GRANTWATCH

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Foundation Work In Long-Term Care

Abstract

Health foundations have invested in services, research, and advocacy to improve the financing and delivery of long-term services and supports. This article describes some of the broad array of approaches they have taken—in such areas as aging in place, assisted living, “culture change” in nursing homes, quality improvement, augmenting the workforce, and paying for care.

Over the next twenty-five years, the nation’s elderly population will grow rapidly, with the greatest increase coming among those over the age of eighty-five. Additionally, the number of people over age sixty-five is expected to double, from thirty-five million to seventy-one million, between 2000 and 2030.1 People are living longer, but often with one or more chronic diseases. The country is also becoming more diverse. By 2030, the proportion of the elderly population who are African American will double; it will triple for Hispanics.2

Ten million elderly and disabled people currently use long-term care services.3 Their care accounts for more than 10 percent of national health expenditures, or about $200 billion a year.4 As the population ages, the demand for affordable, high-quality long-term services and supports will increase. And gaps in the current system will only worsen if no action is taken.

Papers in this issue of Health Affairs document challenges with the current system, including inconsistent quality, troubling workforce problems, inadequate financing, and costs that can bankrupt patients and families.

Foundations have addressed many of these issues. They have made investments in services, research, and advocacy that can provide models and lessons for reform efforts.

Long-Term Care Grant Making

The Grantmakers In Health (GIH) Resource Center includes a descriptive database of work from more than 400 foundations and corporate giving programs that fund in the health area.5 Not all projects mentioned have been evaluated, and available evaluations often focus on intermediate results. Many of the funders noted have extensive portfolios in long-term care and provide detailed information about their activities on their Web sites.

Rather than a comprehensive discussion of all activities in this field, this paper presents illustrative examples of foundations’ efforts in long-term care. Because of space limitations, it omits important areas such as transportation, palliative or end-of-life care, and information or assistive technologies.

Aging In Place

Most people needing long-term care live in the community and want to stay there. Their health and social needs have led a number of foundations to focus on aging in place. The United Hospital Fund (UHF) established its Aging In Place Initiative in 1999 to support residents of so-called naturally occurring retirement communities, which are formerly multigenerational communities that now have high concentrations of seniors. The initiative fosters public-private partnerships to provide health and social services needed by residents of these communities. There are now eighty programs in twenty-five states. The model’s success has led to more than forty funding earmarks in Congress to support program development in these communities.

The United Hospital Fund provides guidance for program development through the Naturally Occurring Retirement Community Blueprint Project Web site (cofunded by the Fan Fox and Leslie R. Samuels Foundation, the Daniels Fund, and the Harry and Jeanette Weinberg Foundation Inc.). The initiative’s most recent effort, the Naturally Occurring Retirement Communities Health Indicators Project, focuses on identifying key health risks in fifty-four sites in New York State, implementing interventions to address them, and assessing the interventions’ effectiveness. All sites have completed the project’s first phase, collecting baseline data on health risks.

The Horizon Foundation in Columbia, Maryland, launched an Aging In Place Initiative in 1999 in collaboration with the Howard County Office on Aging and local nonprofits. The initiative now provides affordable in-home care, home-based mental health services, and fall prevention services. The initiative identified the need for a single, reliable source of information and assistance for older adults. In response, the foundation, with the federal Administration on Aging and county Office on Aging, created Maryland Access Point. It provides service information and referrals to adults over age fifty and others with disabilities, and it averages 2,400 inquiries each
month. The foundation continues to support projects to strengthen the initiative’s capacity to anticipate and meet the needs of seniors. The Robert Wood Johnson Foundation’s (RWJF’s) Community Partnerships for Older Adults program seeks to bring greater coherence to the fragmented array of services available to elderly residents. The eight-year, $20 million initiative created fifteen broad-based community partnerships that directly involve seniors and fashion local solutions to meet locally identified long-term care needs. The types of results reported thus far include reduced rehospitalizations; new zoning ordinances for senior housing; and reduced cultural barriers to services for minority and immigrant seniors.6

Assisted Living

Assisted living arrangements offer options for the elderly and disabled who can no longer remain at their original homes but do not need skilled care in nursing homes. As of 2004, between 600,000 and one million Americans were residing in assisted living facilities.7 Growing interest in alternatives to nursing homes is likely to increase demand for assisted living and for improvements in current facilities. In 2008 the Pew Charitable Trusts funded the Pennsylvania Health Law Project to establish the Pennsylvania Assisted Living Consumer Alliance, a coalition of consumer organizations that advocates on regulatory standards for assisted living facilities in such areas as quality, safety, and patients’ rights. The alliance generated active consumer input on the state’s first-ever draft assisted living regulations. That input resulted in multiple revisions before final regulations were issued.

