Resource Paper

Integrating Long-Term Care:
Lessons from Building Health Systems for People with Chronic Illnesses, a National Program of The Robert Wood Johnson Foundation

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Executive Summary

Long-term care users need a variety of services across numerous settings. For these services to be the most beneficial, they must be integrated and coordinated with each other and with related medical, social, and behavioral health care services. Over the last 20 years, Medicaid publicly financed long-term care has evolved from a primarily institutional set of services to one that increasingly emphasizes care delivered within the home and/or community. It has also begun to see a transition from fee-for-service to managed care and to the exploration of integrating care across services and funding streams. Numerous obstacles have prevented these changes from taking place on a wider scale, leaving the majority of the long-term care delivery system still fragmented, uncoordinated, and rife with misaligned benefit structures and, consequently, inefficient, costly care.

In 1992 The Robert Wood Johnson Foundation (RWJF) launched Building Health Systems for People with Chronic Illnesses (BHS), a national program designed to address deficiencies in the nation’s health care system for individuals with chronic physical or mental impairments. From 1993 to 2002, 32 projects received more than $14 million dollars in funding to improve the organization, delivery, and financing of medical, mental health, and social support services across care settings. By supporting projects that focused on integrating care delivery and financing, BHS, which was ultimately coordinated by the Center for Health Care Strategies (CHCS), helped begin to move the market away from an acute-care focus within the health care system and toward a more social model of care for people with chronic conditions.

Of the 32 original BHS projects, five in particular have yielded operational insights into the common characteristics of successful managed and/or integrated long-term care programs. With funding from RWJF, CHCS undertook a retrospective review of these five innovative projects to glean operational lessons for future philanthropic and policy investments. This paper is divided into three sections, starting with a historical review of the evolution of integrated managed long-term care. The second section outlines the intent of the BHS program and describes the design of the five highlighted programs. Finally, the third part of the paper extracts lessons from these five programs into six broad recommendations to guide future public, foundation, and CHCS investments in integrating managed long-term care effectively for our most vulnerable populations. This synthesis highlights the following findings on:

1. Working with Federal and State Agencies
   - Working with government agencies takes considerable time and patience, but getting buy-in and cooperation is critical to eventual programmatic success.
   - Potential funders of future initiatives or demonstrations aimed at addressing systems change should allow for ample time for planning and development.
2. **Financing**
   - Negotiating rates and integrating funding streams are extremely slow and onerous processes, but can make dramatic differences in the quality and coordination of care.
   - Time, data, infrastructure, and unerring commitment play key roles in achieving full capitation and/or integrated financing. Potential funders of managed/integrated long-term care programming should consider investing in longer term projects aimed at building the necessary infrastructure for agencies to work with state and federal partners to build these innovative financing models.

3. **Quality Assurance and Improvement**
   - During the design phase of the model of care, a quality assurance/improvement process should be developed to protect, maintain, and improve the consumer health outcomes and satisfaction.
   - Long-term care currently lacks a consistent and appropriate set of performance standards and benchmarks. Grant-making organizations should consider investing in research and demonstration projects aimed at developing quality improvement standards, measures and infrastructure specific to both long-term care on its own as well as how it is integrated with primary and acute care.

4. **Integrating Medical, Behavioral Health, and Social Services**
   - The social context is as important as maintaining good health status. Consumers who are active participants in their lives will have increased motivation for keeping their health status intact. In addition, behavioral health is an important (and often ignored or misunderstood) element of this population’s care; however it is often more difficult to integrate than other medical and social support services.
   - Grant-making organizations should consider focusing more closely on the connection and coordination of physical and behavioral health by funding additional pilot programs, demonstration projects, and/or evaluations of existing models to both foster innovation and disseminate lessons in this area.

5. **Interdisciplinary Team Models**
   - Forming a team of medical and social service professionals can improve the coordination of care for frail elders, thereby reducing fragmentation, improving overall quality of life, and enabling them to remain in their communities.
   - The success of interdisciplinary care teams is widely documented. Potential funders should focus on the dissemination of best practices by helping organizations that currently employ the team model to develop operationally useful toolkits and/or protocols that will assist other organizations and agencies in integrating these approaches into broader, more scalable initiatives for integrating care.
6. **Consumer Direction**

- Consumer self-determination is a practical method of improving the quality of life for the chronically ill and frail elderly and is essential for achieving high quality, patient-centered care.

- True consumer self-determination requires an extensive amount of information geared to the culture, language and literacy levels of its audience to ensure that consumers are able to make informed choices. Grant-making organizations interested in fostering innovation in consumer-directed, long-term care should consider investing in developing information systems aimed at supporting consumers in their role as decision-maker, evaluating current models of consumer-directed care, and/or disseminating best practices to other interested parties.

**Introduction**

The nature of illness in America is undergoing a profound change. Medical advances are helping the elderly and people with disabilities to live longer, healthier lives. By 2030, the number of Americans over age 65 is expected to double, accounting for 20 percent of the total population. Today, almost 10 million Americans need long-term care services and supports to assist them in life’s daily activities, a number that is projected to increase due to the growth in the under-65 disabled population as well as the overall aging of the American population. The Centers for Disease Control and Prevention have called this shift a “longevity revolution,” and with it comes an increased need for long-term care services.

For the purposes of this paper, “long-term care” is a general term describing a wide range of medical, nursing, custodial, social, and community services provided over an extended period of time for the chronically ill. For some people, these are lifetime needs, resulting from developmental disabilities, traumatic injuries, or degenerative diseases. For the elderly, the need for long-term care services is often a result of the decreased mobility and cognitive functioning that comes with aging. Although approximately $150 billion was spent on long-term care in 2003, there is a large coverage gap for those who are not poor or near-poor and are, therefore, not covered by Medicaid. Neither employer-sponsored insurance nor Medicare tend to cover long-term custodial care. Many people who need long-term care rely primarily on unpaid help from family, friends, and other informal caregivers. Medicare only pays for a limited number of post-acute days and private insurance is also limited. Medicaid is the single largest source of financing for long-term care, which represents a third of total Medicaid spending. In today’s era of fiscal constraints, states are looking to contain costs in this rapidly growing area.

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3. Ibid.
Long-term care users need a variety of services across numerous settings, and if these services are to be the most beneficial, they must be integrated and coordinated with each other and with related medical, social, and behavioral health care services. Unfortunately, most of this care to date is fragmented, uncoordinated, and rife with misaligned benefit structures leading to inefficient, costly care. It was under these auspices that The Robert Wood Johnson Foundation (RWJF) launched *Building Health Systems for People with Chronic Illnesses* (BHS) in April 1992 to encourage the development and implementation of interventions designed to overcome the fragmentation, financing barriers, and episodic care that still characterizes most systems of chronic care delivery. Thirty-two projects received almost $15 million between 1993 and 2002. This program, coordinated by the Center for Health Care Strategies (CHCS), paralleled several other major RWJF initiatives designed to promote community-based care and integration between Medicare and Medicaid for those dually eligible for both. Indeed, several BHS projects helped spawn new national programs for RWJF, including the *Self-Determination for People with Developmental Disabilities* program and *Community Partnerships for Older Adults*. Of the 32 original projects, five in particular provide valuable insight into the common characteristics of successful managed and/or integrated long-term care programs. This subset consists of five innovative demonstration projects that were all home and community-based and were successfully sustained at the end of the grant period and remain, literally at the cutting edge on issues related to

- Working with federal and state agencies;
- Financing;
- Quality assurance and improvement;
- Integrating medical, behavioral health, and social services;
- Developing an interdisciplinary team model; and
- Consumer direction.

Prior to examining lessons from these five innovators of home- and community-based services, it is beneficial to review the trajectory of managed and integrated long-term care.

**Managed and Integrated Long-Term Care in the Historic and Current Contexts**

**Shift from Institutional Care to Home- and Community-Based Services**

Today, Medicaid provides long-term care services in both institutional and home and community-based settings, but that has not always been the case. When the program was first enacted in 1965, it included only primary and acute care services. In 1968, institutional long-term care, such as nursing facility care, was added. Not surprisingly, the 1970s were marked by large increases in nursing home expenditures and many states began to worry about the sustainability of a long-term care system dominated by
institutional care. In response to the high costs of institutional long-term care, combined with criticism of Medicaid’s institutional bias, the Federal government has made the option of having home health services mandatory for those entitled to a nursing home level of care; however, expenditures for long-term care services provided in institutional settings still dominated spending.

