidence base for doing that at a time when many states were debating insurance parity for mental and physical health.

GROUP 2 (CLOSELY RELATED)

Mental Health Services Development Program (1987–1991)

This program funded state and local initiatives designed to improve access to a broad range of health and community services for the chronically mentally ill. This program supported the development and implementation of 18 financing and service delivery demonstration projects at the state and local levels. Funded initiatives dealt with a variety of issues, such as systems change, substance abuse, housing, and vocational programs, among others.

Mental Health Services Program for Youth (and Replication) (1988–1998)

The original *Mental Health Services Program for Youth* was designed to demonstrate that through a collaborative effort between states and local communities, a more comprehensive, effective service system for seriously mentally ill youth could be developed. The youth who participated in the program were perhaps the most difficult and expensive population that state administrators and multiple service providers are responsible for serving. This program received $20.4 million over a six-year period, which was the largest single influx of money into the children's mental health system at that time. The program worked at the state level, to foster coordination of services between mental health and related child-serving agencies, and made major changes in the public financing systems. At the community level, it promoted interagency cooperation and the development of new mental health and related services for young people.

The replication of the program assisted states to use and apply an array of tools and techniques developed by the eight sites in the original program. Its goal was to help these states and communities better organize and finance a critical component of their health care system for young people with serious mental, emotional, and behavioral disorders and their families. The key components of the states' projects were: pooling public revenue into a single funding stream, often called blended funding; using capitation to manage the blended funding; and contracting with a care management entity to manage the funds and provide all treatment needed for the target population. The projects were judged to be cost-effective.

Caring Across Communities: Addressing Mental Health Needs of Diverse Children and Youth (2005–current)

This program attempted to bring school-connected mental health services to children of immigrants and refugees. Many refugees and their children suffer from post-traumatic stress disorder after having witnessed horrors unimaginable to most Americans. This is in addition to the difficulties of adjusting to life in a new country where one has little or no cultural ties. The goal of this three-year program was to develop different models and a variety of approaches, sharing information along the way. At the end of three years, the Foundation intended to apply the knowledge developed through the pilot program to promulgate best practices and to develop working programs in immigrant communities across the United States. After the first two years of the program, many of the 15 programs had already become established fixtures in the communities they served.

GROUP 3 (DISTANTLY RELATED)

National Demonstration of Early Detection, Intervention, and Prevention of Psychosis in Adolescents and Young Adults (2005–2010)

This $16.9 million program is replicating the Portland Identification and Early Referral (PIER) Program that uses evidence-based psychosocial and pharmacologic interventions in the early identification and treatment of adolescents and young adults with severe mental illness.

Disparities Depression Initiative (2004–2008)

This initiative supported the first of a three-phase effort to address racial and ethnic gaps in the treatment of depression.

THEME IX: OTHER

GROUP 1 (DEFINITELY RELATED)

No programs

GROUP 2 (CLOSELY RELATED)

Community Care Funding Partners Program (1981–1997)

This eight-year $7.15 million matching grants program was designed to encourage community and regional corporations and foundations to support small-scale local health centers serving the medically indigent. Twenty primary care centers were established under this effort in 10 states [Alaska, Delaware, Georgia, Illinois (4), Indiana (2), Michigan (2), Missouri (4), New York, Pennsylvania, and Texas (3)].

Community Partnerships for Older Adults (2000–2010)

This program sought to affect changes in long-term-care policy by promoting community partnerships among older adults and the private, voluntary, and public sectors. The program was designed to mobilize communities to work on long-term-care issues and to bring about improvement in the service system. In the longer term, the hope was that these initial activities would lead to changes in how people actually experienced the process of accessing and receiving services and would help to create improvements in the actual structure, scope, and quality of the long-term-care delivery system. The program was authorized to make up to $25 million available to approximately 35 grantee community partnerships over eight years.