In 1992 the Robert Wood Johnson Foundation supported an effort to create affordable assisted living options in rural communities. The program—titled Coming Home: Integrated Systems of Care for the Rural Elderly—addressed two core issues: real estate development and financing of assisted living for people with limited means; and paying for residents’ health and personal services. In this six-year, $6.5 million project, the NCB Development Corporation provided short-term financing from a revolving loan fund for initial development costs, technical assistance on real estate and project financing issues, and guidance on gaining Medicaid reimbursement for residents’ health and personal services.

The program scored clear successes. Nearly 100 facilities were operating or in development in 13 states by mid-2006, demonstrating that financial and regulatory barriers to creating assisted living for people with low incomes can be overcome. Other results have varied by site, but some sites have noted improvements in residents’ physical and mental health and higher staff satisfaction. Challenges have included inconsistent community backing for some projects and difficulties in obtaining the agreement of states to waive or modify Medicaid regulations to allow service reimbursement.8

Culture Change

Growing interest in patient-centered care, quality improvement, and patient satisfaction has prompted foundations to promote culture change in nursing homes. Early support from the Commonwealth Fund, the Robert Wood Johnson Foundation, the Retirement Research Foundation, and others fostered the development and adoption of new consumer-directed care models. The Eden Alternative and Wellspring models emerged in 1994, and in 1997 the Pioneer Network was established to promote a culture-change movement nationwide.

Since 2003 the Robert Wood Johnson Foundation has supported the Green House Project to transform traditional institutional care into home-like settings. Self-managed teams of workers care for residents according to their individual needs and preferences. Residents have private rooms and baths, define their daily schedules, and share common living areas. The model is designed to meet government regulatory standards and reimbursement criteria—a key to its viability. An early study funded by the Commonwealth Fund indicated that residents in Green Houses had better quality of life and better emotional well-being than those in traditional settings.9 In 2005 the Robert Wood Johnson Foundation funded NCB Capital Impact to develop fifty Green Houses by 2010. The program actually reached that goal ahead of schedule, in December 2008.

The Commonwealth Fund conducted the 2007 National Survey of Nursing Homes. It found that facilities incorporating culture change principles had higher occupancy rates, less staff turnover, and lower operational costs.10

Improving Quality Of Care

Improving quality in long-term care involves institutions, providers, consumers, and their caregivers. Foundations have contributed to quality improvement in a variety of ways over the years. Work by the Commonwealth Fund, Retirement Research Foundation, and others to protect the rights and safety of nursing home residents led to important improvements, including passage of the Nursing Home Reform Act, a key piece of the Omnibus Budget Reconciliation Act (OBRA) of 1987.

The Commonwealth Fund’s Quality of Care for Frail Elders program seeks to transform long-term care facilities into good places to live and work. Its goals are to identify and spread models of resident-centered care, develop nursing home leadership for transformational change, and promote public policy options that support these efforts. Among its varied projects, Commonwealth provided support in 2006 for Advancing Excellence in America’s Nursing Homes, a national effort supported by forty-nine local networks. Participating nursing homes work on at least three of eight measurable goals related to clinical quality and organizational improvement. Commonwealth has awarded grants for development of Web-based educational materials, building network capacity to lead quality improvement efforts, and engaging additional facilities. The Centers for Medicare and Medicaid Services (CMS) has cofunded the effort. By 2008, more than 44 percent of U.S. nursing homes were participating in the campaign. Participating organizations are improving quality faster than those not involved.11

Information about quality of care
and patient satisfaction contributes to quality improvement. It empowers consumers to make better choices when selecting services and creates incentives for institutions to provide high-quality care. The California HealthCare Foundation launched the California Nursing Home Search (CalNHS) Web site in 2002 to provide comparative information—initially just on nursing homes and, later, on a spectrum of providers. The Web site included information on staffing levels, turnover, wages, quality measures, complaints, and costs. In November 2009 the foundation and its partner, the University of California, San Francisco, launched CalQualityCare, an upgraded version of the previous site.12

Foundations have also targeted their funding on specific quality issues. For example, some have focused on the crucial period of transition from hospital to home. In 2000 the John A. Hartford Foundation provided $1.2 million to the University of Colorado to promote the adoption of the Care Transitions Foundation launched the California HealthCare Institute, helped create a national office for policy and advocacy in Washington, D.C., with support from the Atlantic Philanthropies and the SCAN Foundation.

Family and friends are a key source of unpaid support for people with long-term care needs. An estimated fifty-two million Americans, or 31 percent of the adult population, are informal caregivers.17 Caregiving is a key area of foundation activity. The United Hospital Fund has been a leader in this work since launching its Families and Health Care Project in 1996 with planning funds from the Nathan Cummings Foundation. A key part of this project is the fund’s Next Step in Care, which has developed Web-based guides and tools to help family caregivers and providers work together more effectively during patient transitions.