Continued debate surrounding the institutional bias, rising costs, and medical-model of Medicaid’s long-term care services led Congress to pass Section 2176 of the Omnibus Budget Reconciliation Act of 1981. Section 2176 created section 1915(c) of the Social Security Act, authorizing the home- and community-based services (HCBS) waiver option and allowing states considerable flexibility to create new HCBS services covered under the same financial and clinical eligibility provisions as traditional institutional benefits. Using HCBS waivers, states may provide services not usually covered by Medicaid as long as these services are budget neutral and keep people from being institutionalized. Prior to the HCBS waiver program, Medicaid did not reimburse nonmedical services in the community. Today, waivers allow states to offer a variety of social and supportive services including case management, homemaker services, personal care services, and adult day care. States were quick to embrace home- and community-based services waivers and the program grew rapidly from six states spending $3.8 million in 1982 to 48 states spending almost $1.7 billion in 1991. Unfortunately, the establishment of HCBS waivers did little to control the growth of long-term care provided in institutional settings and nursing home expenditures in the 1990s.

The first formal push to strengthen home- and community-based services within the long-term care arena came in the form of a 1999 Supreme Court decision. In *Olmstead v. L.C.*, the Supreme Court interpreted the Americans with Disabilities Act (ADA) and found that persons with disabilities have a right to home and community services that is protected by law. Noting that institutionalization may severely diminish quality of life for patients including everyday life activities of individuals such as family relations, social contacts, economic independence, and cultural enrichment, the Court stated that institutional placement of persons deemed capable of coping with and benefiting from community settings “perpetuates unwarranted assumptions that persons so isolated are incapable or unworthy of participating in community life.” However, the Court did not change Medicaid law or even require an end to the institutional bias, and said nothing specific about removing those unable to handle or benefit from community living from institutional settings. Thus state responsibility to provide community-based treatment is not unlimited, but merely extends to qualified individuals. Despite the limited nature of the *Olmstead* decision, many people believed that it would lead to rapid expansion of Medicaid-funded home and community-based long-term care services for the millions who would benefit from that type of care. However, this has not yet happened. While

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HCBS provided under state waivers continue to grow, this growth has not occurred at the level one would expect from such a landmark decision. The recent state fiscal crisis has hindered the progress of Olmstead compliance plans.\(^7\)

The federal government’s Center for Medicare and Medicaid Services (CMS) responded to Olmstead through the Real Choice Systems Change Grants for Community Living program (RCSC), which was created to assist states and other organizations to develop initiatives that enable people with disabilities or long-term illnesses to reside in their homes and fully participate in community life. RCSC has awarded approximately $188 million dollars from 2001 to 2004 to all 50 States, the District of Columbia, and two territories, in order to create infrastructure and service options with the goal of long-term community integration. With this financial support, states have been able to address issues such as personal assistance services, direct service worker shortages, transitions from institutions to the community, respite service for caregivers and family members, and better transportation options.\(^8\) CMS recently released the FY 2005 RCSC solicitation, focusing on two types of grants: the first is a $165,000 grant for states to support the development and implementation of Family-to-Family Health Care Information and Education Centers, while the second is a much larger grant aimed at Systems Transformation. This $3.5 million Systems Transformation grant will provide selected states with more substantial resources for building state infrastructure for a more coherent system of long-term care supports.

When first enacted, government funding aimed at meeting long-term care needs was available primarily when an individual was placed in an institutional setting. Today, however, home- and community-based services account for 35 percent of all Medicaid long-term care expenditures.\(^9\) Home- and community-based services are viewed as preferable alternatives to institutional-based care for a number of reasons. First, they are viewed to be more cost-effective on a per capita basis. Second, most long-term care users would prefer, given the choice, to remain in their homes and/or communities and should have the right to do so, as evidenced by the Olmstead decision. However, nursing facility care remains an entitlement, while home- and community-based services are not. As a result, eligibility, enrollment, and funding for HCBS have been limited and any programmatic savings that may result have not been enough to control rapid growth of long-term care expenditures overall.

**The Move to Managed Long-Term Care**

By the early 1990s, managed care had become the dominant form of primary and acute care service delivery in the commercial sector and was rapidly entering the Medicaid market.

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Subsequent to the managed care explosion in the 1990s, states began to realize the need to move beyond home- and community-based waiver programs to bring long-term care costs under control. With two-thirds of Medicaid expenditures targeted to individuals eligible for the program as a result of age (65 or over) or disability, the rate of growth for long-term expenditures was quickly surpassing that of the basic Medicaid program. Many states began to realize that excluding these populations and services from their managed care programs would limit their overall ability to generate savings and use managed care in the most effective way. Managed long-term care appealed to several states for a number of reasons. First, as in managed acute care, states thought they would be able to reduce high-cost institutional services. In addition, states thought that managed long-term care would be another vehicle through which to improve access to less costly home- and community-based services, which would, in turn, improve consumer satisfaction. By building on their Medicaid managed acute care experience, innovator states hoped they could deliver care to the neediest populations in the most organized way while achieving cost savings.

The first Medicaid managed long-term care programs had been implemented in the late 1980s. Florida’s small Frail Elder Program (FEP) was first implemented in 1987 as a three-year federal demonstration program. FEP’s primary goal was to deliver a continuum of acute care, short-term institutional care and home- and community-based long-term care to frail elderly Supplemental Security Income (SSI) recipients, both to improve health and enhance their ability to remain in the community. In 1989 it was “mainstreamed” by the state to continue operation through a capitated, risk-based contract between the state’s Medicaid Agency and the Medicaid HMO licensee that operated the demonstration waiver program. Several companies have held a contract with the state to operate the FEP as a regular HMO product since then but, as a demonstration, total enrollment remains very low. The much more comprehensive Arizona Long-Term Care System began operation in 1989, enrolling aged, blind, and disabled Medicaid eligible who are either in nursing homes or at risk of nursing home placement. It remains the only Medicaid managed long-term care program that operates both statewide and on a mandatory basis. From 1989 to 2001 the enrolled population grew from 10,000 to 32,000 and the proportion of people in institutions during that period decreased from 95 percent to 50 percent. There is also some early evidence of improved cost and utilization efficiencies; from 1989 to 1998 the average length of stay for inpatient care decreased from seven to five days, nursing home expenditures per member per month decreased from $1,424 to $1,110, and the program achieved overall medical savings of $166 per member per month.

Since the late 1990s, the number of states experimenting with managed long-term care programs grew, although the models used varied from state to state. Some states such as Texas chose to follow the experience of Arizona and capitate primary, acute and long-term care services together into a single blended rate. Other states, such as New York and

Wisconsin, created programs that capitate long-term care separately from primary and acute care services. For example, Wisconsin’s Family Care program is a managed long-term care program that combines the state, federal, and local funding for community and institutional long-term care into a single capitated benefit. The services under capitation include traditional long-term care services such as skilled nursing facility care, adult day care, and supportive home care, as well as some related medical care such as home health and therapy.

While a number of states have been able to start managed long-term care programs, the overall penetration rate for such programs, 1.7 percent in 2004, remains small. There are a number of barriers that have prevented these programs from going completely to scale. One is the resistance from many long-term care providers, which often see managed care contracting as a threat to economic survival, in the case of providers, and advocacy groups, which have concerns about the accessibility of necessary care. Another barrier has been a shortage of organizations capable of providing managed long-term care for state purchasers. In general, states that develop managed long-term care programs try to build the capacity of their current long-term infrastructure to undertake managed care or to establish business relationships with managed care organizations (MCO) that have experience in managing the care of populations in need of long-term care. Until now, however, organizations that have successfully merged managed care experience with expertise in long-term care have been hard to come by. In general, most managed care organizations do not have long-term care experience; conversely, entities experienced in providing care to those needing long-term care services usually do not have the same experience in managed care. As a result, the managed long-term care market has resulted in both MCOs expanding into the long-term care business and long-term care organizations expanding into managed care. However, to date, the managed long-term care marketplace has been dominated by the latter and these often small, nonprofit organizations have affected the overall market’s ability to go to scale.

The Integration of Medicare and Medicaid

While Medicare and Medicaid generally cover different populations, there are approximately six million individuals who are dually eligible for both programs. For these beneficiaries, largely low-income elderly and younger people with disabilities, Medicaid fills in the gaps in coverage left by Medicare, particularly in the area of long-term care. Dual eligibles represent a costly subset for both programs as these individuals tend to have the greatest needs and the fewest resources to meet them. Most have substantial medical, social, and long-term care needs, accounting for 70 percent of all Medicaid expenditures while representing roughly 20 percent of its enrollees. In addition, the duals currently account for 22 percent of all of Medicare expenditures, a percentage that continues to grow. Care for the duals is further complicated by the largely disorganized intersection of Medicare and Medicaid, as each is governed by its own delivery, financing, and administrative policies and procedures that result in misaligned

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12 Saucier, op.cit.
13 Ibid.
benefit structures, opportunities for cost-shifting, and unresolved tensions between the federal and state governments.

