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Overview of the Robert Wood Johnson Foundation grantmaking in Long-Term Care

Promoting Consumer Choice and Innovative Financing Models

Lessons Learned From 25 Years of Supporting Long-Term Care

A Demographic Shift and an Uncertain Outlook

The aging of the American population represents a significant challenge–on both social and economic fronts–that will continue to grow in the coming decades. More of us will need assistance with long-term care as we age, and many of us will want to have choices about how, where and from whom we receive such assistance. As more people want to receive services in a home- or community-based setting, rather than an institutional one, demand for noninstitutional models of service delivery is on the rise. From a strictly economic perspective, long-term-care expenditures represent one of the largest financial risks facing older Americans today: few people have saved adequately (or purchased insurance) for the costs of potential long-term-care needs; state Medicaid budgets are overwhelmed; and Medicare covers little in the way of long-term care.

A History of Promising New Approaches in Long-Term Care

In the 1980s and 1990s, cognizant of these demographic shifts and changing trends, the Robert Wood Johnson Foundation directed resources toward improving home- and community-based services; testing the integration of health and long-term-care services in a variety of settings; and measuring the implications of several innovative financing demonstrations.

Today, after more than 25 years and an array of programs focused on service delivery and financing in long-term care, the Foundation's projects have advanced the conversation around consumer choice, quality care, and financing issues. Programs such as *Cash & Counseling,* The GREEN HOUSE Project, and the *Partnership for Long-Term Care* promote consumer choice and innovative financing models in long-term care. Many of the lessons learned from these and other Robert Wood Johnson Foundation programs can help to inform future long-term-care policy reform efforts, possibly serving as templates for models yet to be created.

Building on Lessons Learned

Over the years, several Robert Wood Johnson Foundation programs have tested groundbreaking concepts related to choice and financing in long-term care. One early example was the *Rural Hospital Program of Extended Care* (informally known as the "swing bed" program) that took place in 1981. This program provided funding for rural hospitals to use their excess beds to provide long-term-care services. Such a shift not only benefited rural hospitals in financially precarious conditions, but also addressed the nursing home shortage at the time–and proved to be an innovative model for using existing government funds for long-term care in nontraditional settings.

Recognizing that people who need help with long-term-care services can come from any income bracket and any geographic setting, the Foundation worked with real estate developers to support affordable assisted living in rural areas through

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Robert Wood Johnson Foundation

Route 1 and College Road East
P.O. Box 2316
Princeton, NJ 08543-2316

www.rwjf.org

Coming Home: Affordable Assisted Living for the Rural Elderly (1992–2005). Evaluation of this program indicated that the daunting task of meeting the long-term-care needs of our nation's seniors requires collaboration by all stakeholders, including government officials, housing experts and long-term-care providers. The Foundation's *Medicare Medicaid Integration Program* (1996–2006) tested the operation and design of delivery systems that integrate long-term care and acute care services under combined Medicare and Medicaid capitation payments for elderly people; this program is now a model for integration of care nationwide. The Foundation's *Promoting Long-Term Care Policy Development and Debate* (2001–2007), based at Georgetown University, is an effort to establish a broader understanding of the financing of long-term care, develop a range of policy solutions and seek new answers to the question of how to cope with long-term-care challenges. The program has produced fact sheets and policy papers on timely topics such as spousal impoverishment protections under Medicaid.

Starting Small and Replicating Success

The Foundation has been a leader in promoting programs on a small scale, and then supporting what works through broad replication initiatives. The *Program for All-Inclusive Care of the Elderly (PACE)* program, the origination of which dates back to the 1970s, is perhaps the best example of how effective this approach can be. The small demonstration program that took place more than two decades ago is now an effective, comprehensive long-term-care service delivery and financing program for our nation's frail elderly and has received permanent provider status by the federal government.

This pilot demonstration model is one that the Foundation has supported through many programs. Cash & Counseling, which started out as a three-state demonstration in the 1990s, is now being implemented in 12 more states. The Green House Project began with one home in Tupelo, Miss., in 2003 and, following a promising pilot site evaluation, is now being replicated in dozens of communities across the country. The Partnership for Long-Term Care program, originally a four-state demonstration initiated in 1987, is now available to every state and the District of Columbia. With these programs, the Foundation started small with an innovative concept, determined which aspects were successful, and promoted replication and expansion where it was warranted.