Organizational Approach to Identifying and Improving Care for Patients with Low Literacy and Chronic Disease (2004–2008)

This program supported the design, implementation, and evaluation of an organizational approach to be used by the health care delivery system to improve their services for individuals with low health literacy and chronic disease. Health literacy includes the ability to understand instructions on prescription drug bottles, appointment slips, medical education brochures, doctor's directions and consent forms, and the ability to negotiate complex health care systems. Health literacy is not simply the ability to read. It requires a complex group of reading, listening, analytical, and decision-making skills, and the ability to apply these skills to health situations. Two grants, totaling $300,000, were funded in this program.

GROUP 3 (DISTANTLY RELATED)

The Foundation funded a diverse set of other national programs
that were distantly related to the chronic care priority:

Community Programs for Affordable Health Care (1980–1990)

Service Credit Banking Program for Elderly (1986–1991)

Local Funding Partnerships (1988–current)

Service Credit Banking in Managed Care (1992–1999)

Health of the Public: An Academic Challenge (1992–2000)

Old Disease, New Challenge: Tuberculosis in the 1990s (1993–1998)

Hablamos Juntos: Improving Patient-Provider Communication for Latinos (2000–2009)

Active Living Resource Center (2000–2010)

Dartmouth Atlas Project (2004–current)

Appendix 4

Classification Groups for National Programs

Chronic Care Group 1 (Definitely Related)

Advancing Diabetes Self-Management

Allies Against Asthma: A Program to Combine Clinical and
    Public Health Approaches to Chronic Illness

Building Community Supports for Diabetes Care

Building Health Systems for People with Chronic Illnesses

Chronic Care Initiatives in HMOs

Chronic Disease Care Program

Dementia Care and Respite Services Program

Depression in Primary Care: Linking Clinical and System Strategies

Funding Partnership for People with Disabilities

Hospital Initiatives in Long-Term Care

Improving Asthma Care for Children

Improving Chronic Illness Care

Improving Service Systems for People with Disabilities

Independent Choices: Enhancing Consumer Direction for
    People with Disabilities

Managing Pediatric Asthma: Emergency Department Demonstration Program

On Lok Approach to Care for the Elderly

Partners in Caregiving: The Dementia Services Program

Partnership for Solutions: Better Lives for People with Chronic Conditions

Program for the Health-Impaired Elderly

Program on Chronic Mental Illness

Program to Promote Long-Term Care Insurance for the Elderly

Self-Determination for Persons with Developmental Disabilities

State Initiatives in Long-Term Care

Chronic Care Group 2 (Closely Related)

Aligning Forces for Quality: The Regional Market Project

Better Jobs Better Care: Building a Strong Long-Term Care Workforce

Caring Across Communities: Addressing Mental Health Needs of
    Diverse Children and Youth

Cash & Counseling

Coming Home: Affordable Assisted Living

Community Care Funding Partners Program

Community Partnerships for Older Adults

Faith in Action

Faith in Action: Replication of The Interfaith Volunteer
    Caregivers Program

Green House Initiative

Home Care Research Initiative

Interfaith Volunteer Caregivers Program

Life-Care-At-Home Communities Demonstration

Medicaid Managed Care Program

Medicare/Medicaid Integration Program

Mental Health Services Development Program

Mental Health Services Program for Youth

Mental Health Services Program for Youth Replication

New Health Partnerships: Improving Care by Engaging Patients

No Place Like Home: Providing Supportive Services in Senior Housing

Organizational Approach to Identifying and Improving Care for
    Patients with Low Literacy and Chronic Disease

Pursuing Perfection: Raising the Bar for Health Care Performance

Replication of the Foundation's Programs on Mental Illness

Research and Demonstrations to Improve Long-Term and
    Ambulatory Care Quality

Research and Development Program to Improve Patient Functional Status

Statewide System of Care for Chronically Ill Elderly in Massachusetts

Supportive Services Program for Older Persons

Supportive Services Program in Senior Housing

Chronic Care Group 3 (Distantly Related)

Active Living Resource Center

AIDS Health Services Program

AIDS Prevention and Service Projects

Caring Connections: An initiative to promote and expand consumer engagement in end of life care

Center to Advance Palliative Care

Community Programs for Affordable Health Care

Community-State Partnerships to Improve End-of-Life Care

Dartmouth Atlas Project

Dental Training for Care of the Handicapped

Disparities Depression Initiative

Hablamos Juntos: Improving Patient-Provider Communication for Latinos

Health Care for the Homeless Program

Health of the Public: An Academic Challenge

Homeless Families Program

National Demonstration of Early Detection, Intervention and Prevention of Psychosis in Adolescents and Young Adults