Following the widespread introduction of managed long-term care in the 1990s, states also became interested in developing managed care approaches that would integrate the financing and delivery of services provided to duals through Medicare and Medicaid. Through integration, states hope to improve the quality, coordination, and cost-effectiveness of care for this population by addressing the fragmentation in delivery systems, ensuring access to primary and preventive care, improving accountability for health outcomes, providing incentives for the appropriate use of medical services, and reducing administrative differences between Medicare and Medicaid.\(^\text{14}\) This growing interest was spurred by the relative success of an early model for integration, the Program for All-Inclusive Care of the Elderly (PACE). PACE was modeled after On Lok Senior Health Services, which uses funding from Medicare and Medicaid to create interdisciplinary teams of providers that meet seniors’ health and social support needs in an adult day care setting. While PACE has proven successful at integrating the delivery of Medicaid and Medicare services for a nursing home certified population without requiring a lengthy state waiver process, PACE programs have limited participation. In general, PACE is not available for those at risk but not yet eligible for long-term care or people with certain disabilities; it has limited service provider networks which may limit consumer choice; and it is more suited to urban areas. As a result, a number of states have chosen to borrow concepts from PACE and other managed long-term care programs to develop innovative integrated care models of their own.

Minnesota was the first state to implement a fully integrated model combining the range of Medicare and Medicaid financing and services. The program, Minnesota Senior Health Options (MSHO), which received early support from RWJF uses a combined Section 1115 Medicaid demonstration waiver and Section 222 Medicare payment waiver to provide acute, long-term care, and social services to the entire aged population via a single, uniform contract between the state and MSHO health plans. These plans manage and coordinate personalized care for individuals age 65 and up who are eligible for Medicaid and/or Medicare and reside in seven urban and three rural counties in Minnesota. MSHO was sufficiently successful that it spawned, again with RWJF support through the Medicaid Managed Care Program (MMCP) directed by CHCS, a companion program for people with disabilities, the Minnesota Disability Health Options (MnDHO), in 2001.

Minnesota inspired other states to develop integrated care programs of their own. RWJF responded by providing a number of states with planning grants and technical support via the BHS grant program and the Medicare/Medicaid Integration Project (MMIP). With support from BHS, MMIP, and MMCP, Wisconsin developed and implemented both a managed long-term care program, Family Care, and its integrated care program, the

Wisconsin Partnership Program. MMIP also supported the development of the Massachusetts Health Senior Care Options, which was implemented in 2004.

Implementing integrated care programs for dual eligibles has proven difficult and many states have been unable to move from the design stage to implementation. It is telling that of the 14 states that received MMIP grants to create integrated care demonstration projects, only the three mentioned above have been able to do so. Several states, including Colorado, Florida, and Texas, modified their original plans to fully integrate and focused instead on integrating Medicaid acute and long-term care services. However, even in states like Minnesota where true integration has been achieved, the size and scope of integrated care programs remains limited. The difficulties lie in obtaining federal approval, developing plan capacity to integrate care, and navigating the operational differences between Medicare and Medicaid. The federal approval process includes both the time required to submit, review, and approve multiple waiver proposals as well as the time it takes for the state and federal government to negotiate and agree upon a Medicare payment methodology for frail dual eligibles. Securing federal and state agreement on how much Medicare will pay health plans has been a contentious issue, taking considerable time and effort on both sides. Developing plan capacity to integrate care for dual eligibles presents another significant challenge as most participating health plans have limited experience in providing the full range of covered services. As with managed long-term care programs, most participating health plans have experience in either acute or long-term care and/or Medicare or Medicaid, but not all four at the same time. In addition, many of these plans are being asked to assume more financial risk than is feasible for many small, nontraditional providers. As a result, some states have had to spend a considerable amount of time negotiating with plans to bring them on board. Finally, the operational differences between Medicaid and Medicare can add an additional element of complexity to the implementation of integrated care programs, often requiring a significant amount of time to build infrastructure that is able to meet both programs’ needs.

With the passage of the Medicare Modernization Act of 2003 (MMA), a new opportunity to integrate Medicaid and Medicare for dual eligible beneficiaries at scale has emerged. In addition to a new prescription drug benefit for Medicare beneficiaries, the MMA also includes a provision that allows health plans to be designated as Medicare Advantage Special Needs Plans (SNPs). As a SNP, health plans will be able to limit enrollment to dual eligibles. As a result, a managed care organization (MCO) already providing capitated long-term care services via Medicaid could conceivably become a SNP to receive capitation for Medicare acute care services as well. Conversely, an existing Medicare Advantage plan that qualifies for SNP status could contract with the state to become a Medicaid MCO. In both cases, states and MCOs are given new flexibility to coordinate and integrate Medicare and Medicaid benefits without the need for a waiver. SNPs do not, however, automatically confer the ability to blend the Medicare and Medicaid financing streams—a remaining barrier to full integration.
Building Health Systems for People with Chronic Illnesses

In 1992, RWJF launched *Building Health Systems for People with Chronic Illnesses* (BHS), a national program designed to address deficiencies in the nation’s health care system to treat and serve individuals with chronic physical or mental impairments. RWJF saw the BHS program as a vehicle to quickly generate ideas in the field of chronic care and the program was established at the same time the Foundation adopted chronic care as one of its three major goal areas.\(^{15}\) From 1993 to 2002, 32 projects received more than $14 million dollars to improve the organization, delivery, and financing of the full range of medical, mental health, and social support services across care settings.

BHS funded two types of programs:

- 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 existing initiatives to determine impact on outcomes, service costs and quality of care, especially from the consumer perspective.

Projects were selected based on: (a) potential for substantially changing health care policy or practice; (b) use of innovative financing mechanisms to achieve systems improvements; (c) applicability in community settings and for a variety of populations groups; (d) potential for improving both clinical and functional health outcomes; (e) evidence of consumer direction; and (f) overall innovation.\(^{16}\)

In general, the projects selected focused on developing systems of care for one or more of the following populations: people with disabilities, people with severe and/or persistent mental illness, children with special health care needs, and the frail elderly. Projects were expected to:

- Integrate services into a continuum of care by delivering medical and supportive care services, both clinical and non-clinical, for people with chronic health conditions across care settings.
- Reallocate resources away from the traditional acute care emphasis so that they are better suited toward people with chronic conditions.
- Promote early intervention.
- Maintain the independence of people with chronic health conditions by enabling them to remain in their homes and communities for as long as possible.
- Provide consumer choice.
- Institute non-categorical approaches by delivering services that are not specific to a single health condition or illness.


Program Results

By supporting projects that focused on integrating care delivery and financing, BHS helped to inch the market 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 models:

- A self-determination model for people with developmental disabilities, which begat RWJF’s 19-state Self-Determination for People with Developmental Disabilities initiative.
- 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.
- Community-based models of care for children with special health care needs and their families.
- Models that integrate affordable permanent housing with health care, mental health, and substance abuse services.
- Projects aimed at overcoming barriers to employment for people with disabilities.

Select Building Health Systems Grantees

Although the Building Health Systems program did not solicit projects that aimed solely at developing managed and/or integrated long-term care programs, nine of the selected grantees did fall within this framework, including:

- Albert Einstein Health Care Network’s Demonstration of an Integrated Care Program for Chronically Ill Residents;
- Beth Abraham Hospital’s Managed Care Demonstration for Chronically Ill People Under Age 55;
- Center for Elders Independence’s Planning and Development of a Capitated System of Care for Medicare/Medicaid Eligible Disabled and Severely Ill;
- Corporation for Supportive Housing’s Development of an Integrated Housing, Health and Supportive Services Network for Disabled Adults;
- East Boston Neighborhood Health Center Corporation’s Model Health System for Adults and Children with AIDS;
- Independence Care Systems’ Design for a Specialized HMO for Disabled Persons in NYC;
- Metropolitan Jewish Geriatric Center’s Home-Centered Care System for Adults with Chronic Disorders;
- Monroe County (NY) Coalition for Long-term Care’s Community Based Continuum of Care Networks for Frail Elderly People; and
- Wisconsin Department of Health and Family Service’s Statewide System of Managed Care for People with Chronic Disorders.

17 Building Health Systems National Program Report, op.cit.
While all of these programs made important contributions to the field, five of these innovators may provide truly valuable insight into the core components required of a successful managed and/or integrated long-term care program. Following are descriptions of these five programs.