Cash & Counseling: Putting Dollars and Decisions in the Hands of Consumers

In the early 1990s, the confluence of three trends pointed toward the need for a new direction in the delivery and financing of long-term-care services:

1. The number of people with age-related disabilities was on the rise (especially when viewed against a backdrop of a rising life expectancy);
2. People with disabilities were indicating a preference for autonomy in decisions about long-term care; and
3. Government resources for long-term care were being spread more thinly.

The Medicaid program, at the time, restricted its coverage for supportive services at home to assistance provided by licensed agencies. The Cash & Counseling program, funded jointly by the Robert Wood Johnson Foundation and the U.S. Department of Health and Human Services, was the first of its kind, offering frail elders and adults and children with disabilities the option to manage a budget and determine what mix of goods and services would best meet their personal needs.

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Specifically, the Cash & Counseling model consists of the following elements. First, eligible consumers receive a traditional assessment and subsequent care plan, and a dollar value is assigned to that care plan. The consumers are then provided with sufficient information to make a personal choice between managing an individualized budget and their own services, or going the traditional route with services and financing coordinated by the Medicaid agency. If the individual consumer decides to manage his or her own budget and care planning then the consumer, together with an assigned counselor, develops a spending plan to meet his or her personal assistance needs–essentially help at home with activities like bathing, dressing and meal preparation. The spending plan can also include equipment, services, or other items that increase a participant's independence or ability to manage a disability. The counselor is also available to help identify care assistants or otherwise help the consumer gain access to available community resources.

An independent evaluation, by Mathematica Policy Research, Inc., of the initial three-state demonstration concluded that the Cash & Counseling program:

1. Improved the quality of life for participants;
2. Reduced participants' unmet needs for care; and
3. Significantly improved the lives of participants' primary caregivers.

The evaluation also showed that under the program Medicaid costs did rise, but that was primarily because enrollees actually received more of the care that they were authorized to receive. However, nonpersonal Medicaid costs, such as those for institutional care, were slightly lower under the program, possibly off-setting the higher personal care costs.

In sum, findings show that Cash & Counseling programs can be implemented successfully by states to serve populations with various disabilities and in various age groups, thereby increasing beneficiary satisfaction and improving disability-related health outcomes, and these programs need not cost Medicaid more than traditional services. Today, based on the encouraging results from the initial three states, Cash & Counseling programs are being implemented in 12 more states. Moreover, as a result of passage of the Deficit Reduction Act of 2005, states can now offer the Cash & Counseling option within their regular state Medicaid plans without first obtaining a waiver.

The Green House Project: A Novel Approach to Residential Long-Term Care

For many Americans who need and want assistance with long-term care, the only available residential options are skilled nursing homes or other large, institutional facilities. Yet studies show that more Americans than ever before desire to receive assistance in smaller, community-based settings and to continue to live life much in the same way they did before moving into a long-term-care setting. The premise for the Green House Project, created by geriatrician William Thomas, is the recognition that older Americans deserve better options when they need intensive medical and personal assistance and can no longer live at home. The Green House Project's philosophy is that all people–regardless of age, frailty, mental capacity, or income level–have the right to receive the help they need together with the comforts of home.

The Green House approach is an innovative noninstitutional model for providing long-term care that emphasizes resident autonomy with regard to both service delivery and care environment, while meeting required state and federal regulatory and reimbursement

criteria. The Green House Project is supported by the Robert Wood Johnson Foundation. NCB Capital Impact, working with its partners, provides technical assistance, pre-development loans and ongoing support to assist providers who want to establish one or more Green House homes.

Each Green House home is a self-contained house for approximately 10 people; each resident (referred to as an "elder") has his or her own bedroom and a full bathroom. Each Green House home has a central hearth with an adjacent open kitchen and dining area easily accessible from the private bedrooms, allowing elders to control their own levels of social engagement. The household operates on no fixed schedule; instead, the people who work and live in Green House homes collaborate to create a daily routine that supports individual needs and wishes. Elder assistants help the elders with activities of daily living and cook and clean in the homes. A clinical support team visits according to what is required by regulatory mandate and according to residents' needs and preferences. It is in this manner that elders living in Green House homes receive needed assistance and care without that care becoming the sole focus of their existence.