Old Disease, New Challenge: Tuberculosis in the 1990s

Prescription for Health: Promoting Healthy Behaviors in Primary Care Research Networks

Program of Coordinated Care for Children with Communicative Disorders

Program on the Care of Critically Ill Hospitalized Adults (SUPPORT)

Promoting Excellence in End-of-Life Care

Rewarding Results: Aligning Incentives with High-Quality Health Care

Robert Wood Johnson Foundation Local Funding Partnerships

Service Credit Banking In Managed Care

Service Credit Banking Program for Elderly

Social Health Maintenance Organization

Strengthening the Consumer-Purchaser Disclosure Project to Ensure a Performance-Based Health Care System

Targeted End-of-Life Projects Initiative

Urban Hospital Program of Extended-Care Services

Vulnerable Populations Portfolio Teamwide Communications Support

Unrelated Programs

Access Project, The

Achieving Competence Today (ACT) Collaborative: Disseminating an Action-Based Interprofessional Curriculum that Incorporates Quality Improvement

Active for Life: Increasing Physical Activity Levels in Adults Age 50 and Older

Active Living by Design

Active Living Research

Addiction Prevention and Treatment Teamwide Communications Support

Addressing Tobacco in Health Care

Advancing Recovery: State/Provider Partnerships for Quality Addiction Care

Advantages of Decentralizing Teaching Hospital Management

After School: Connecting Children at Risk With Responsible Adults to Help Reduce Youth Substance Abuse and Other Health-Compromising Behaviors

All Kids Count: Establishing Immunization Monitoring and Follow-up Systems

Audience Research and Communications to Increase Public Awareness and Action for Tobacco Control

Bridging the Gap: Research Informing Practice and Policy for Healthy Youth Behavior

Building Advocacy for Policy Change to Improve the Nation's Health

Building the Evidence Base for Public Health Accreditation and Quality Improvement

Campaign to Reduce Youth Alcohol and Drug Use

Center for Health and Health Care in Schools, The

Changes in Health Care Financing and Organization

Child Nutrition Authorization

Childhood Obesity Teamwide Communications Support

Children's Futures: Improving Health and Development Outcomes for Children in Trenton, N.J

Clinical Nurse Scholars Program

Colleagues in Caring: Regional Collaboratives for Nursing Work Force Development

Common Ground: Transforming Public Health Information Systems

Communities Creating Healthy Environments: Improving Access to Healthy Foods and Safe Places to Play in Communities of Color

Communities in Charge: Financing and Delivering Health Care to the Uninsured

Community-Based Childhood Obesity Prevention Within the Injury Free Coalition for Kids Initiative Sites

Community-Based Radio Initiative

Community Health Assessment and Improvement Plans for Public Health Accreditation

Community Hospital-Medical Staff Group Practices

Consolidate Health Services for High-Risk Young People

Consumer Voices for Coverage: Strengthening State Advocacy Networks to Expand Health Coverage

Convergence Partnership for Healthy Eating and Active Living

Core Support and Infrastructure Development for the American Nonsmokers' Rights Foundation

Coverage Teamwide Communications Support

Covering Kids & Families

Covering Kids: A National Health Access Initiative for Low-Income, Uninsured Children

Creating a Center of Excellence to Improve Data Gathering and Study to Strengthen the Evidence Base, Performance and Impact of State Public Health

Cutting Back: Managed Care Screening and Brief Intervention for Risky Drinking

Demonstration and Research on Health Care Costs

Dental Services for High-Risk Children

Dental Services Research Scholars Program

Dental Student Aid Program

Developing a Program to Improve Cooperation Among Federal, State and Local Leaders When Responding to Natural and Man-Made Disasters

Developing a Resource Center for Quality Improvement of Public Health System Functions

Unrelated Programs (cont'd)