*Albert Einstein Health Care Network*

The Albert Einstein Health Care Network in Philadelphia, sought to develop an integrated acute and long-term care program for chronically ill elderly individuals living in personal care homes. Personal care homes (PCH) are a type of assisted living facility in which residents are provided assistance and/or supervision in Activities of Daily Living and Instrumental Activities of Daily Living, such as dressing, bathing, and eating. These facilities are not intended to be health care facilities and generally do not provide skilled nursing care. In the 1990s, Albert Einstein found that the primary care needs of PCH clients in the Philadelphia area were not being met; instead, residents were using hospitals and emergency departments for their regular medical services. To address this concern Albert Einstein, along with the Philadelphia Corporation for Aging, Area Agencies for Aging, the Pennsylvania Department of Public Welfare, and other local stakeholders, designed a resident-centered model of integrated care. Goals of the program included:

- To improve health outcomes for personal care home residents with a nursing facility level of need;
- To demonstrate cost savings for residents receiving waiver services in personal care homes;
- To avoid or delay unnecessary transitioning to more intensive loci of care;
- To establish a pooled funding arrangement using Supplemental Security Income, Medicare capitation, and Medicaid waivers; and
- To present the personal care home as a viable and vital health care delivery site within the continuum of care.

After almost two years of planning and building relationships to ensure that all the relevant stakeholders were satisfied as to regulations, policies, and procedures, a model of care was established. This model, the Personal Care Partnership, focuses on a multidisciplinary care team including a primary care physician, geriatric nurse practitioner, and case manager. The program began enrolling eligible residents, those 60 and older who require nursing facility level of care and meet eligibility standards of Pennsylvania’s HCBS waivers, in 18 personal care homes in the Philadelphia area. Each PCH is screened and approved by the Department of Public Welfare to ensure that facilities are in good standing and currently licensed with no more than 50 percent of its resident population diagnosed with significant mental health problems. Following an initial screening and assessment of residents to determine eligibility, the care team works with each resident to develop an individualized care plan.

Today, Albert Einstein continues to provide services via the Personal Care Partnership at 12 personal care homes in the Philadelphia area. An evaluation of the program was
recently completed and found that health outcomes and patient satisfaction improved as a result of the program. In fact, the Personal Care Partnership Program (PCPP) delayed entry into a nursing facility for 11 residents, saving an estimated $232,075 in placement costs.\(^\text{18}\) In addition, the evaluation found that the average cost of providing care to the Personal Care Partnership resident was $50.32 less per day than placement in a nursing home at Medical Assistance/Medicaid reimbursement rates. Unfortunately, Albert Einstein discontinued working with six of the 18 original homes and was unable to reach its goal of integrated funding streams. The Department of Public Welfare has not moved forward in replicating and/or expanding the Personal Care Partnership model to other parts of the state at this time. The PCCP is a prime example of the challenges that inevitably result from attempts to collaborate with multiple government agencies to implement integration across service delivery and financing. While the PCPP, like so many others, was unsuccessful in achieving truly integrated care, its experience may help others to avoid the usual pitfalls associated with such an endeavor.

**Center for Elder Independence**

With a planning grant from BHS, the Center for Elder Independence (CEI) in Oakland, California, established the Serving Seniors in Environments of High Risk (SSEHR) program to develop a comprehensive and capitated model for providing acute 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, who qualify for both Medicare and Medicaid. The four major goals of SSEHR were to:

- Develop a model of community-based long-term care that integrated medical care, social services and home-based supports beyond, but similar to, PACE;
- Develop a capitation model for Medicaid contracting;
- Pilot the new model, documenting outcomes along the way; and
- Implement the model to serve 300 elders by year three of the program.

CEI attempted to pursue a Medicaid contract with the state of California either through a waiver or by establishing itself as a provider-sponsored organization (PSO), however, it soon realized that the processes required to obtain the approval and waivers necessary to become a PSO and/or to pool mental health and substance abuse funds were lengthy and too cumbersome to continue. As a result, CEI shifted its focus and began negotiations with the Alameda Alliance for Health, a local managed care organization, to secure a Medicare+Choice contract for its dual eligible enrollees. Unfortunately, this partnership also fell through and CEI made the decision to forego formally integrated care and to focus instead on chronic care management via acute and supportive services. In this endeavor, CEI received a grant from the California HealthCare Foundation to develop a care management strategy and protocol and has also worked with California’s In-Home Supportive Services program to help the state create a continuum of care for elderly dual-eligibles.

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Today, CEI’s Serving Seniors in Environments of High Risk program is geared primarily toward chronic care management. It has developed a nurse-driven case management model that focuses on assessment, patient and family health education, and community-based long-term care services for high-risk dual eligibles. In addition, SSEHR developed a number of disease management protocols aimed at providers who interact with the targeted population. Although SSEHR never succeeded at implementing a comprehensive capitated program, the risk screening tools and services, such as adult day health, it developed for the dual eligible population have been institutionalized as fee for service components of a comprehensive range of services provided jointly by CEI and its partner, the Over 60 Health Center, a federally qualified medical center in Berkeley, California.

The Center for Elder Independence’s SSEHR program experienced all of the barriers confronting other comprehensive capitation-based models, including lengthy state and federal approval processes, inexperienced partners, and lack of government support. While CEI did not have the internal capabilities to overcome these barriers, it was able to improve care for this population and continue to provide lessons for other entities eager to learn from its successes and failures.

Corporation for Supportive Housing
Through the development of the Health, Housing, and Integrated Services Network (HHISN), the Corporation for Supportive Housing (CSH) in Oakland, California, sought to expand access to health and social services for formerly homeless people and low-income adults with chronic conditions. HHISN aimed to develop a unique and replicable model for creating a network of public and private agencies to deliver and finance integrated housing, health care, and social services in San Francisco and the nearby Alameda and Contra Costa counties. HHISN sought to serve its target population by bringing together landlords and health care and social service providers working in the fields of primary health care, mental health, substance abuse treatment, and specialty care, who often serve the same consumers, but rarely work in an integrated, coordinated fashion. HHISN’s goals were to:

- Provide integrated, flexible services;
- Establish appropriate, risk-adjusted capitation rates for health care services;
- Overcome the barriers inherent in categorical funding that limit the pooling of resources; and
- Document the cost-effectiveness of the intervention.

Project staff worked at both the program level and the system level, to enhance integrated service delivery capacity by establishing multidisciplinary care teams linked to housing and develop the core administrative infrastructure to provide a comprehensive array of health care and related services.

HHISN successfully brought together more than 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. CSH served as a fiscal intermediary, applying for and receiving funds on behalf of the service providers,
collecting data, and ensuring proper reporting. This made it easier to draw on funding sources with categorical limitations. In addition, the project established 10 Integrated Service Teams to deliver primary health care, client-centered treatment for mental health and substance abuse, as well as other health and supportive service (including employment opportunities), all linked to stable, affordable housing. While each team varied based on the needs of consumers at each site, the Integrated Service Teams generally consisted of a:

- Primary care physician;
- Licensed clinical social worker or other professional staff with clinical skills and linkages to mental health and substance abuse treatment;
- Community member with personal experience in dealing with homelessness, mental illness, substance abuse or HIV/AIDS to provide peer support;
- Vocational or employment counselor;
- Housing specialist/coordinator;
- Social activities resource; and
- Money-management counselor.

By 1999, HHISN had served almost 1,000 individuals. In addition, CSH has worked with housing and mental health service providers to implement new services based on the HHISN model in San Mateo, Santa Clara, and Marin counties. A post-grant study conducted by the University of California at Berkley found that participants in HHISN had a 58 percent decline in emergency room use, a 57 percent decline reduction in hospital inpatient days, and virtually no use of residential mental health facilities.

Although HHISN continues to serve consumers in California today, the project was unable to meet its goal of establishing risk-adjusted capitation rates to finance managed care health services through the network. This was largely the result of a lack of readiness and capacity to do so among many of the network’s participating organizations as well as the existence of policy barriers within Medicaid, which does not pay for a variety of the service available through the HHISN model.

HHISN remains particularly relevant for people with disabilities who need long-term support and services. By linking trusted community-based housing and health or social services organization, HHISN offers people with disabilities a trusted resource for helping them navigate an overwhelmingly fragmented system. Housing will continue to play an important role in future managed and long-term care models, in particular those that focus on maintaining consumers in the community. The HHISN project, though it did not accomplish all of its goals, made contributions that will help other similarly motivated organizations achieve further breakthroughs.

*Independence Care System*

Independence Care System (ICS) received a planning grant through BHS to design a model for providing long-term care in a full-service managed care organization to severely disabled and/or chronically ill Medicaid clients in New York City.
ICS began operation in 2000 and today provides a wide range of health and social services for over 700 Medicaid-eligible members with physical disabilities in New York City.

