



Building Health Systems for People with Chronic Illnesses

An RWJF national program

SUMMARY

From 1992 through 2002, the Robert Wood Johnson Foundation (RWJF) funded *Building Health Systems for People With Chronic Illnesses*. It is a national program that encompassed a broad range of initiatives covering the full spectrum of medical, mental health and supportive service needs of people with disabilities and chronic health conditions.

RWJF designed Building Health Systems to address deficiencies in the nation's system to treat and serve individuals with chronic physical or mental impairment—some 99 million Americans at the time. These deficiencies—administrative, institutional, professional and financial—resulted in a system of care that was often fragmented, unresponsive, inappropriate, lacking in consumer choice and based in institutions, rather than occurring at home or in the community.

These barriers contributed significantly to the high cost of care for chronically ill people—estimated when the program began at \$470 billion annually—representing an enormous part of the nation's total health care expenditure.

Key Results

In general, the program director believed that by supporting projects that strove to integrate care delivery and financing, Building Health Systems advanced the movement away from an acute-care focus within the health care system and toward a social health model of care for people with chronic conditions.

More specifically, the program created the following:

- A self-determination model for people with developmental disabilities, which was replicated by RWJF in a national program, *Self-Determination for Persons With Developmental Disabilities*. (See the [Program Results](#).)
- Models of care that integrated medical, social and long-term care services, along with their respective funding streams, for elders and people with disabilities.

- Models of care for children with special health care needs and their families that move care to the community provider level and offer a range of family supports.
- Models that integrate affordable permanent housing with health care, mental health care and addiction services, all of which are available onsite to tenants—including the formerly homeless, the frail elderly and people with disabilities.
- Projects aimed at overcoming barriers to employment for people with disabilities.

The Program

The RWJF Board of Trustees originally authorized the program in 1992 for up to \$15 million. (Financial readjustments at RWJF in 1995 caused a \$2 million reduction in the authorization.) To oversee the projects, RWJF established the Building Health Systems national program office at the Genesee Hospital in Rochester, N.Y.

In 1995, RWJF decided to transfer the program funds to the Center for Health Care Strategies in Princeton, N.J., which then became the national program office. (At the time, the Center for Health Care Strategies was also managing the *Medicaid Managed Care Program for RWJF*; the Building Health Systems move was intended to capitalize on the potential for synergy between the two programs.)

Thirty-two projects received a total of \$14,454,287 in funding over five funding rounds. Building Health Systems encouraged a broad range of ideas and interventions to overcome the fragmentation, financing barriers and episodic care that characterized existing systems of chronic care. All of the grants targeted one or more of these population groups:

- People with physical or developmental disabilities.
- People with severe, persistent mental illness.
- Children with special health care needs.
- Frail, elderly individuals.

Key Lessons Learned

In 2005, Lindsay Palmer and Stephen Somers of the Center for Health Care Strategies conducted a review of the program with funding from RWJF for managing the program. Palmer and Somers focused on five projects that yielded especially useful lessons for future philanthropic and policy investments. The report, *Integrating Long-Term Care*, is available [online](#).

The **Lessons Learned** section of this report provides greater detail. The report highlighted seven lessons:

1. Persevere when trying to get buy-in and cooperation from government agencies, despite the amount of time and patience required.
2. Stay with the slow and onerous processes of setting payment rates and integrating funding streams because accomplishing these can make dramatic differences in the quality and coordination of care.
3. Develop a quality assurance/improvement process during the design phase to protect, maintain, and improve consumer health outcomes and satisfaction.
4. Integrate social services with medical care to help increase consumers' motivation for maintaining better health.
5. Integrate behavioral health services into programs of acute and long-term care because people with chronic physical or mental impairments are at higher risk of behavioral health problems.
6. Form an interdisciplinary team of medical and social service professionals to improve the coordination of care for frail elders, reduce fragmentation of services, improve overall quality of life, and enable more clients to remain in their communities.
7. Facilitate consumer choice and self-determination to improve the quality of life for the chronically ill and frail elderly, and to achieve higher quality health care.

THE PROBLEM

In the early 1990s, approximately 99 million Americans had some sort of chronic physical or mental impairment, according to data collected by the Center for Health Care Strategies at the time. Of this population, an estimated 41 million were limited in their daily activities and 12 million were unable to live independently. The center predicted that by 2020 the number of Americans with chronic illness would increase to 134 million.

The deficiencies of the nation's medical and supportive service system had serious consequences for the health and well being of this population.

- Persons with a chronic health condition often find themselves negotiating a bureaucratic maze of fragmented and unresponsive services.
- They frequently shuttle back and forth between acute and long-term care settings.
- In the former, the acute interventions often have to be modified to take into account the patients' chronic conditions; in the latter, patients are isolated from home and community.

- The divisions between acute and long-term care are reinforced by professional and institutional boundaries.
- Financing typically originates from separate sources that are difficult to blend (Medicare and Medicaid, for instance) and is often inadequate and targeted too narrowly (for example, targeted toward temporary housing for chronically ill homeless people, rather than toward permanent housing that incorporates health care, mental health care and addiction services).
- The upshot is a system that encourages costly, institutionally based treatments rather than less expensive preventive or supportive services in the home or community.
- Such inefficiencies have made the cost of care for chronically ill people—which the center estimated at the time to be \$470 billion annually—an enormously costly part of the nation's total health care expenditure.

CONTEXT

RWJF saw the Building Health Systems program as a vehicle to quickly generate innovative ideas in the field of chronic care. RWJF established it at the same time it 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. Intended to draw disabled persons into the mainstream of public life, the law created a new paradigm for issues involving chronic care. With its emphasis on consumer involvement, direction and self-determination, the law provided a focus on self-determination for people with developmental disabilities and on removing health and other systems barriers to employment for people with disabilities.

PROGRAM DESIGN

Because effective care and treatment of people with chronic illness and disabilities involve such a broad range of services, the Building Health Systems program adopted a holistic view of the health care system.

It encouraged the submission of diverse investigator-initiated proposals—with a focus on overcoming the fragmentation, financing barriers and episodic care that has characterized existing systems of care for people with chronic conditions.

The program emphasized efforts based on "social-health" models of caring—i.e., community-based care oriented toward health and well-being. To that end, the program gave priority to interventions that were comprehensive, noncategorical, nondisease-specific and lodged in the community.

Many of these efforts significantly enhanced the role of the individual consumer as an integral decision-maker in care choices. This view expanded over the course of the program to include linkages with housing, informal caregivers and employment for people with disabilities.

Building Health Systems funded 32 projects through 37 grants, which totaled \$14,454,287. The first grant was awarded in October 1993. The final grant was awarded in January 2002. The program closed in December 2003.