Developing Leadership in Reducing Substance Abuse

Developing Local Infant Mortality Review Committees

Developing Payment-Reform Strategies for High-Value Care

Disparities Teamwide Communications Support

Documenting Quality: Two Film Products

Emergency Medical Response Program

Enabling Consumers, Employers, and Public Payers to Make Informed Decisions About the Purchase and Management of Health Care Benefits

Engaging Leaders in Advocacy for Public Health System Improvement Through Accreditation and Quality Improvement

Establishing a National Public Health Accrediting Organization

Evaluating Innovations in Nursing Education

Evaluating Quality Improvement Training Programs

Expecting Success: Excellence in Cardiac Care

Faculty Fellowships in Health Care Finance

Family Friends: A Program to Enable Older Volunteers to Assist Disabled Children and Their Families

Family Practice Faculty Fellowships Program

Family Support Services Program

Fighting Back: Community Initiatives to Reduce Demand for Illegal Drugs and Alcohol

Finding Answers: Disparities Research for Change

Free To Grow: Head Start Partnerships to Promote Substance-Free Communities

General Pediatric Academic Development Program

Generalist Physician Faculty Scholars Program

Generalist Physician Initiative

Generalist Provider Research Initiative

Guaranteed Student Loan Program for Medical, Dental, and Osteopathic Students

Haiti Relief Efforts

Harold Amos Medical Faculty Development Program

Health Care Costs: Research and Analysis

Health Care for the Uninsured Program

Health e-Technologies: Building the Science of eHealth

Health Games Research: Advancing effectiveness of interactive games for health

Health Impact Assessment Portfolio

Health Policy Partnerships in Diversity

Health Professions Partnership Initiative

Health Tracking

Healthy Eating by Design

Healthy Eating Research: Building Evidence to Prevent Childhood Obesity

Healthy Futures: A Program to Improve Maternal and Infant Care in the South

Healthy Kids, Healthy Communities: Supporting Community Action to Prevent Childhood Obesity

Healthy Kids Replication Program

Healthy Nations: Reducing Substance Abuse Among Native Americans

Healthy Weight Commitment Evaluation

Helping Young Smokers Quit: Identifying Best Practices for Tobacco Cessation

Hospital-Based Rural Health Care Program

Hospital-Sponsored Ambulatory Dental Services Program

Human Capital Diversity Program

Human Capital Teamwide Communications Support

IMPACS: Improving Malpractice Prevention and Compensation Systems

Improving Child Health Services: Removing Categorical Barriers to Care

Improving the Health of Native Americans

Improving the Quality of Hospital Care

Improving the Science of Continuous Quality Improvement Program and Evaluation

Infant Health and Development Program

Infant Health and Development Program Replication

Information for Action: School Policies to Prevent Childhood Obesity

Information for State Health Policy

InformationLinks: Connecting Public Health with Health Information Exchanges

Injury Free Coalition for Kids: Dissemination of a Model Injury Prevention Program for Children and Adolescents

Innovators Combating Substance Abuse

Interdisciplinary Nursing Quality Research Initiative

Intergenerational Programming within the Active for Life Program Sites to Reduce Childhood Obesity

Investigator Awards in Health Policy Research

Jobs to Careers: Promoting Work-Based Learning for Quality Care

Ladder to Leadership: Developing the Next Generation of Community Health Leaders

Ladders in Nursing Careers Program

Lead States in Public Health Quality Improvement

Leadership for Healthy Communities: Advancing Policies to Support Healthy Eating and Active Living

Leading Change: Disparities Solutions Initiative

Legal and Ethical Problems in the Care of the Critically Ill

Legis 50

Living Cities: The National Community Development Initiative

Making the Grade: State and Local Partnerships to Establish School-Based Health Centers

A Matter of Degree: Reducing High-Risk Drinking Among College Students

Maximizing Enrollment: Transforming State Health Coverage

Medicaid Leadership Institute

Medical Malpractice Program

Medical Student Aid Program

Medical Student Aid Supplement

Mobilizing Action Toward Community Health

Multistate Initiative to Help Build a Health Information Infrastructure

Municipal Health Services Program

National Center for Tobacco-Free Kids

National Expansion of Playworks: A Program that Promotes Physical Activity and Play at School—2008–12