ICS realized not long after it began the planning process that a full capitation model that included hospital inpatient and outpatient services would be difficult to achieve. The State Department of Health wanted a Medicaid only, partially capitated model. The State legislation that was enacted in 1997 authorizing managed long-term care plans, including ICS, adopted this approach. As a result, Medicaid includes all long-term care, prescription drug, dentistry, and podiatry in the capitation rate that ICS receives. All acute care services are billed fee for service. For the dual eligibles that make up roughly 50 percent of ICS’ membership, Medicare is billed directly for its covered services.

Despite the somewhat scaled-back approach ICS took in terms of financing, the organization has developed a highly interactive and successful program model based on three fundamental premises:

1. People with disabilities need medical services episodically while their daily living needs are primarily social and, as such, their service system should blend the social and medical models of care.
2. Each individual with disabilities has unique needs and preference, which must be recognized and addressed.
3. People with disabilities typically know a great deal about their bodies and needs and can, with professional back-up to facilitate system navigation, often take the lead role in planning and managing their own health care and social supports.

At the heart of ICS’ program model is an interdisciplinary, consumer-centered care management process in which either a nurse or social worker serves as the primary case manager. The care team works closely with each individual consumer soon after enrollment to develop a care plan that is then reviewed every four months and reassessed annually. However, ICS strives to provide services that go well beyond the more traditional care management process. Over the last five years, the organization developed five program areas that combine care management and direct services to better support the needs of ICS consumers. These program areas are:

- Pressure Ulcer and Intervention Program;
- ICS Wheelchair Purchase and Repair Service Program;
- Home Care Aide Services Program;
- Consumer-Directed Personal Assistance Services; and
- Social Activities Program.

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ICS has achieved great success in providing a wide range of health and social support services to people with disabilities in a coordinated and community-based setting. By enabling consumers to remain active participants in their own lives through a holistic approach, ICS provides new motivation for keeping their health status intact. Though it was forced to take a more incremental approach to managed long-term care, ICS has developed a distinctive skill set and knowledge base that will help it expand the scope and population for whom it provides care in the future. ICS expects to expand its service area to Brooklyn in December 2005 and still plans to pursue full capitation down the road. In the meantime, it has developed a model from which many states can learn.

*Wisconsin Department of Health and Family Services*

Wisconsin’s Department of Health and Family Services received both a BHS planning and implementation grant to develop and implement a community-based managed care program called the Wisconsin Partnership Program (WPP). In addition, it received subsequent support under RWJF’s MMIP. The overall goal of WPP is to provide a more responsive health and long-term care system for Wisconsin that improves both access and quality of the care provided. In addition Wisconsin 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.

WPP developed two models of integrated acute and long-term care, one for frail elderly and one for people with disabilities. Both models of care are provided through a collaborative team approach. First, the state collaborates with the Centers for Medicare and Medicaid Services as well as with non-profit community-based organizations (CBOs). The CBOs collaborate with the state as purchaser and with health and long-term care providers who deliver services and collaborate with each other and with the consumer’s family. WPP’s care management model centers around interdisciplinary care teams that are responsible for the provision of a comprehensive set of acute and long-term care services. The team includes a nurse, nurse practitioner, social worker or independent living coordinator, the consumer, and the consumer’s primary care physician. WPP began as a partially capitated Medicaid pre-paid health plan in December 1995, providing services through four community-based organizations in five counties in Wisconsin. By 1999, the program had converted to a fully-capitated, dual Medicaid and Medicare waiver that combines Medicaid and Medicare funds into one funding stream. Overall, the Wisconsin Partnership Program has increased consumers’ ability to live in the community. In addition, WPP has improved the quality of health care service delivery while containing costs.

Since the BHS grants ended, state funds have been appropriated to sustain the program, which has also expanded into additional counties. In 2004, WPP was providing integrated care to 1,644 people in six counties in Wisconsin. The success of the program inspired the state of Wisconsin to experiment with a more flexible county-based model, Wisconsin Family Care, which is extending managed long-term care to additional

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portions of the state. WPP, 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.

Operationally Useful Lessons for the Next Generation of Managed/Integrated Long-Term Care Programs

Of the 32 original *Building Health Systems for People with Chronic Illnesses* (BHS) projects, a number provide valuable insight into the common characteristics of successful managed and/or integrated long-term care programs. This subset consists of five innovative demonstration projects that were all home- and community-based and achieved success that continued beyond the conclusion of the BHS program. Several of these projects were, and remain, literally at the cutting edge. All provide operationally useful lessons for future innovative systems of long-term care on issues related to

- Working with federal and state agencies;
- Financing;
- Quality assurance and improvement;
- Integrating medical, behavioral health, and social services;
- Developing an interdisciplinary team model; and
- Consumer direction.

The following section details each of these lessons and offers critical considerations for future investments in innovative delivery systems for people with long-term care needs.

1. The Political Process: Working with Federal and State Agencies

**Lesson 1:** Working with government agencies takes considerable time and patience, but getting buy-in and cooperation is critical to eventual programmatic success.

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 a quick nor an easy process and often requires considerable time, patience, and persistence. As a result, many attempts to innovate within Medicaid and/or Medicare have gone nowhere because of state or organization frustration with the political process. However, those who do persevere are able to achieve a level of programmatic success that is otherwise unattainable.

The Albert Einstein Healthcare Network 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 communication and decision-making. PCPP staff felt they spent significant amounts of time during the planning stage
relaying information to each participating entity to ensure that all of the relevant agency staff were kept up to date. In addition, there were separate chains of command for each partner 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 PCPP, which seemed quick to state government representatives but painfully slow to program staff. Another result of working with numerous state and local agencies was that each member came into the program with a different motivation for participating that ranged from finding long-term solutions to the constant and unnecessary emergency and acute care utilization of the personal care home population (Albert Einstein Medical Center), to expanding the use of the waiver program (Philadelphia Corporation for Aging), to responding to a call for more community-based options (Pennsylvania’s Department of Public Welfare). While none of these motivations were mutually exclusive, it took considerable time on the part of the program staff to move the project forward in a way that made each participant happy while at the same time meeting the overall goals of the project.

The Wisconsin Partnership Program (WPP) worked very closely with multiple state and federal agencies to integrate Medicaid and Medicare primary, acute, and long-term care services and financing. The program worked extensively with the Healthcare Financing Administration (known today as the Center for Medicare and 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, and while many other states interested in implementing similar programs backed out as a result of the lengthy planning and approval time, Wisconsin continued until it had achieved its goal. Program staff emphasize the need to make contact with the appropriate government agencies/partners early on in the process and to be patient since putting all the necessary infrastructure in place takes time. WPP also found it absolutely essential to address disconnects between Medicaid and Medicare to achieve full integration of care. While the silo nature of the two programs and the tension and potential for cost-shifting that exist between them is common knowledge, the areas in which the two programs are completely disconnected can be just as important and are often overlooked. One such example is that each program has its own prescribed dates for member enrollment and disenrollment. This is a seemingly small conflict, but one that can have tremendous impact when attempting to streamline both programs into one. According to WPP staff, resolving this and similar problems requires in-depth working knowledge of both Medicaid and Medicare regulations. As a result of its diligence, the Wisconsin Partnership Program has become a national model for delivering services to frail elderly and people with disabilities, successfully demonstrating that integrating acute and long-term care is feasible, can be implemented in the community, and works for multiple age and target groups in both urban and rural settings.

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21 Wisconsin Department of Health and Family Services, op.cit.
Next Step: While the planning and implementation of projects that involve collaboration with and/or approval from one or more government entities can take a significant amount of time, demonstration projects and similar grant opportunities are not always built around such a lengthy timeline. As a result, potential funders of future initiatives or demonstrations aimed at addressing systems change should allow for an appropriate amount of time for planning and development or should consider facilitating innovative ways to achieve the same end through different and less time and/or resource intensive means. For example, the Medicare Advantage Special Needs Plans created by the MMA may provide a new opportunity for states to integrate Medicare and Medicaid financing and services without a waiver, thus saving time and money.

2. Financing: Integration, Capitation, and Risk Adjustment

Lesson 2: Negotiating, setting rates and integrating funding streams are extremely slow and onerous processes, but can make dramatic differences in the quality and coordination of care.

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. In the recent past, many states that had hoped to pursue innovative programs aimed at capitating acute and/or long-term care services provided either through Medicaid alone or Medicaid and Medicare, chose not to as a result of the lengthy processes required to do so. At issue is the question of how risk should be distributed across payors and suppliers. For programs aimed at high-risk populations that require 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 that will make or break their overall success. For many organizations to go fully at risk for these populations, a higher capitation rate is needed. However, frailty adjustors and risk-adjustment are not easy to agree upon; they both require gathering a significant amount of information regarding past, current, and predicted service utilization that is made more difficult by the fact that managed and integrated care models are expected to change utilization patterns. However, those initiatives that have been able to wade through the arduous financing processes have found that the reward, namely a lack of the resources and flexibility needed to achieve more coordinated care, was well worth the wait.