National Advisory Committee

RWJF established the national advisory committee for the program in 1992. The national program office and RWJF staff selected its members to represent the range of issues involved in the program, including those concerning children, elders, people with disabilities, mental health, financing and care coordination. (See [Appendix 1](#) for a list of members.)

The committee met during each of the five funding rounds to review proposals and select grantees, and during the annual conferences. In addition, they assisted in site visits, both as grantees were selected and once the projects got underway.

Project Selection

National advisory committee members and national program staff chose 32 projects from 2,050 letters of intent (pre-applications) submitted over five funding rounds (some of these projects also received renewal grants). See the [Project List](#) for a list of projects in this program that have links to fuller descriptions in National Program Project Reports. See [Appendix 2](#) for brief descriptions of the other projects.

Advisers and staff sought projects that responded to the full spectrum of medical, mental health and supportive services for people with chronic health conditions—with an emphasis on noninstitutional services.

As detailed in the program's 1992 call for proposals, Building Health Systems considered two types of projects:

Demonstrations of new service systems that provide more appropriate, integrated services, improve patient satisfaction and contribute to better health outcomes, greater efficiency and reduced costs.

Evaluations of initiatives already in place to determine their impact on outcomes, service costs and quality of care, especially from the consumer perspective. Evaluations could be incorporated into proposals to demonstrate new service systems.

Proposed projects were expected to contain the following features:

- **Integrating services into a continuum of care.** Delivering care for people with chronic health conditions across care settings and integrating the care with clinical and nonclinical supportive services.
- **Reallocating resources.** Redirecting the existing delivery and financing systems, which currently emphasize acute care, so that they are better suited to people with chronic health conditions.
- **Promoting early intervention.** Providing timely, proactive medical and nonmedical interventions.
- **Maintaining the independence of people with chronic health conditions.** Helping people with chronic health conditions remain in their own homes and communities as long as possible.
- **Providing consumer choice.** Giving patients and their caregivers a role in the design, implementation and ongoing modification of their health care and supportive services.
- **Instituting noncategorical approaches.** Delivering services that are not specific to a single health condition or illness but can be used by individuals with different chronic health conditions. (Projects designed for people with specific illnesses or conditions would be supported only if they involved the integration of multiple service sectors and financing streams.)

The sites selected served one or more of the following populations:

- People with physical or developmental disabilities.
- People with severe, persistent mental illness.
- Children with special health care needs.
- Frail, elderly individuals.

In general, the projects focused on the following:

- **Developing systems of care for people with physical or developmental disabilities.** The projects emphasized developing projects that encourage independence and self-sufficiency by:
 - Promoting the transition and integration of people with disabilities into community settings and
 - Enabling people with disabilities to overcome health care and health insurance barriers that impede their employment.

- **Developing systems of care for children with complex health care needs who have serious physical, emotional or developmental conditions, and children whose ability to conduct activities of daily living and perform age-appropriate tasks is impaired.** These children may require extensive preventive, restorative and maintenance care, specialty health care and coordination of health, school and community services. The projects emphasized creating family-centered systems of care and optimizing the coordination of service delivery across primary care and acute care settings and in homes, schools and communities.
- **Developing systems of care for elderly individuals with chronic illnesses, especially those with more than one chronic condition.** The projects emphasized integrating health care and social services. Of special interest were efforts to link health care with housing and community support services for elderly individuals living in naturally occurring retirement communities—i.e., buildings or neighborhoods with a disproportionately large percentage of elderly individuals—while emphasizing consumer choice and independence.
- **Overcoming health care barriers to employment for people with disabilities.** The projects emphasized bringing together service delivery and financing that promote opportunities for self-directed, supported employment. These approaches involved program and policy shifts to blend resources to include clinical and vocational services. In addition, these initiatives sought innovative service delivery and financing models that promoted self-directed community support, based on shared decision-making among consumers, their family members and providers.

THE PROGRAM

RWJF established the national program office for Building Health Systems in 1992 under the direction of F. Marc LaForce, M.D., program director, and Sandra DiPasquale, Ph.D., deputy director. The national program office was originally based at Genesee Hospital and the University of Rochester School of Medicine and Dentistry in Rochester, N. Y.

In 1995, RWJF decided to transfer the program funds to the Center for Health Care Strategies in Princeton, N.J., which then became the national program office. (At the time, the Center for Health Care strategies was also managing the *Medicaid Managed Care Program* for RWJF. The Building Health Systems move was intended to capitalize on the potential for synergy between the two programs.)

LaForce remained at Genesee Hospital. At the Center for Health Care Strategies, Jay Wussow became deputy director. RWJF made six grants to support the national program office to provide technical assistance and direction to the projects and to facilitate the work of the program's National Advisory Committee.

In 2002, the Center for Health Care Strategies transferred administrative responsibilities for the program back to RWJF.

National Program Office Activities

The national program office:

- Administered the application process, including developing and distributing calls for proposals, application packages and budget guidelines.
- Worked with RWJF staff and the national advisory committee to select finalists among the applicants for program funding.
- Conducted committee meetings, annual conferences involving all staff from all projects and technical assistance meetings with individual project staff.
- Conducted site visits to review and provide assistance to individual grant projects.
- Monitored the progress of the projects, provided technical assistance to staff of the projects and facilitated networking among them.
- Maintained the program's Web site and assisted in disseminating project findings.

Communications

The national program office published two monographs on themes addressed by Building Health Systems:

- *Practicing Comprehensive Care: A Physician's Operations Manual for Implementing a Medical Home for Children With Special Health Care Needs*
- *Health Care and Health Insurance Barriers to Employment for People With Disabilities*

The program has published two newsletters, the first when the national program office was based at Genesee Hospital, and the second, *Health Strategies Quarterly*, published quarterly from 1996 to 1998, by the national program office at the Center for Health Care Strategies.

In 2005, the center published the review, *Integrating Long-Term Care: Lessons from Building Health Systems for People With Chronic Illnesses*, containing key operational lessons for future philanthropic and policy investments. The report is available [online](#).

The national program office convened five annual conferences. The culminating conference, entitled "Chronic Illness in America," was held June 15–16, 2000, in Washington. Approximately 175 Building Health Systems project staff and health care policy-makers and researchers attended that conference. Presenters described all Building Health Systems projects to an audience of analysts, providers, consumers and public policy-makers on the state and federal levels.

At other venues, national program office staff made additional presentations. (See the [Bibliography](#) for details.) Project bibliographies for individual grantees are included under the descriptions of each project.

OVERALL PROGRAM RESULTS

Given the broad mission and objectives of the program, identifying the specific changes that occurred as a result of the funded projects was difficult.

The program director thought that by supporting projects that strove to integrate care delivery and financing, Building Health Systems advanced the movement away from an acute-care focus within the health care system and toward a social health model of care for people with chronic conditions.