Unrelated Programs (cont'd)

National Health Care Purchasing Institute

National Policy and Legal Analysis Network to Prevent Childhood Obesity

National Preventive Dentistry Demonstration Program

National Program for Public Health Research

National Quality Forum

National Tobacco Control Technical Assistance Consortium

New Connections: Increasing Diversity of RWJF Programming

New Jersey Grants Program

New Jersey Health Initiatives

New Jersey Nursing Initiative: So a Nurse Will Be There for You

New Jersey Partnership for Healthy Kids: Communities Making
    a Difference to Prevent Childhood Obesity

New Jersey Walks and Bikes

New Routes to Community Health

Nurse Faculty Fellowship Program

Nurse-Family Partnership

Nursing Services Manpower Development Program

Nursing Teamwide Communications Support

Obesity Prevention in Children: Synergy with Diabetes Initiative

Office of Health Statistics and Analysis

Opening Doors: A Program to Reduce Sociocultural Barriers to Health Care

Partners Investing in Nursing's Future

Partners with Tobacco Use Research Centers: Advancing
    Transdisciplinary Science and Policy Studies

Partnership for a Healthier America

Partnerships for Quality Education

Partnerships for Training: Regional Education Systems for Nurse
    Practitioners, Certified Nurse-Midwives, and Physician Assistants

Paths to Recovery: Changing the Process of Care for Substance
    Abuse Programs

Physician Program to Improve and Control Costs

Pilot Program of Research to Integrate Substance Abuse Issues into
    Mainstream Medicine

Pilot Replication in New York City of the Free to Grow Program

Pioneer Portfolio Teamwide Communications Support

Pioneer Special Solicitation

Pipeline, Profession and Practice: Community-Based Dental Education

Policy Advocacy on Tobacco and Health: An Initiative to Build Capacity in
    Communities of Color for Tobacco Policy Change

Practice Sights: State Primary Care Development Strategies

Preparing Physicians for the Future: A Program in Medical Education

Preprofessional Minority Programs

Preventing Partner Violence in Immigrant Communities:
    Strengthening What Works

Prevention of Hospital Falls

Primary Care Practice Loan Guarantee Program

Primary Care Residency Program

Primary Care Training for Emergency Nurses

Private-Sector Initiative on Health Promotion

Program for Enhancing Hospital Care for the Elderly

Program for Prepaid Managed Health Care

Program to Address Sociocultural Barriers to Health Care in
    Hispanic Communities

Program to Improve Maternal and Infant Health in New Jersey

Program to Strengthen Primary Care Health Centers

Project HealthDesign: Rethinking the Power and Potential of
    Personal Health Records

Providing Assistance to Public Health Agencies Preparing for Accreditation

Public Health Informatics Fellows Training Program

Public Health Informatics Institute

Public Health Law Field-Building

Public Health Law Research: Making the Case for Laws That
    Improve Health

Public Health Pipeline: The Future Generation of Public Health Professionals

Public Health Services and Systems Research

Public Health Teamwide Communications Support

Quality/Equality Team Consumer Engagement Strategy

Quality/Equality Teamwide Communications Support

Reach Out: Physicians' Initiative to Expand Care to
    Underserved Americans

Reclaiming Futures: Communities Helping Teens Overcome Drugs,
    Alcohol and Crime

Reducing Underage Drinking Through Community and State Coalitions

Regionalized Perinatal Care Program

Research and Evaluation General Program Support

Research Initiative on Health Insurance

Research Network on the Etiology of Tobacco Dependence

Resources for Recovery: State Practices that Expand
    Treatment Opportunities

Response to Economic Hard Times

Robert Wood Johnson Foundation Alumni Network

Robert Wood Johnson Foundation Center for Health Policy at Meharry

Robert Wood Johnson Foundation Center to Prevent Childhood Obesity

Robert Wood Johnson Foundation Clinical Scholars Program

Robert Wood Johnson Foundation Commission to Build a Healthier America

Robert Wood Johnson Foundation Community Health Leaders

Robert Wood Johnson Foundation Executive Nurse Fellows

Robert Wood Johnson Foundation Health & Society Scholars

Robert Wood Johnson Foundation Health Policy Fellows

Robert Wood Johnson Foundation Initiative on the Future of Nursing

Robert Wood Johnson Foundation New Careers in Nursing

Robert Wood Johnson Foundation Nurse Faculty Scholars

Robert Wood Johnson Foundation Physician Faculty Scholars

Robert Wood Johnson Foundation Practice-Based Research
    Network in Public Health