One of the biggest challenges ICS faced during the design and implementation of its managed long-term care program for people with disabilities was risk adjustment. In fact, ICS spent most of the early years in an intense negotiation with the state over this critical financing issue. Getting the state to set a rate was relatively easy; early on in the process the state decided that it would use average fee-for-service rates as the upper payment limit (UPL) and subtract 5% from the UPL to establish a rate. They agreed to pay a

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22 Saucier, op.cit.
higher rate for those members between the ages of 21–65 who require 12-24 hours of personal care services a day because of the disproportionately high costs associated with this level of service. However, the state would not entertain the idea of further risk adjustment, particularly extending this additional rate cell to members over 65. As a result the state actually paid less for the elderly because the rates were based on the total over 65 year old eligible population and not just physically disabled individuals over 65 like those in the plan. ICS received a capitation rate of $5,200 per member per month (PMPM) for a person age 64, but once that same individual turned 65, it only received $3,200 PMPM in 2003. Although only 10% of ICS’ members were elderly, ICS lost approximately $1M a year in the first few years of operation because the ICS members over 65 were functionally similar as those 21–65, but the rates were significantly different. This situation was finally corrected in the 2004 rates. After a few years of battling with the state to no avail, and operating in a deficit in the process, ICS realized it was going to have to operate within the state’s rate-setting framework.

ICS actively sought to change its case mix to meet the State’s concerns about serving an average population. It essentially managed the intake of members who needed exceptionally high hours of personal care and sought to increase the number of members with lower needs. Although ICS was disappointed that the state would not embrace risk adjustment for rate setting, it realized that continued growth in enrollment and managing member mix would allow it to ensure sustainability. At the same time, while the percentage of members requiring 12–24 hours of personal care has been reduced from 27% to 22%, this figure is still two and a half times more than the percentage in the Medicaid fee-for-service system.

The Albert Einstein Healthcare Network was also unable to achieve its initial goals of integrating funding streams with risk adjustment due to reluctance from state and local partners. Einstein had originally hoped to pool Supplemental Security Income, Medicaid capitation, and Medicaid waiver funding. Project staff believed that by doing so, PCPP would be able to eliminate waste, improve cost-efficiencies and use “savings” to fund additional services. Unfortunately, the time and effort devoted to obtaining approval for pooled funding hindered Einstein’s ability to pursue this goal. As a result, PCPP staff began looking at risk adjustment to increase the capitation rate for high-risk residents, taking two approaches. First, it worked with Health Partners, a hospital-owned managed care organization in the Philadelphia area that works primarily in Medicaid managed care. Health Partners soon backed out of the project in large part because of the PCPP’s inability to provide it with the data it needed to develop a risk adjusted approach. PCPP next turned to the State, which was not willing to adjust the capitation rate for high-risk residents despite their need for more services.

One of the Center for Elder Independence’s main objectives in creating the Serving Seniors in Environments of High Risk project was to develop a capitation model for Medi-Cal, California’s Medicaid program. CEI and its partner organization, the Over 60 Health Center, first attempted to reach this objective by pursuing a Medicaid contract with the state of California through a waiver to establish themselves as a PSO. However, the PSO option proved not to be viable as California state government was not sufficiently
motivated to facilitate a capitated approach. As a result, CEI began negotiations with the Alameda Alliance for Health, a managed care organization, to obtain a Medicare managed care contract instead and focus on members who were dually eligible for both Medicare and Medicaid. Unfortunately, following an actuarial analysis, Alameda Alliance realized that it did not have the experience necessary for taking on the risk of caring for this subpopulation and backed out.

Not surprisingly, the only state-based BHS grantee to integrate financing, WPP, was the only one able to overcome all the administrative and regulatory barriers to fully capitate its program. However, it took the WPP several years to do so, requiring two separate CMS waivers to combine the Medicare and Medicaid resources into one funding stream. WPP began operations as a partially capitated Medicaid pre-paid health plan in 1995 and was not able to convert to a fully capitated, dual Medicaid and Medicare plan until 1999. In return for single fixed payment per person, the Wisconsin Partnership Program receives additional flexibility that affects programmatic success in several ways. First, it improves the collaboration and overall success of the multidisciplinary care team. Second, the scope of services provided can be much more comprehensive. For example, a physician’s phone consultation can be paid for by WPP where they it is not normally paid for by Medicare and Medicaid.23 Finally, the overall coordination and quality of care provided can be greatly improved when a single capitation rate is used.

**Next Step:** Fully capititating and integrating financing for long-term care users, and dual eligibles in particular, is a challenge that is infrequently solved. When viable models do emerge, they are likely to occur in areas where inpatient utilization, institutionalization and associated costs are higher and provide more incentives for overcoming regulatory and financial barriers. In these situations, state and federal governments are more amenable to innovation and negotiation, providing potential risk-taking entities with more room (and reason) to experiment. In places where these factors are not yet present, time is needed to develop infrastructure and the will to undertake such efforts, and an incremental approach is often more successful. Potential funders of managed/integrated long-term care programming should consider investing in longer term projects aimed at building the necessary infrastructure for agencies to work with state and federal partners to build these innovative financing models.

### 3. Quality Assurance and Improvement

**Lesson 3:** During the design phase of the care model, a quality assurance/improvement process should be developed to protect, maintain, and improve consumer health outcomes and satisfaction.

Assuring, improving, and evaluating quality in health and long-term care can be used in a number of ways including: determining whether a facility meets established guidelines or

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23 Wisconsin Department of Health and Family Services, op. cit.
standards, rewarding best practices, creating clinical protocols, restructuring the processes of care, or improving cost-efficiencies. As Americans age and the need for long-term care services grows, assuring and improving the quality of care delivered, as well as the patient’s quality of life, will become increasingly important. Unfortunately, evaluating quality within long-term care is particularly challenging, thanks to the myriad services, providers, and delivery systems that are involved in long-term care 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 require significant amounts of time and resources and are more likely to succeed in programs that build existing models of health care.

The overall success of the Wisconsin Partnership Program (WPP) has allowed it to move away from the regulation of structure and process and toward outcomes. Because few programs are able to collect Medicare and Medicaid data, very little is known with regard to “good performance” in acute and long-term care for frail elderly and people with disabilities. A WPP goal is to collect data to establish performance benchmarks for community-based long-term care. In addition, WPP works with the University of Wisconsin at Madison to evaluate program staff and consumer experiences and to develop cutting-edge quality assurance protocols and quality indicators based on consumer values. As a result of this ongoing research, consumer-defined quality indicators have been included in the internal quality assurance systems used by each of the WPP’s community-based organizations. Quality improvement studies have also been developed for use with each of the participating organizations to test and, eventually, refine quality indicator measures. Through these internal processes, WPP is able to ensure that its members receive the highest quality care possible.

Independence Care System (ICS) has recently taken on annual quality improvement projects to maintain and improve consumer health outcomes. To date, these projects have mainly focused on disease and condition management, around areas that are particularly relevant to the needs of their members such as pressure ulcer assessment and interventions. In 2005, for example, ICS established three QI focus areas. The first was on increasing access to specialty care provided for people with multiple sclerosis, which affects approximately 20 percent of ICS members. ICS developed and provided consumer education about osteoporosis as well. Because close to 25 percent of ICS’ members have diabetes as a secondary diagnosis, the last quality improvement project was around diabetes self-management focused on yearly eye and foot exams as well as providing all new members who have diabetes with glucometers. In general, ICS tries to be strategic about the types of quality improvement projects it undertakes, focusing primarily on the conditions that can have the most impact on care.

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25 Wisconsin Department of Health and Family Services, op.cit.
Next Step: Long-term care as a whole currently lacks a consistent and appropriate set of performance standards and benchmarks. Grant-making organizations should consider investing in research and demonstration projects aimed at developing quality improvement standards, measures, and infrastructure specific to both long-term care on its own as well as how it is integrated with primary and acute care.

4. Integrating Medical, Behavioral Health and Social Services

Long-term care has been historically dominated by the traditional medical model, in which focus is placed primarily on an individual’s disease or condition rather than his/her overall needs. However, this model fails to take into account the effect an individual’s behavioral health and social supports has on their physical health. Long-term care users, in particular, are more likely to require the care of many specialty providers to treat individual conditions and it is easy for these consumers to come to see themselves as others may—as the sum of their different conditions. The result is often a sense of futility and social isolation. The lives of low-income long-term care users may be further complicated by additional worries of housing, food, paying bills, and the like. Not surprisingly, behavioral health is a substantial need among those who require long-term care services. High quality care programs, including several implemented by BHS grantees, are those that take a more holistic approach to patient care, including social support services and behavioral health services in their continuum of care.