Of note were models created by the projects in the following seven areas:

- **Self-determination for people with developmental disabilities.** This model, by Monadnock Development Services, developed in a project that initially served 45 individuals in rural New Hampshire (see [Program Results](#) on ID#s 023006 and PC 379).
 - It allowed persons with disabilities to make their own decisions about how their needs were met, with the help of a planning team composed of relatives or friends of their choosing.
 - Evidence of cost savings and improved quality of life for the participants influenced New Hampshire's decision to extend the self-determination paradigm to all people with developmental disabilities in the state.
 - It also led to RWJF's national program, *Self-Determination for People With Developmental Disabilities Program*.
- **Integrating medical, social and long-term care services for elders and people with disabilities.** Building Health Systems supported several models of care that integrated medical, social and long-term care services, along with their respective funding streams, for elders and people with disabilities. Outcomes of these projects include the following:
 - The primary physician became more strongly involved in managing the integration of acute and chronic care.
 - The agencies responsible for assessment and continuing care management improved the coordination of services.
 - Fixed, prospective, [capitated payment](#) for providers according to negotiated rates. (Click highlighted words for definitions in a glossary.)

- **Care for children with special needs.** Staff at a number of projects developed models of care for children with special health care needs and their families. As a result, care and a range of family support services moved to the community provider level.
 - These projects, notably the Pediatric Alliance for Coordinated Care (see [Program Results](#) on ID#s 024816 and 031307) and the Missouri Partnership for Enhanced Delivery of Services (see [Program Results](#) on ID# 035558), offered models for implementing a [medical home](#) for a special needs child in the community using a primary care pediatrician, rather than a [tertiary care](#) center.
- **Blending supportive housing with health care.** Building Health Systems identified models that married affordable permanent housing to health care, mental health care and addiction services, all of which were available to tenants where they lived.
 - One of these models—the Health, Housing and Integrated Services Network designed by the Corporation for Supportive Housing in Oakland, Calif. (see [Program Results](#) on ID# 027072)—was targeted at formerly homeless people. This population tends to use the highest-cost public systems when it has medical problems—notably, emergency departments, hospital psychiatric beds, alcohol and drug detoxification, residential treatment programs and, in some instances, jails. The result is a huge, avoidable burden on the health care, mental health, addiction and corrections systems.
- **Integrating health and social services for the frail elderly.** Some projects targeted the frail elderly, integrating health and social services in their homes or residential facilities.
 - The Council on Aging of the Cincinnati Area developed a demonstration and evaluation project to enhance care for the frail elderly by linking acute and long-term care services (see [Program Results](#) on ID# 024817).
 - In Minneapolis, the Fairview Foundation created Fairview Partners, an integrated health network of providers to improve the quality and delivery of health services to chronically ill nursing home patients (see [Program Results](#) on ID# 024818).
- **Helping people with disabilities leave nursing homes and reenter the community.**
 - People with disabilities were the focus of another project—at the Alpha One Independent Living Center in Portland, Maine, evaluated by the University of Maine (see [Program Results](#) on ID#s 031306 and 031715)—that helped people with disabilities leave nursing homes and reestablish their lives in the community.
- **Helping people with disabilities overcome barriers to employment.** Building Health Systems developed a group of projects aimed at overcoming barriers to employment for people with disabilities. This focus, which RWJF had not envisioned when it established the program, was given a programmatic emphasis in the later funding rounds, reflecting a recognition that economic independence is as essential as

housing to quality of life. Program staff members met with representatives of the Social Security Administration and state agencies, and with individuals with disabilities who were struggling to return to employment, to learn about barriers to employment. Of particular concern were barriers that stem from inadequacies within the health care system and from eligibility criteria of public health care programs that discourage employment.

- Several state-based projects funded by Building Health Systems—in Oregon (ID# 035433), Vermont (ID# 035436) and Wisconsin (ID#s 031312 and 035441)—developed and evaluated models that ensure access to health coverage for people with disabilities who choose to enter or return to the workforce.
- Oregon Health Sciences University evaluated these initiatives (ID# 035694). George Washington University's Center for Study and Advancement of Disability Policy provided technical assistance (ID#s 036250 and 042031). See [Program Results](#) on ID# 035694, et al. covering all of these projects.)

COMMON CHARACTERISTICS OF EFFECTIVELY MANAGED AND/OR INTEGRATED CARE INITIATIVES

The program also provided valuable insights into the common characteristics of effectively managed and/or integrated care initiatives.

Lindsay Palmer and Stephen Somers, Ph.D., president of the Center for Health Care Strategies, conducted a review of the program in 2005 with program funding. Palmer and Somers focused on five projects that yielded especially useful lessons for future philanthropic and policy investments.

The lessons, summarized in the report *Integrating Long-Term Care: Lessons from Building Health Systems for People With Chronic Illnesses*, are listed below in [Lessons Learned](#). The report is available [online](#).

The five projects (with fuller treatment of three of the projects provided through the links) include the following:

Demonstration of an Integrated Care Program for Chronically Ill Residents in Personal Care Homes

The Albert Einstein Health Care Network, a health care system in Philadelphia, developed the Personal Care Partnership Program. It integrated acute and long-term care and served chronically ill elderly individuals living in personal care homes. Personal care homes are a type of assisted-living facility that provide residents with assistance and/or supervision in the daily tasks of life such as dressing, bathing and eating but do not provide skilled nursing care.

In the 1990s, staff at Albert Einstein found that the primary care needs of residents of personal care homes in the Philadelphia area were not being met; residents were using hospitals and emergency departments for regular health needs. Under RWJF grant ID# 035672, project staff worked with the Philadelphia Corporation for Aging (a private, nonprofit organization), other [Area Agencies on Aging](#), the Pennsylvania Department of Public Welfare and other local stakeholders to achieve five main goals:

- Improve health outcomes for residents.
- Demonstrate cost savings.
- Avoid or delay the unnecessary transition of residents to more intensive sites of care.
- Establish pooled funding by integrating funds from [Supplemental Security Income](#), Medicare capitation and Medicaid [waivers](#).
- Present the personal care home as a viable and vital health care delivery site within the continuum of care.

Findings

After almost two years of planning and building relationships to ensure that all the relevant stakeholders were satisfied as to regulations, policies and procedures, the Personal Care Partnership began enrolling residents in 18 personal care homes.

An assessment (see [Program Results](#) on ID#s 035627 and 042438) showed that the model—which delivers care through a multidisciplinary care team consisting of a primary care physician, geriatric nurse practitioner and case manager:

- Improved health outcomes and patient satisfaction.
- Delayed entry into a nursing facility for 11 residents, saving an estimated \$232,075.
- Albert Einstein Health Care Network discontinued working with six of the 18 original homes, and was not able to reach its goal of integrating funding streams.