Robert Wood Johnson Foundation Scholars in Health Policy Research

Rural Health Networks: A Strategy for Improving Rural Delivery Systems

Rural Hospital Program of Extended-Care Services

Rural Infant Care Program

Unrelated Programs (cont'd)

Rural Practice Project

Salud America! The RWJF Research Network to Prevent Obesity Among Latino Children

School-Based Adolescent Health Care Program

School Health Services Program

Secondary Analysis of Foundation Data

Shreveport-Bossier Community Renewal Project

Small Supplements for Select Closing Grants

Smoke-Free Families: Innovations to Stop Smoking During and Beyond Pregnancy

Smoke-Free New Jersey

SmokeLess States: National Tobacco Policy Initiative

Smoking Cessation Leadership Center

Sound Partners for Community Health

Southern Rural Access Program

Speaking Together: National Language Services Network

Start Strong: Building Healthy Teen Relationships

State Action for Oral Health Access

State Coverage Initiatives

State Forums Partnership Program

State Health Access Reform Evaluation

State Health Leadership Initiative

State Solutions: An Initiative to Improve Enrollment in Medicare Savings Programs

Statewide Evaluations of Childhood Obesity Prevention Policies

Strategy for the Quality Alliance Steering Committee

Strengthening Hospital Nursing: A Program to Improve Patient Care

Strengthening the Patient-Provider Relationship in a Changing Health Care Environment

Substance Abuse Policy Research Program

Summer Medical and Dental Education Program

Supplemental Service Grant Support Program

Supporting Advocacy to Reduce Tobacco Use and Direct Tobacco-Related State Revenue to Health Priorities

Supporting Families After Welfare Reform: Access to Medicaid, SCHIP and Food Stamps

Supporting Regional Response Team Learning Networks

Targeted Quality Solicitation of Regional Technical Assessment

Targeted Quality Solicitation on Equity and Patient-Centeredness

Targeted Research for Coverage

Targeted Research to Inform the Quality Team's Consumer Demand Strategy

Targeted Solicitation on Quality Improvement and Performance Measurement

Teaching Hospital General Medicine Group Practice

Teaching Nursing Home Program

Tobacco Policy Change: A Collaborative for Healthier Communities and States

Tobacco Policy Research and Evaluation Program

Tobacco Reallocation Dollars

Tobacco Teamwide Communications Support

Transforming Care at the Bedside

Transforming Hospital Culture

Tsunami Long-Term Relief Efforts

Turning Point: Collaborating for a New Century in Public Health

Urban Health Initiative: Working to Ensure the Health and Safety of Children

Urban Health Program

Urgent Matters

Vote and Vaccinate: A Community-Based Strategy to Promote Adult Immunization

Wisdom at Work: Retaining Experienced Nurses

Workers' Compensation Health Initiative

Young Epidemiology Scholars (YES) Program: A National Effort to Attract the Attention of Young Scholars to the Health of the Public

Robert Wood Johnson Foundation

Endnotes

1 *www.rwjf.org/files/research/72051.tobaccocampaigns.050311.pdf*

2 *www.rwjf.org/files/research/71944.eol.final.30311.pdf*

3 The Breakthrough Series Collaborative was created by Don Berwick, MD, and his team at the Institute for Healthcare Improvement (IHI) in Cambridge, Mass. The collaborative is a short-term (six- to 15-month) learning system that brings together a large number of teams from hospitals or clinics to seek improvement in a focused topic area.

4 Coleman K, Austin BT, Brach C and Wagner EH. "Evidence on the Chronic Care Model in the New Millennium." *Health Affairs*, 28: 175–185, 2009.

5 Final Narrative Report to RWJF, ID# 016973, the second Technical Assistance and Direction Grant for the program.