Lesson 4A: The social context is as important as maintaining good health status; consumers who are active participants in their lives will have increased motivation for keeping their health status intact.

Some of the most successful long-term care programs are those that integrate medical and social services and, in doing so, improve consumer health status and overall quality of life. Many organizations, including ICS and CSH, found that by including social and other supportive services in their continuum of care, consumers are more likely to take a more proactive role in their health care.

ICS places a great deal of emphasis on making social and supportive services available to their consumers. ICS offers two discrete services, in addition to care management, as part of services that are not a part of traditional Medicaid:

- **Wheelchair Purchase and Repair Service Program.** The majority of ICS’ members rely on some type of wheeled mobility device for their primary means of mobility such as a manual wheelchair or scooter. ICS provides access to a physical therapist specialized in seating and mobility services for those needing new equipment. Wheelchairs are not issued without a home visit to ensure the equipment can fit through hallways and into elevators. In addition, ICS provides

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26 Surpin, op. cit.
prompt repair service that allows participants to stay mobile. Most repairs are
done within the person’s home; otherwise they are taken to the ICS repair shop
and returned within 48 hours. In addition, members can take a wheelchair care
and maintenance training class and have access to the ICS repair shop to perform
preventive maintenance such as lubrication, monitoring battery capacity, and
tightening bolts.

- Social Activities Program. In 2005, ICS launched a new social activities program
that included: organized activities such as support groups (i.e., Weight Watchers)
and affinity groups (writers, Artists on Wheels); classes in ESL/GED, computer
skills, woodwork, and social events. In addition, ICS supports athletic teams and
advocacy walks.

CSH’s HHISN successfully linked housing and other supportive services to medical
services within community-based settings. Housing, in particular, is an important and
often overlooked aspect of long-term care, particularly for individuals with extremely
low-incomes for whom homelessness is often a problem as well as for those who want to
transition out of a nursing facility but do not have family or homes of their own to go
into. In general, housing conditions can greatly enhance or impede a person’s functional
disability, independence, and quality of life. CSH defines supportive housing as “a
unique type of housing setting that lets homeless and disabled people connect to homes,
health care, jobs, and their communities.” In addition to housing, CSH provides
supportive services that assist members with their mental and medical illnesses, facilitate
going and keeping jobs, and offer peer support. In particular, HHISN offered access
counseling, vocational services, money management workshops, and social and
recreational activities. Through HHISN, CSH hopes to help those who are chronically
homeless and/or disabled replace “chaos with stability in their lives” so that they can
focus on obtaining access to needed health care.

**Lesson 4B:** Behavioral health is an important (and often ignored or misunderstood)
element of this population's care; however it is often more difficult to integrate than
other medical and social support services.

There is a substantial need for behavioral health services among consumers of long-term
care. Studies have shown that behavioral and physical health are very much connected;
individuals with physical problems are more likely to have mental health problems and
vice versa. In addition, an institutional bias remains in the area of behavioral health,
because those who reside in the community have difficulty accessing the behavioral
health system (aside from medication) despite persistent need. Whether or not people
with long-term care needs are able to access this type of care can have a profound impact
on the success of their overall health care.

The Albert Einstein Health Care Network faced significant pushback from the state
regarding the participation of personal care home residents that require substantial mental

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27 R.I. Stone, *Long-term Care for the Elderly with Disabilities: Current Policy, Emerging Trends, and
health services. During the planning process, the State Advisory Committee expressed their concern that the Personal Care Partnership Program not become a mental health demonstration project. Because the number of residents who have mental health diagnoses is higher in Philadelphia personal care homes than in the rest of the state, the Advisory Committee sought to make the population served by the program more representative of the state, and placed a 50 percent cap on the number of clients with mental diagnoses that could participate. Project staff, however, felt that this was not a representative cap given the needs among this population nationally. In addition, the cap created programmatic challenges by limiting the facilities that could participate in the program and often made it challenging for the program staff to establish and maintain the program census.

In general, ICS had more difficulty engaging providers to participate in the ICS care model than the program leadership originally expected. This was most acutely felt among mental health providers despite the overwhelming need among ICS clients. As a result, ICS has not been able to offer the type of services, such as group therapy, it originally envisioned and is using more informal support groups to fill the gap.

Like ICS, the Center for Elder Independence included behavioral health services in its original capitated care model. However, in the course of pursuing a Medicaid contract, CEI soon realized 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 CEI’s internal capacity. As a result, CEI gave up integrating behavioral health services into its overall capitation model and tried to focus on the coordination of acute and long-term care services instead.

In general, those organizations that achieved some level of success in integrating behavioral health services into models of acute and long-term care coordination used an interdisciplinary care team approach. HHISN employs a number of counselors and social workers as part of its care team as a means of addressing the needs of the populations it serves and motivating individuals to change abusive and risky behavior. As a result of the care team, HHISN clients have received client-centered treatment for mental health and substance abuse and have been able to stay out of residential mental health facilities.

**Next Step:** BHS went a long way to spur innovation in the integration of physical, behavioral health, and social support services. However, while social supports have been integrated with relative ease, behavioral health remains overwhelmingly carved-out. As a result, grant-making organizations should consider focusing more closely on the connection and coordination of physical and behavioral health by funding additional pilot programs, demonstration projects, and/or evaluations of existing models in order to both foster innovation and disseminate lessons in this area.
5. The Interdisciplinary Team Model

**Lesson 5:** Forming a team of medical and social service professionals can improve the coordination of care for frail elders, thereby reducing fragmentation, improving overall quality of life, and enabling them to remain in their communities.

Long-term care users generally require varied and complex services found 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 which is then often supported by informal care given by friends and family members. Coordinating care delivered by these multiple, disparate entities can be challenging for both providers and consumers. While consumers struggle with navigation issues and try 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 BHS grantees have found success through a care management approach that uses a multi-disciplinary group of providers in order to increase care coordination and improve consumer outcomes and satisfaction.

HHISN created 10 Integrated Service Teams to deliver and coordinate care for people with chronic conditions in San Francisco, Alameda, and Contra Costa counties. These teams included primary care providers such as physicians and nurse practitioners that were linked to local full-service clinics; licensed clinical social workers or other clinical staff with linkages to mental health and substance abuse treatment services; and peer support members. In addition, the Integrated Service Teams included or were closely connected to individuals responsible for arranging social and vocational activities.

Albert Einstein Health Care Network’s PCPP created a model of care that centered around an interdisciplinary care team. This team is comprised of a nurse practitioner from a local hospital and a care manager from the Area Agency on Aging system, both of whom work in concert with each participating resident’s community physician. The role of the nurse practitioner is to provide primary care as well as formal and informal training to facility staff around topics of patient care specific to each resident’s care needs; the care manager is responsible for coordinating all services. Together, the interdisciplinary team monitored the enhanced array of services provided through the PCPP in order to support residents in maintaining their health status. In general, the interdisciplinary team model worked exceedingly well for the PCPP. Many of the program executives believe that the nurse practitioner, in particular, is a critical piece of the PCPP’s medical model of care, creating new opportunities for care monitoring that would otherwise not exist. The nurse practitioner’s interactions with residents allowed for personalized care, which helped to improve the quality of life for consumers and improved quality of care overall. The nurse practitioner’s ability to work independently, prescribe medication, and manage complex chronic conditions led to improved health outcomes for residents. The program’s evaluation showed stabilization of care for the study group as well as
numerous examples of avoided hospitalization and nursing home placement.\textsuperscript{28} In addition, the staff training that the nurse practitioner provided improved job performance and led to improved consumer health outcomes.

WPP found that the collaborative, interdisciplinary team model is a successful route to achieving the major goal of the program, to improve access to high quality, coordinated and community-based care while containing costs. In fact, the team approach was unanimously deemed essential by those involved in the program. The greatest impact of the team approach is in facilitating integration of service delivery. According to the Wisconsin Department of Health and Family Services:

> When consumers are served by an integrated and interdisciplinary team, rather than by multiple providers, each individual is treated as a whole person rather than as a collection of broken parts, illnesses, and conditions. The team brings together various areas of expertise, and the collaboration between team members makes it possible to spot the relationship between a consumer’s different needs—between the consumer’s health, psychosocial, and daily living needs. This makes it much more likely that problems will be solved before they interact and create new complications. And it makes it much less likely that care will be fragmented, redundant, or discontinuous. The team makes decisions jointly, enhancing the information each discipline has about what the other disciplines know and do. The result is higher quality care.\textsuperscript{29}

In addition, the WPP found that with the integration of management and financing that result from a model of care centered around an interdisciplinary team model with team members that come from multiple programs and participating agencies, there is a better understanding of what consumer needs are, what resources are available, and what the relative costs and benefits are for both the program and the consumer. In addition, the shared financial responsibility removes any motivation to shift costs and allows the team, as a whole, to better identify unnecessary spending.