The project was an example of the challenges that result from attempts to collaborate with multiple government agencies to implement integration across service delivery and financing.

Planning and Development of a Capitated System of Care for Medicare/Medicaid-Eligible Disabled and Severely Ill Elders

The Center for Elders Independence in Oakland, Calif., established the Serving Seniors in Environments of High Risk initiative to develop a comprehensive and [capitation](#) model for providing acute care, long-term care, mental health services and substance abuse

services. Clients were from an inner-city community of low-income adults and seniors, ages 50 and older, who qualified for both Medicare and Medicaid.

The four major goals were to:

- Develop a model of community-based long-term care that integrated medical care, social services and home-based supports.
- Develop a [capitation](#) model for Medicaid contracting.
- Pilot the new model.
- Implement the model to serve 300 elders by the third year.

Results

- Project staff members attempted to pursue a Medicaid contract with the state of California either through a [waiver](#) or by establishing the project as a [provider sponsored organization](#). They soon decided, however, that the process was too cumbersome to continue.
- Project staff members then shifted focus and began negotiations with a local managed care organization to secure a [Medicare+Choice](#) contract for its enrollees eligible for both Medicare and Medicaid. Unfortunately, this partnership also fell through and project staff made the decision to forego formally integrating care on all the fronts they had planned.
- In the end, they focused instead on chronic care [case management](#) through coordination of acute and supportive services. Project nurses provided patient assessment, patient and family health education and coordinated community-based long-term care services. Project staff also developed risk screening tools and disease management protocols for health providers caring for these individuals.

Development of an Integrated Housing, Health and Supportive Services Network for Disabled Adults

Through the development of the Health, Housing, and Integrated Services Network, the Corporation for Supportive Housing in Oakland, Calif., sought to expand access to health and social services for formerly homeless and/or low-income adults with chronic conditions in San Francisco and nearby Alameda and Contra Costa counties (see [Program Results](#) on ID# 027072).

The project brought together 30 public and private nonprofit health care, mental health, social service and housing providers to jointly fund and deliver affordable housing and integrated services to consumers.

Results

- The network established 10 integrated service teams to deliver primary health care, client-centered treatment for mental health problems and substance abuse, and other health, supportive and housing services. The teams included a primary care physician, clinical social worker, community members with personal experience in dealing with homelessness, substance abuse or HIV/AIDS, an employment/vocational counselor, a housing specialist/coordinator and a money-management counselor.
- By 1999, the network was serving almost 1,000 individuals.
- However, the project was unable to meet one of its key goals: establishing **risk-adjusted capitation** rates to finance managed care health services through the network.
- Many of the network's participating organizations lacked readiness and capacity to work within such a financing arrangement.
- Policy barriers within Medicaid also prevented that agency from paying for a variety of the services that the network provided.
- Nonetheless, wrote Palmer and Somers from the Center for Health Care Strategies in their report *Integrating Long-Term Care: Lessons From Building Health Systems for People With Chronic Illnesses*, by linking community-based housing with health and social services, the project continued in 2005 to offer chronically ill, low-income or formerly homeless people help with navigating a fragmented health and social services system and to remain in the community.

Findings

A post-grant study (not funded by RWJF) conducted by the University of California at Berkeley from found that over the course of the project from mid-1995 to mid-1998:

- Residents had a 58 percent reduction in emergency department use.
- Residents had a 57 percent reduction in hospital inpatient days.
- Residents had virtually no use of residential mental health facilities.

Design for a Specialized HMO for Disabled Persons in New York City

In New York City, Independence Care Systems—a nonprofit, managed care organization for adults with disabilities and chronic illnesses—designed and developed a model for providing long-term care in a full-service managed care organization to severely disabled and/or cognitively impaired patients receiving **Supplemental Security Income** benefits.

Results

- Operations began in 2000. By 2005, the program was serving approximately 650 Medicaid-eligible members.

- At the heart of the model is an interdisciplinary, consumer-centered care management process in which either a nurse or social worker serves as the primary case manager.
- The primary case manager, along with the care team, works closely with each individual consumer soon after enrollment to develop a care plan that they then review every four months, with a major reassessment annually.
- The initiative also provides services that go beyond traditional care management. These include:
 - A pressure ulcer prevention and intervention program.
 - A wheelchair purchase and repair services program.
 - A home care aide service program.
 - Consumer-directed personal assistance services.
 - A social activities program.
- Although project staff sought to achieve a full **capitation** model that included hospital inpatient and outpatient services, negotiations with the New York State Department of Health as well as providers proved difficult.
- The organization decided to forego full **capitation** in favor of a partially capitated model.
 - As a result, Medicaid covers all long-term care, prescription drugs, dentistry, and podiatry at the **capitation** rate.
 - Independence Care Systems bills all acute care services as fee-for-service.
 - For people eligible for both Medicare and Medicaid, who make up roughly half of the clients, the organization bills Medicare directly for covered services.
- In the report *Integrating Long-Term Care: Lessons From Building Health Systems for People With Chronic Illnesses* Palmer and Somers wrote, "By enabling consumers to remain active participants in their own lives through a holistic approach, [Independence Care Systems] provides new motivation [to participants] for keeping their health status intact."

Statewide System of Managed Care for People With Chronic Disorders

The State of Wisconsin Department of Health and Social Services designed and developed the Wisconsin Partnership Program to provide a more responsive health and long-term care system to improve both access to and the quality of the care provided (see [Program Results](#) on ID#s 023246 and 023010).

In addition, the department hoped that the integration of Medicare and Medicaid would prove a cost-effective means of providing care by controlling expensive emergency, acute and institutional care.

Results

The program developed two models of integrated acute and long-term care—one for frail elderly people and one for people with disabilities.

- In both models, the department worked with nonprofit community-based organizations that collaborated with the department as purchaser. They also worked with health and long-term care providers who delivered services.
- The organizations also collaborated with each other and with the consumer's family.
- Interdisciplinary teams—made up of a nurse, nurse practitioner, social worker or independent living coordinator, the consumer, and the consumer's primary care physician—were responsible for provision of a comprehensive set of acute and long-term care services for each participant.
- The initiative began as a partially capitated Medicare pre-paid health plan in December 1995, providing services through four community-based organizations in five counties.
- By 1999, the program had converted to a fully capitated, dual Medicaid and Medicare [waiver](#) that combined Medicaid and Medicare funds into one funding stream.
- Since the Building Health Systems program ended, the state has appropriated funds to sustain its program, which has expanded into additional counties.
- In 2004, the Wisconsin Partnership Program was providing integrated care to 1,644 people in six counties.
- According to Palmer and Somers in *Integrating Long-Term Care: Lessons From Building Health Systems for People With Chronic Illnesses*, "[The initiative], along with kindred programs such as Minnesota Senior Health Options and Minnesota Disability Health Options, continues to serve as the foremost national model for integrating Medicare and Medicaid services."