Among its many grants supporting family caregivers and health professionals, the Langeloth Foundation and the Robert Wood Johnson Foundation have funded Better Jobs Better Care in 2003. This four-year, $15.5 million initiative was designed to test new approaches to recruitment and retention of high-quality direct care workers.16 Coalition in demonstration projects in five states established goals for both provider practice and public policy change. All projects focused on compensation, opportunities for advancement, and organizational support for workers. Evaluators reported that although the projects varied on important dimensions, the initiative demonstrated that diverse stakeholders could work together to develop and implement provider practice interventions. The five projects had only moderate success in achieving their policy goals.

Another program, operating in the community, is the Geriatric Interdisciplinary Teams in Practice Initiative, the model uses special training nurses to help patients and their family caregivers manage their posthospital care at home. Patients who received the intervention found to have lower rehospitalization rates. By 2007, more than 100 hospitals had adopted the program.

Foundations have also supported quality improvement in home health care. Funding from Atlantic Philanthropies enabled the Visiting Nurse Service of New York to establish and operate the Collaboration for Homecare Advancement in Management and Practice program, the first national initiative to promote geriatric home care excellence. In 2008 Hartford added support for the Visiting Nurse Service to expand the use of this program to home care agencies nationwide. Evidence-based guidelines for home care best practices were produced in a research and consensus process.

Workforce

Health professionals, direct care workers, and family caregivers all play vital roles in care for the elderly and disabled. The United States faces potential shortages across all of these groups. For each person over age eighty-five today, there are more than thirty potential caregivers between the ages of twenty and sixty-three, but by 2050 it is estimated that there will be only eleven.14 A number of funders mentioned in this paper supported the Institute of Medicine’s (IOM’s) report, Re-tooling for an Aging America: Building the Health Care Workforce, released in April 2008. The Hartford Foundation has been a leader in expanding the supply and geriatric competence of physicians, nurses, and other professionals who care for elderly patients.

Most hands-on care for those needing long-term care services is provided by paraprofessionals. Low wage and benefit levels, lack of advancement opportunities, risk of work-related injuries, and emotional stress contribute to high staff turnover—as high as 67 percent for certified nurse assistants working in nursing homes in 2007.15

Funders have worked to change these conditions. The Robert Wood Johnson Foundation and the Atlantic Philanthropies funded Better Jobs Better Care in 2003. This four-year, $15.5 million initiative was designed to test new approaches to recruitment and retention of high-quality direct care workers.16 Coalition in demonstration projects in five states established goals for both provider practice and public policy change. All projects focused on compensation, opportunities for advancement, and organizational support for workers. Evaluators reported that although the projects varied on important dimensions, the initiative demonstrated that diverse stakeholders could work together to develop and implement provider practice interventions. The five projects had only moderate success in achieving their policy goals.

PHI, based in Bronx, New York, and formerly named the Paraprofessional Healthcare Institute, helped create and implement Better Jobs Better Care. PHI works to improve the lives work environments of direct care workers. It lists twenty foundations as ongoing contributors including the Atlantic Philanthropies; the Retirement Research Foundation; and the Hartford, Jacob and Valeria Langeloth, Charles Stewart Mott, Nathan Cummings, Public Welfare, and Samuels Foundations. These organizations recognize PHI as a leader in training, technical assistance, and advocacy to improve conditions for direct care workers. PHI recently expanded its policy activities by establishing a national office for policy and advocacy in Washington, D.C., with support from the Atlantic Philanthropies and the SCAN Foundation.

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Among its many grants supporting family caregivers and health professionals, the Langeloth Foundation has funded the National Family Caregivers Association to develop and implement its Communicating Effectively curriculum for family caregivers. The program prepared 450 trainers, who trained more than 11,000 caregivers.

Those providing care to frail elderly and disabled people also include neighbors in the community. In 1983 the Robert Wood Johnson Foundation funded a demonstration program to establish local interfaith volunteer projects to provide informal care to frail elders and the disabled. Additional funding from the Atlantic Philanthropies, the Commonwealth Fund, Pew, and the Public Welfare Foundation helped expand the number of projects and lower their startup costs. In 1993 the Robert Wood Johnson Foundation decided to take the program to scale through its Faith in Action initiative. The initiative has demonstrated that diverse congregations can be mobilized to meet the needs of frail elderly and disabled people. Today there are more
than 600 programs nationwide serving 75,000 people annually.18

Organizing And Paying For Care
In seeking to improve access to and payment for long-term care, foundations have supported projects that also involve government. The Program of All-Inclusive Care for the Elderly (PACE) is one example. Originally developed by On Lok Inc., a San Francisco–based nonprofit, in the 1970s, PACE is the only fully integrated model of care for the frail elderly. Major grants from the Robert Wood Johnson, Hartford, and Retirement Research Foundations enabled On Lok to test a risk-based financing system encompassing Medicare, Medicaid, and private payers. When federal legislation provided Medicare and Medicaid waivers for ten additional sites, foundation support enabled On Lok to provide technical assistance for replication.