**Next Step:** The experience of the BHS grantees demonstrates the success of the multidisciplinary team approach to care and its ability to coordinate and improve the overall quality of care for people with complex acute and long-term care needs. Here, potential funders should focus on the dissemination of best practices by helping organizations that currently employ the team model to develop operationally useful toolkits and/or protocols that will assist other organizations and agencies to integrate these approaches into broader, more scalable initiatives for integrating care.

\textsuperscript{28} Campbell, op.cit.
\textsuperscript{29} Wisconsin Department of Health and Family Service, op.cit.
6. Consumer Direction

Lesson 6: Consumer self-determination is a practical method of improving the quality of life for the chronically ill and frail elderly and is essential for achieving high quality, patient-centered care.

Historically, health care systems have been paternalistic and care planning has not typically incorporated consumers’ views and preferences. Today, however, patient-centered care is a hallmark of quality and many organizations are pushing for consumers to have increasing responsibility and decision making power about the type and amount of care they receive. Developing systems of care that fully enable consumers to choose the type and quantity of care they receive, and who delivers it, is challenging and made more so when individuals who have impairments are restricted in their ability to communicate their choices. However, several of the BHS grantees successfully engaged consumers by making them an active part of the care planning process, whether it is via the hiring of personal assistance workers, additional interactions with providers, or as a member of the care team itself.

The Albert Einstein Healthcare Network’s Personal Care Partnership Program continues to operate under the belief that each and every personal care home resident has the right to express some preference regarding the type and scope of care they receive. As a result, PCPP relies primarily on the care planning process to achieve consumer self-direction. Consumers who are interested in participating in the development of their care plan during an initial assessment are allowed to discuss and even in some cases select the type of care services they receive. In addition, by including a nurse practitioner as a member of the care team, the PCPP was able to increase the number of times consumers routinely interact with providers increasing opportunities to listen to consumer concern and feedback.

The Wisconsin Partnership Program (WPP) took consumer participation in the care planning process a step further by making him or her a member of the multidisciplinary team along with health care providers and social services coordinators. Because the team, as a unit, is expected to collaborate on the development of the care plan, coordinate all service delivery, and be responsible for decisions regarding expenditures and subsequent outcomes, the consumer can play a large role in the decision-making process regarding his or her care. Program staff have made it quite clear that “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.” Choice is in the hands of the consumer even before he or she enters the program as all care is delivered in the member’s home or a setting of his or her choice. In addition, consumers are able, and even encouraged, to keep their previous physician. Finally, WPP works both with health care providers with experience in acute care or skilled home care roles and with social service providers located in community settings to

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31 Wisconsin Department of Health and Family Services, op.cit.
reconcile different perceptions of what high quality, patient-centered care means so that they can work together to ensure consumer health and satisfaction.

Independence Care Systems (ICS) is facilitating consumer choice and engagement within its care model through a number of methods. ICS starts with a Personal Assistance Services Program in which members are given the ability to hire and supervise their own personal assistants through a contracted agency. For the 20 percent of its members who participate in this program, ICS also provides consumer training on their roles and responsibilities in terms of recruiting, hiring, and supervising their personal assistants; personal assistant training on the role and responsibilities of the assistant; and a central registry of personal assistants to aid consumers and assistant in connecting with each other. In addition to the Personal Assistance Services Program, ICS also encourages consumers to be actively involved in the development of their care plan. As part of this, care managers work with participants to help them distinguish between needs and wants, to develop personal goals, and to learn how to make choices. ICS recognizes that not every consumer is going to want or be able to be as actively engaged in his or her care as others and as a result the level of consumer involvement varies based on interest and medical need.

**Next Step:** In today’s health care system, consumer choice and self-determination are considered hallmarks of quality care. However, there is a significant difference between choosing a home care worker and making complex medical decisions. In reality, consumer direction is not a single approach but a term that encompasses a range of models that vary in how much decision-making control is shifted to the consumer. The more complex the decision, the more information consumers will need to make informed choices. True consumer self-determination requires an extensive amount of information geared to the culture, language, and literacy levels of its audience to ensure that consumers are able to make informed choices. Grant-making organizations interested in fostering innovation in consumer directed long-term care should consider investing in developing information systems aimed at supporting consumers in their role as decision-maker, evaluating current models of consumer-directed care, and/or disseminating best practices to other interested parties.

**Conclusion**

Medicaid long-term care has come a long way in the last 20 years — evolving from a primarily institutional set of services to one that increasingly emphasizes care delivered within the home and/or community, from fee-for-service to managed care, to the relatively recent exploration of integrating care across services and funding streams. However, numerous obstacles have prevented these changes from taking place on a wider scale. Despite the introduction of home- and community- based services waivers in the 1980s and their subsequent popularity and growth, institutional services remain the only entitlement within Medicaid long-term care. Institutional care still accounts for the majority of Medicaid long-term care expenditures despite the popularity of home- and
community-based services among consumers and support from Olmstead and the long-term care advocacy community. In addition, while interest among states in managed long-term care has been high, they have faced numerous barriers in efforts to implement these types of programs and many such initiatives have been terminated during the development process. Thus, while managed care continues to dominate the Medicaid market for primary and acute care, the Medicaid managed long-term care market is still at a very early stage with only a small portion of the potential market enrolled.

With the baby boom generation about to reach retirement age, long-term care will become an even more critical and perhaps controversial part of the overall health care debate within the United States. It will certainly continue to evolve and is likely to push harder to shift funding away from institutional care and toward the home- and community-based service options that are viewed as able to provide the highest quality care and improve consumer satisfaction and quality of life for the greatest cost-efficiencies. This is evidenced by Vermont’s recently approved Long-term Care Plan, an 1115 Medicaid demonstration waiver, which is taking unprecedented steps to end the institutional bias within Medicaid and to establish home- and community-based services as part of the program’s entitlement. Under this program, adults with disabilities and the frail elderly will have equal access to both nursing facility care and home- and community-based services and may choose according to their needs and preferences. In addition, the recently proposed Improving Long-Term Care Choices Act of 2005, introduced by Senators Grassley, Bayh, and Clinton, seeks to give states the option of providing home- and community-based services as part of their State Medicaid Plan. In doing so, the bill aims to provide states with new flexibility to design long-term benefits that will reduce the reliance on costly institutional settings without the need for waivers. In addition, the bill seeks more stringent needs-based eligibility criteria for institutionalized care. Together, these provisions would make home- and community-based services a more formal part of the Medicaid long-term care benefit package.

Over the next 20 years, we can expect to see an even greater shift toward the integration of acute and long-term care services and of Medicare and Medicaid financed care. Integrated care programs represent a new and important opportunity for achieving better care outcomes and greater cost-efficiencies for the highest-cost subgroup in the health care system. The early successes of CMS Medicare-Medicaid demonstrations, including MSHO, MnDHO, the Wisconsin Partnership Program, and Massachusetts Health Senior Care Options, has led numerous states to turn their attention toward integrated care in hopes of achieving similar outcomes. The Medicare Modernization Act’s Special Needs Plans are likely to present new opportunities to mainstream the types of systemic improvements that are being tested by state integrated care demonstrations and to allow for integration across services and funding streams for dual eligibles in a much simpler manner. This fact has not been lost on many Medicaid managed care organizations, 46 of which had been approved to operate as Medicare Advantage SNPs as of June 2005. In addition, the legislation proposed by Senators Grassley, Bayh, and Clinton also contains a provision to remove administrative barriers to integrating acute and long-term care services for the duals such as identification cards, marketing requirements and others.
The experiences of many of the grantees of The Robert Wood Johnson Foundation’s *Building Health Systems for People with Chronic Illnesses* clearly illustrate the types of challenges and opportunities that state agencies and other organizations face during the development and implementation of the first managed/integrated long-term care programs. Their successes and setbacks have helped pave the way for future programs by highlighting the importance of social and behavioral health services in providing holistic care to consumers with long-term care needs, documenting the success of multidisciplinary teams in integrating services and improving coordination and quality of care, displaying the potential of consumer self-determination, as well as the potential pitfalls that come with working with government agencies to achieve fully capitated, risk-adjusted, and/or integrated models of care.