LESSONS LEARNED

Palmer and Somers highlighted seven operational lessons for future philanthropic and policy investments and summarized them in the report *Integrating Long-Term Care: Lessons From Building Health Systems for People With Chronic Illnesses*.

1. **Persevere when trying to get buy-in and cooperation from government agencies, despite the amount of time and patience required.** Effecting change related to publicly financed health care programs such as Medicaid and Medicare necessitates

working with government entities, whether they are local, state, federal or some combination thereof. Working with government agencies is neither quick nor easy and often requires considerable time, patience and persistence. As a result, many attempts to innovate within Medicaid and/or Medicare have gone nowhere because those attempting to innovate become frustrated with the political process. However, those who do persevere are able to achieve a level of effectiveness otherwise unattainable. (Center for Health Care Strategies/Palmer and Somers)

The following examples illustrate the challenges and benefits of getting buy-in and cooperation from government agencies:

- The Albert Einstein Healthcare Network (see [Program Results](#) on ID#s 035627 and 042438) worked with a number of state and local agencies to develop the Personal Care Partnership Program, including local [Area Agencies on Aging](#), the Pennsylvania Department of Public Welfare, the Pennsylvania Department of Aging and other local/state government officials.

The engagement of multiple partners from across the state resulted in slower communications and decision-making. Project staff spent significant amounts of time during the planning stage relaying information to each participating entity to ensure that all of the relevant agency staff was kept up to date.

In addition, each partner had a separate chain of command, and making decisions to move forward on almost all issues took large amounts of time.

As a result, it took 18 months to approve the plans for the initiative. This seemed quick to state government representatives but painfully slow to program staff.

- The Wisconsin Partnership Program (see [Program Results](#) on ID#s 023246 and 023010) worked closely with multiple state and federal agencies to integrate Medicaid and Medicare primary, acute and long-term care services and financing.

Project staff worked extensively with the Health Care Financing Administration (since renamed the [Centers for Medicare & Medicaid Services](#)) to obtain two separate [waivers](#) that would allow it to achieve its goal of full integration. This process took more than four years to complete.

Project staff emphasized the need to make contact with the appropriate government agencies/partners early on in the process and to be patient since putting the necessary infrastructure in place takes time. They also found it essential to address incompatibilities between Medicaid and Medicare to achieve full integration of care.

For example, each program has its own prescribed dates for member enrollment and disenrollment. This seemingly small conflict can have tremendous impact on attempts to streamline both programs into one. Resolving this and similar problems required in-depth working knowledge of both Medicaid and Medicare regulations.

2. **Stay with the slow and onerous processes of setting payment rates and integrating funding streams because accomplishing these steps can make dramatic differences in the quality and coordination of care.** The setting of payment rates and the integration of multiple funding streams have historically been and remain controversial and technically challenging areas for managed and integrated long-term care programs. At issue is the question of how risk should be distributed across those who pay and those who supply goods and services. For programs aimed at high-risk populations requiring more services than the average Medicaid or Medicare consumer, such as frail elders or people with disabilities, rate-setting and [risk-adjustment](#) often involve a contentious process. Many organizations need a higher [capitation](#) rate to take on full risk for higher risk populations. However, [risk-adjustment](#) formulas are not easy to agree upon. They require gathering a significant amount of information regarding past, current and predicted service utilization. This is made more difficult because managed and integrated care models are expected to change utilization patterns. Those projects able to wade through the arduous financing processes have found that the reward—namely, the resources and flexibility to achieve more coordinated care—was well worth the effort. (Center for Health Care Strategies/Palmer and Somers)

The following examples illustrate the challenges and potential rewards in this area:

- Risk-adjustment was one of the biggest challenges Independence Care Systems of New York City faced during the design and implementation of its managed long-term care program for people with disabilities.

Getting the state department of health to set a rate was relatively easy. Early on in the process, the department decided that it would use average fee-for-service rates as the upper payment limit. It even agreed to pay a higher rate for those members who require 12–24 hours of personal care services a day.

However, the department would not include [case management](#) services, which it saw as overhead, in the rates, nor would it entertain the idea of further risk-adjustment. This was a particular problem for the elderly, for whom the state actually paid less because of the belief that Medicare would (or should) be covering them.

As a result, Independence Care Systems received a [capitation](#) rate of \$5,200 per member per month for a person of 64, but once that same individual turned 65, only \$3,200 per member per month. This created significant service delivery challenges for the organization.

After years of battling with the department and operating in a deficit, project staff acceded to operating within the state's framework. As a result, the organization decided to forego including acute care such as hospital and physician services in its [capitation](#) rate and changed its case load and actively sought out additional members who met its eligibility standards but had fewer medical needs.

- Only the state-based initiative to integrate financing—the Wisconsin Partnership Program (see [Program Results](#) on ID#s 023246 and 023010)—was able to overcome all the administrative and regulatory barriers to use a full capitation rate for its program.

Project staff nonetheless still needed several years to gain the two separate [waivers](#) required from the [Centers for Medicare & Medicaid Services](#) to combine the Medicare and Medicaid resources into one funding stream. The arrangement allows a flexibility that affects programmatic effectiveness in several ways.

First, it improves the collaboration and overall effectiveness of the multidisciplinary care team. Second, the scope of services provided can be much more comprehensive.

- For example, a physician's phone consultation—which is not normally paid for by Medicare or Medicaid—can be covered by the [capitation](#) rate.

Finally, the overall coordination and quality of care provided can be greatly improved when a single capitation rate is used.

3. **Develop a quality assurance/improvement process during the design phase to protect, maintain and improve consumer health outcomes and satisfaction.**

Evaluating quality within long-term care can be particularly challenging because of the myriad services, providers and delivery systems involved and the lack of agreed-upon measures of quality in long-term care. As a result, instituting quality assurance/improvement processes within long-term-care programs often requires significant amounts of time and resources. These processes are also most likely to work in programs that use existing models of health care. (Center for Health Care Strategies/Palmer and Somers)

The following examples illustrate this point:

- Because the Wisconsin Partnership Program (see [Program Results](#) on ID#s 023246 and 023010) has access to a shared Medicare-Medicaid database, the program is able to study and analyze both acute and long-term care data for its enrollees. The partnership also works with the University of Wisconsin at Madison to evaluate project staff and consumer experiences and to develop quality assurance protocols and quality indicators based on consumer values. As a result of this ongoing research, each of the partnership's community-based organizations used quality indicators based on consumers' definitions of quality.
- Independence Care System in New York City (ID# 027073) took on annual quality improvement projects to maintain and improve consumer health outcomes for its long-term-care initiative for severely disabled and/or cognitively impaired patients. As of 2005, these projects were mainly focused on disease management, around areas that were particularly relevant to the needs of their members.