Congress made PACE a permanent part of Medicare in 1993. The original PACE funders, as well as many state and local foundations, have been instrumental in continued replication of the PACE model.

The Robert Wood Johnson Foundation’s Partnership for Long-Term Care demonstration project, launched in four sites in 1987, brought together private insurers and state Medicaid programs to offer long-term care insurance protection. Policy holders receive private coverage up to a specified dollar amount and thereafter become eligible for Medicaid assistance for long-term care services. Positive results from the demonstration sites prompted Congress in 2005 to give all states the option of developing Partnership programs. The foundation is funding technical assistance for new programs through its Long-Term Care Partnership Expansion Program.

The Robert Wood Johnson Foundation also joined with the U.S. Department of Health and Human Services to fund a separate three-state demonstration program. This one, called Cash and Counseling, was intended to give Medicaid consumers more control over both what supportive services they receive at home and who provides them. The program offers frail elderly and adults with disabilities the option of managing a budget and making decisions regarding services and personal care workers outside of standard Medicaid rules.

Based on the demonstration results, states no longer need to apply for a federal Medicaid waiver to offer Cash and Counseling. The original three states grew to fifteen. With funding from the Department of Health and Human Services, the Robert Wood Johnson Foundation, and the Atlantic Philanthropies, the Boston College School of Social Work recently created the National Resource Center for Participant-Directed Services to provide technical assistance to states on replicating the Cash and Counseling Model.

On The Horizon
Foundations have focused on improving long-term care services, informing policy decisions, advocating for change, and supporting programs that provide models for reform. The newest entry into this field is the SCAN Foundation, established in 2008, which also funded this thematic issue of Health Affairs.

The SCAN Foundation proposes to make a national priority of creating a sustainable continuum of high-quality care for seniors. It intends to do so by advocating for an increased commitment by policymakers to reform and by providing them with options for change. Accompanying its policy work are efforts to raise public awareness, advance promising service delivery models, and support the rapid adoption of innovative technologies that benefit both the elderly and their caregivers. In its first year, SCAN has supported meetings and publications that serve the policy community. It created the SCAN-HealthTech Center on Technology and Aging and has partnered with Kaiser Health News to support free, in-depth coverage of health policy issues affecting the elderly.

Agenda For Action
Over the past few decades, improvements have been made in both long-term care policy and services, but much remains to be done. Funders have given limited attention thus far to some important issues that should become part of philanthropy’s agenda. With the growing diversity of the population, strategies to reduce racial and ethnic disparities in care will become increasingly important. New technologies offer hope for sustaining independence of the frail elderly and disabled, and foundations can contribute to ensuring their appropriate use and constraining their impact on costs.

Foundations are well suited to test models for integrating acute, chronic, and long-term care; or to facilitate connections between health care and community-based services, both of which are vital to the well-being of frail elderly and disabled people. Concerns about workforce shortages and the projected increase in the ratio of elderly to potential caregivers call for further foundation efforts to build an adequate pool of front-line caregivers, ensure that health professions training adequately addresses the full range of needs of long-term care patients, and strengthen supports for family caregivers.

Access to Medicaid long-term care benefits is at risk whenever state budgets are stressed. Funders have supported advocates to protect beneficiaries, and other grantmakers should follow their lead. The outcome of the national debate on health care reform is likely to affect future efforts to provide insurance coverage for long-term care. Building public support for this policy agenda and developing affordable options for individuals and taxpayers are both consistent with foundations’ roles as agents of social change. The challenges ahead are considerable, but the aging of the population and its need for long-term care services are relentless. Responses from all sectors, including philanthropy, will define whether those needs are adequately met.

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NOTES


2 Reynolds CF, Lim SH, Stowell K, Keller Q, Leana C. Getting to equal: meeting the health service needs of aging minorities. Presentation at: How will we meet the health service needs of an aging America? 16th Annual Princeton Conference of the Council on Health Care Economics and Policy; 2009 May 20–21; Princeton, NJ.


5 The GHI database is a tool for tracking funders’ activities. It cannot, however, be used to analyze trends in giving. It does not capture all health grants or all work of foundations that define themselves primarily as health funders.


12 CalQualityCare can be accessed at http://calqualitycare.org


16 Gerontol. 2008;48(Special Issue I). This issue of the journal Gerontology contains articles that provide background on the initiative, results of funded research projects, and initial evaluation results.