- For example, because some 25 percent of members have diabetes as a secondary diagnosis, project staff established a quality improvement project around diabetes self-management focused on yearly eye and foot exams as well as providing all new members who have diabetes with glucometers.

4. **Integrate social services with medical care to help increase consumers' motivation for maintaining better health.** (Center for Health Care Strategies/Palmer and Somers)

- Independence Care System in New York City makes social and supportive services—for example, a wheelchair purchase and repair service program and a social activities program—available to their consumers, despite the fact that they are not funded by Medicaid to provide them. The organization commits a substantial portion of its "extra resources"—that is, any money left over from managing care under capitated rates—to creating and maintaining these supplemental services.
- The Corporation for Supportive Housing (see [Program Results](#) on ID# 027072) in Oakland, Calif., in its Health, Housing, and Integrated Services Network linked housing and other supportive services (such as counseling, vocational services, money management workshops and social and recreational activities) to medical services within community-based settings.

5. **Integrate behavioral health services into programs of acute and long-term care because people with chronic physical or mental impairments are at higher risk of behavioral health problems.** There is a substantial need for behavioral health services among consumers of long-term care. Several projects in Building Health Systems integrated social supports with relative ease, but incorporating behavioral health services remained challenging. (Center for Health Care Strategies/Palmer and Somers)

The following examples illustrate this point:

- The Albert Einstein Health Care Network in Philadelphia (see [Program Results](#) on ID#s 035627 and 042438) faced significant resistance from the state advisory committee convened to oversee the project regarding the participation of personal care home residents who required substantial mental health services.

During the planning process, members of the advisory committee expressed their desire to prevent the Personal Care Partnership Program from becoming a mental health demonstration project. Because the number of residents who have mental health diagnoses is higher in Philadelphia personal care homes than in those in the rest of the state, the advisory committee sought to make the population served by the program more representative of the overall population of the state.

They placed a cap limiting the number of residents with mental diagnoses to 50 percent of residents per home. (Project staff believed that this was not a

representative proportion relative to the personal care home population nationally.) The cap created programmatic challenges by limiting the facilities that could participate in the program and often made it challenging for project staff to maintain enough facilities and residents to carry out the program.

- In Oakland, Calif., the Center for Elders Independence (ID# 035555) included behavioral health services in its original capitated care model. In the course of pursuing a Medicaid contract, project staff soon realized, however, that the processes required to obtain the approval and [waivers](#) necessary to pool mental health and substance abuse funds from agencies and organizations outside of Medicaid would overwhelm the organization's internal capacity. As a result, the center gave up integrating behavioral health services into its overall [capitation](#) model and focused on the coordination of acute and long-term-care services instead.

In general, organizations that most effectively integrated behavioral health services used an interdisciplinary care team approach.

- The Corporation for Supportive Housing (see [Program Results](#) on ID# 027072), for example, employs a number of counselors and social workers as part of its care team. Their clients have received client-centered treatment for mental health and substance abuse and have been able to stay out of residential mental health facilities.

- 6. Form an interdisciplinary team of medical and social service professionals to improve the coordination of care for frail elders, reduce fragmentation of services, improve overall quality of life and enable more clients to remain in their communities.** Long-term-care users generally require varied and complex services across numerous settings, each with its own delivery system. It is not unusual, therefore, for a single individual to receive care from multiple providers, specialists and agencies.

Consumers struggle to navigate the various delivery systems and to learn which provider is responsible for which aspect of their care. Providers struggle with the inefficiencies that arise from such a fragmented care system, which may result in missing or duplicated services.

Managed care generally offers some opportunities for care coordination and integration; however, barriers continue to exist. Several of the Building Health Systems projects worked through a care-management approach that used a multidisciplinary group of providers to increase care coordination and improve consumer outcomes and satisfaction. (Center for Health Care Strategies/Palmer and Somers)

For instance:

- The Personal Care Partnership Program, developed by the Albert Einstein Health Care Network in Philadelphia (see [Program Results](#) on ID#s 035627 and 042438), uses a team consisting of a nurse practitioner (who provides primary care) from a local hospital and a care manager (who coordinates all other services) from the [Area Agency on Aging](#) system, both of whom work in concert with each participating resident's community physician. The interdisciplinary team together monitored the array of services provided to residents through the partnership.

7. **Facilitate consumer choice and self-determination to improve the quality of life for the chronically ill and frail elderly and to achieve higher quality health care.** In today's health care system, consumer choice and self-determination are hallmarks of high quality care. Developing systems of care that fully enable consumers to choose the type and quantity of care they receive, and who delivers it, is always a challenge, more so when individuals who have impairments are restricted in their ability to communicate their choices. (Center for Health Care Strategies/Palmer and Somers)

Several of the Building Health Systems projects engaged consumers by making them an active part of the care planning process:

- Independence Care Systems of New York City (ID# 027073) facilitated consumer choice and engagement within its care model through a number of methods, including a personal assistance services program in which members were given the ability to hire and supervise their own personal assistants through a contracted agency. Project staff also encouraged members to be involved in the development of their care plan. As part of care plan development, care managers worked with participants to help them distinguish between needs and wants, to develop personal goals, and to learn how to make choices.
- The Wisconsin Partnership Program (see [Program Results](#) on ID#s 023246 and 023010) made the consumer a member of the multidisciplinary team along with health care providers and social services coordinators. The center report quoted Wisconsin project staff: "The participating member or consumer is the central figure on the team and his or her desires and expectations figure prominently in the overall care plan as well as in individual solutions to specific care issues."

Other programmatic lessons covered in the original 2003 version of this report include the following:

8. **Evaluators need to develop new methodologies to assess satisfaction and quality of life for individuals with disabilities and/or functional impairments.** While reliable methodologies for assessing the financial impact of demonstration projects are well established, the field has not progressed as far in developing methodologies that assess quality of life. As a result, some program grantees developed their own evaluation methods. (National Program Director)

9. **The economic and financial forces of the late 1990s have seriously decreased the incentives for health systems to integrate care.** In fact, financial pressure is actually moving providers away from integrated care models. This was apparent when one Building Health Systems project (East Boston Neighborhood Health Center, ID# 023005) developed an infrastructure designed to take advantage of potential managed care and integrated care models. When these models ran into financial barriers as a result of reduced Medicare and Medicaid rates, the grantee was temporarily forced into Chapter 11 bankruptcy. (National Program Director)
10. **Imposing a model of care on existing financing structures is very challenging since financial incentives tend to drive the delivery of care.** For example, one Building Health Systems project, Wake Forest University School of Medicine, developed the Community Care Coordination Network (see [Program Results](#) on ID# 023009), a well-regarded managed care delivery model serving low-income frail elders in community settings. When they analyzed the outcomes of their demonstration, however, project staff realized that providers did not align themselves with the care model because financial incentives favored a fee-for-service structure. Without the advantages of a [capitation](#) arrangement, care outcomes were not significantly different for the demonstration than for patients receiving nonintegrated care. (National Program Director)
11. **It is difficult to foster an environment in which small demonstration projects, serving between 50 and 400 consumers, can be expanded to serve several thousand consumers.** The only projects that were able to take their models to scale were those that were designed to enroll larger numbers of consumers and that had the advantage of federal [waivers](#) allowing them to pool funding streams. (National Program Director)

AFTERWARD

Since the program ended, the Center for Health Care Strategies continues to maintain information about the projects on its [Web site](#) and post copies of issue briefs and monographs for public dissemination.

RWJF pursued several of the themes that Building Health Systems addressed.

- The project conducted by [Monadnock Developmental Services](#) spawned an RWJF national program entitled *Self-Determination for Persons With Developmental Disabilities*. This program responded to the growing interest among persons with developmental disabilities in support systems that enable them to be contributing members of their communities.
- RWJF continues to support the [Corporation for Supportive Housing](#) in its work to provide housing and social services for people suffering chronic, long-term homelessness with ID#s 043050 and 051162 for Taking Health Care Home; ID#

053461 for supportive housing to help reintegrate ex-offenders; ID# 053649 for a matching grants fund, and ID# 053463 for supportive housing in Baltimore.

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APPENDIX 1

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APPENDIX 2

Brief Project Descriptions of Projects without a Separate Report

(See [Project List](#) for links to projects with separate Program Results reports)

Systems of Care for People with Disabilities

Design for a Specialized HMO for Disabled Persons in New York City

Home Care Associates Training Institute/Independence Care System (New York, N.Y.)

\$149,485 (June 1995 to May 1996) ID# 027073

Rick Surpin

(212) 993-7104

This planning project designed a model for providing long-term care in a full-service managed care organization to severely disabled and cognitively impaired [Supplemental Security Income](#) clients in urban areas.

Home-Centered Care System for Adults with Chronic Disorders

Metropolitan Jewish Geriatric Center (Brooklyn, N.Y.)

\$474,038 (January 1995 to December 1997) ID# 024820

Dennis L. Kodner, Ph.D.

(718) 630-2550

The grantee developed a comprehensive, [capitated](#) managed care system, building on existing home-centered programs, for nursing home-certified, chronically ill and disabled persons age 18 and over, who are eligible for both Medicaid and Medicare, or only for Medicaid.

Managed Care Demonstration for Chronically Ill People under Age 55

Beth Abraham Hospital (Bronx, N.Y.)

\$267,100 (October 1993 to September 1995) ID# 023003

Susan Aldrich

(718) 920-5910

Beth Abraham Hospital adapted the [PACE](#) program model for the frail elderly to chronically ill individuals under age 55 whose level of disability qualified them for nursing home level care under New York's Medicaid program.

Model Health System for Adults and Children with AIDS

East Boston Neighborhood Health Center Corporation (East Boston, Mass.)

\$326,856 (October 1993 to September 1996) ID# 023005

James O. Taylor, M.D.
(607) 569-5800

The grantee developed and implemented a comprehensive, [capitated](#), community-based pilot project for Medicaid-eligible adults and children with severe chronic illnesses and disabilities, building on the principals of a [PACE](#) program model already in place.

Promoting Personal Assistance Services in Home Care Agencies for People with Disabilities

The Institute for Rehabilitation and Research (Houston, Texas)
\$172,445 (March 1997 to February 2001) ID# 031313
Lex Frieden
(713) 797-5283

The Institute convened a national panel of experts to identify public policy strategies that promote consumer-directed, community-based programs that address health care and other support needs of persons with physical disabilities.

Systems of Care for Children with Special Health Care Needs

Planning a Comprehensive Care System for Chronically Ill Children

Richland Memorial Hospital (Columbia, S.C.)
\$100,641 (October 1993 to March 1995) ID# 023008
Judith Baskins
(803) 434-3770

The grantee conducted a feasibility study and developed a business plan to apply the [PACE](#) model for frail elders to children, from birth to age 18, with chronic illnesses.

Planning for a Managed Care Program for Special Needs Children

Michigan State Department of Public Health (Lansing, Mich.)
\$286,771 (March 1995 to April 1997) ID# 024810
Ronald Uken
(517) 335-8961

The Michigan Department of Public Health used this planning grant to develop a statewide managed care program for children with special care need who were eligible both for Medicaid and Title V programs, which are funded under the Social Security Act and focus on maternal and child health care.

Systems of Care for Frail Elderly Individuals

Assessment of Strategies to Make Long-Term Care Insurance Affordable and Available to Older Adults

County of Monroe, N.Y. (Rochester, N.Y.)

\$234,621 (March 1997 to November 1998) ID# 031311

Helena Temkin-Greener, Ph.D.

(716) 325-1991

Monroe County assessed the actuarial and marketing feasibility of two strategies to increase access to long-term care insurance for older adults: (1) integrating two existing long-term care projects so that all services are managed and out-of-pocket costs are lowered; and (2) developing financing options for those who do not meet medical underwriting criteria for private insurance.

Comprehensive Health and Supportive Services as a Medicare Option

Dartmouth Medical School (Hanover, N.H.)

\$467,855 (December 1993 to March 1996) ID# 023004

Joanne Lynn, M.D.

(202) 467-2222

The grantee developed and tested an alternative package of Medicare benefits designed for chronically ill individuals age 75 or older, which emphasized support services, rather than acute-care benefits, and was to be provided at the same cost.

Development of a Telemedicine Network to Assist Frail Elders and Children with Chronic Illnesses to Remain in their Homes

Visiting Nurses of Aroostook (Caribou, Maine)

\$171,659 (December 1998 to May 2000) ID# 035559

Aroostook Visiting Nurses (transfer grant)

\$278,343 (June 2000 to November 2002) ID#039501

Diane Berry, R.N.

(207) 532-9261

berry@ainop.com

Aroostook Visiting Nurses took over the original grant because of a reorganization of the corporate structure of the original grantee. Project staff are working with the Regional Medical Center in Lubec, Maine to develop telemedicine services that will enable frail elders and children with chronic illnesses to remain in their homes, improve their health status, and reduce their health care costs.

Evaluation of Oregon's Assisted Living Program

University of Minnesota School of Public Health (Minneapolis, Minn.)

\$521,697 (January 1995 to April 2000) ID# 024811

Rosalie A. Kane, D.S.W.

(612) 624-5171

The University of Minnesota School of Public Health evaluated the Oregon Assisted Living Program, which has been designated as a substitute for nursing homes, to measure, among other things, its influence on consumer choices, its impact on participant outcomes and costs, and its potential for replication.

Planning and Development of a Capitated System of Care for Medicare/Medicaid-Eligible Disabled and Severely Ill Elders

Center for Elders Independence (Oakland, Calif.)

\$209,136 (December 1998 to June 2003) ID# 035555

Peter Szutu, M.P.H.

(510) 433-1150

With this planning grant, the grantee developed a new model to provide health care, long-term care, mental health services, and substance abuse services to an inner-city community of low-income adults and seniors, ages 50 and older.

Program to Provide Health Care Transportation and Home-Delivered Services to People with Chronic Illness and Disability

Special Transportation Services (Nashville, Tenn.)

\$125,000 (December 1998 to June 2000) ID# 035556

Jack Jakobik

(615) 862-5965

The grantee studied the effectiveness of a technology-assisted transportation coordination system that linked medical offices and clinic appointment calendars to a central database of available taxis and special transit buses in order to provide rides to elderly and disabled individuals.

APPENDIX 3

Glossary

ADLs—Activities of Daily Living: an assessment scale that allows a health professional to establish the levels at which an individual functions in caring for himself or herself and performing the basic daily tasks of life, such as eating, transferring in and out of bed, toileting, dressing and bathing.

Area Agencies on Aging (AAAs)—Agencies in communities across the country that plan, coordinate and offer services that help older adults remain in their homes—if that is their preference—aided by services such as Meals-on-Wheels, homemaker assistance and whatever else it may take to make independent living a viable option. By making a range of options available, AAAs make it possible for older individuals to *choose* the services and living arrangement that suit them best.

Capitated payment—A method of paying health care providers or insurers in which a fixed amount is paid per enrollee to cover a defined set of services over a specified period, regardless of actual services provided.

Capitation—A method for payment to health care providers that is common or targeted in most managed care arenas. Unlike the older fee-for-service arrangement, in which the provider is paid per procedure, capitation involves a prepaid amount per month to the provider per covered member, and is usually expressed as a PMPM (per member per month) fee. The provider is then responsible for providing all contracted services required by members of that group during that month for the fixed fee, regardless of the amount of charges actually incurred.

Case management—The process by which all health-related matters of a case are managed by a physician, nurse, or designated health or social services professional. The individual who handles case management is called a case manager.

Centers for Medicare & Medicaid Services (CMS)—formerly the Health Care Financing Administration (HCFA), the federal agency, located within the Health and Human Resources Department that administers the Medicare and Medicaid programs.

Medical home—a provider that offers accessible, continuous, comprehensive, family-centered, coordinated care, usually for children. Medical homes provide the level of care traditionally provided by pediatricians in an office setting.

Medicare+Choice—the primary goal of the Medicare+ Choice program, enacted under the Balanced Budget Act of 1997, was to provide Medicare beneficiaries with a wider range of health plan choices such as Medicare managed care plans—including HMOs and preferred provider organizations.

PACE—Programs for All-inclusive Care for the Elderly. This model of a program is based on a capitated benefit authorized by the Balanced Budget Act of 1997 and features a comprehensive service delivery system and integrated Medicare and Medicaid financing. PACE programs provide social and medical services primarily in an adult day health center, supplemented by in-home and referral services in accordance with the participant's needs.

Provider sponsored organizations—Under Medicare+Choice, physicians, hospitals and allied health professionals had the opportunity to organize provider sponsored organizations and contract directly with the government for Medicare-risk contracts, eliminating the administrative/insurance "middleman." Through this new type of managed care organization, providers were able to develop and own the assets and infrastructure of the company and control all aspects of health care delivery.

Risk-adjusted—An insurance/managed care mechanism that compensates for the above-average costs of the patients with serious, chronic health problems, so that the consequences of poor risk selection are ameliorated and the incentives to engage in aggressive risk selection—in which plans and providers seek only healthy patients, and try to avoid those with chronic health problems—are reduced.

Risk-pool—A fund of money set up to distribute risk among participants (health plans, providers or individuals) and thus insure that the losses faced by any one participant are minimized.

Social Security Disability Insurance (SSDI)—A federal "insurance program" for workers who become unable to work. It is administered by the Social Security Administration, funded by "FICA" (Federal Insurance Compensation Act) tax withheld from workers' pay and by employer contributions, and pays qualifying disabled workers both cash and health care benefits. Workers who have worked and paid FICA tax for at least 5 of the 10 years prior to onset of their disability typically are covered by SSDI.

Supplemental Security Income (SSI)—A federal cash benefit program for persons who are 65 or older, blind or disabled and who have few assets and low income. It is administered by the Social Security Administration and funded by tax revenues.

Tertiary care center—Medical centers offering the most complex level of care, such as burn units or major cardio-vascular surgery units.

Waiver—Formal governmental (usually federal) permission to have certain requirements for programs disregarded.

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Grantee Websites

www.chcs.org. Contains summaries of individual Building Health Systems projects, along with papers and monographs. Princeton, NJ: Center for Health Care Strategies.

PROJECT LIST

Reports on the projects managed under this National Program are listed below. Click on a project's title to see the complete report, which typically includes a summary, description of the project's objectives, its results or findings, post grant activities and a list of key products.

Health Care as a Barrier to Employment for People With Disabilities

- [Three-State Study Reveals Unexpected Barriers to Work for the Disabled \(August 2003\)](#)

Systems of Care for Children With Special Health Care Needs

- [New Coordinated Care Model Shows Promise for Chronically Ill Children \(August 2003\)](#)
- [Partnership Streamlines Care for Families with Disabled Children in Rural Missouri \(August 2003\)](#)

Systems of Care for Frail Elderly Individuals

- [Additional Funding to Coordinate Services for Elderly in Cincinnati Doesn't Improve Health Care \(August 2003\)](#)
- [Continuing Care Networks Succeed with Multidiscipline Team Approach \(June 2006\)](#)
- [Coordinated Health Care Experiment Unsuccessful \(August 2003\)](#)
- [Minneapolis Integrated Provider Network Reduces Hospitalization of Nursing Home Residents and Shares Risk Among Providers \(August 2003\)](#)
- [Philly Program Integrates Services in Care Homes for Low-Income, Chronically Ill Elderly \(June 2006\)](#)
- [Wisconsin Partners Up to Offer Managed Care for the Elderly, Disabled \(August 2003\)](#)

Systems of Care for People With Disabilities

- [Giving Clients Freedom to Choose Services Helps People with Severe Mental Disabilities \(August 2003\)](#)
- [Home to the Community—Helping Disabled Adults Return to the Community in Maine \(August 2003\)](#)
- [Network Coordinates Housing and Medical Services for Disabled and Chronically Ill Adults \(June 2006\)](#)