The first skilled nursing Green House homes, based in Tupelo, Miss., were the subject of a two-year study conducted by a team at the University of Minnesota. The study compared outcomes of the Green House model to outcomes from a traditional nursing facility on the same campus, as well as another nursing facility operated by the same organization in another part of the state. The research found that the Green House model gave elders more privacy and control in their daily lives and that elders had lower rates of depression, utilized fewer anti-psychotic drugs, and maintained better levels of physical function. In addition, the study found that due to resident, family, and staff satisfaction, the Green House homes experienced significantly lower annual staff turnover rates and fewer complaints at the state level. From a financing perspective, the initial results showed that the model could be achieved within current Medicaid rates.

Currently, The Green House Project has 10 operating Green House campuses in nine states and 20 organizations in development in an additional 16 states. The Green House Project is also working closely with national organizations and federal agencies, including the Centers for Medicare and Medicaid Services (CMS), to find ways to make it easier for nursing home providers to adopt the Green House model. This program can provide an example of how long-term-care dollars could be allocated differently to better support the quality of care and quality of life that older Americans deserve.

The Partnership for Long-Term Care: A Public/Private Partnership Model Encourages Shared Responsibility

Long-term-care expenditures represent one of the largest financial risks facing the elderly today. Given that the average cost of a year of long-term care was $72,240 in 2004; the average length of time that an individual needs assistance with long-term care is two and a half years; and few people have purchased long-term-care insurance to help cover these costs, it is easy to see that many Americans may face an economic crisis in the years ahead. Moreover, overloaded state and federal Medicaid budgets are on the same path toward disaster, with long-term-care costs on the rise. The Robert Wood Johnson Foundation's Partnership for Long-Term Care project, initially a four-state demonstration that began in 1987, was an effort to address this oncoming crisis.

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Under the Partnership program, states are provided with resources to plan and implement public/private partnerships. The program joins private long-term-care insurance companies with Medicaid agencies to offer high-quality insurance protection against impoverishment from the high costs of long-term care. Under the program, consumers who purchase such policies are insured for long-term care up to a pre-set dollar level through the private insurer. Once the private insurance is exhausted, the consumers can continue receiving assistance with long-term care under Medicaid, without spending down their assets, as is usually required to meet the criteria for Medicaid eligibility.

The public policy implications of this program are significant for individuals, families and government programs. By participating in this program, individuals take on at least some personal responsibility for their own care, potentially enabling states' Medicaid programs to spend fewer dollars for these participants in the long run. Additionally, because participation in this program delays the point at which they qualify for Medicaid, fewer of these people will have to spend down all of their assets, and thereby avoid burdening loved ones with their long-term-care costs.

Results from the four participating states are very promising. For example, the sale of long-term-care insurance policies in Partnership states grew by 7 percent over a five-year period, as compared to no growth at all in non-Partnership states during that same time period. Perhaps more importantly, the data show that the individuals buying Partnership policies have a lower net-worth than those buying non-Partnership policies, which addresses some policymakers' predictions that only the wealthy will purchase long-term-care insurance.

The experiences of the Partnership model in the original demonstration states have also laid the groundwork for expansion of this program: as a result of the Deficit Reduction Act of 2005, the remaining 46 states and the District of Columbia can now create their own Partnership programs. The Robert Wood Johnson Foundation, in conjunction with the Center for Health Care Strategies, Inc., is providing technical assistance to states developing Partnership programs as part of the *Long-Term Care Partnership Expansion* Program.

Conclusion

By changing the law and removing the waiver requirement so that states can make Cash & Counseling part of their regular state Medicaid plans, Congress has made it likely that more elderly disabled Americans will ultimately be able to benefit from this program. And, similarly, now that federal law allows all states to offer Partnership plans, it is likely that fewer Americans will be forced to impoverish themselves in an effort to pay for their long-term-care needs.

The Green House Project is still in a relatively embryonic phase, when considered in relation to some of these more well-established programs. But the swell of interest and commitment by long-term-care providers across the country, as well as the evaluative outcomes indicating resident and caregiver satisfaction, indicate that the Green House model may well have promise on a broader scale.

After more than 25 years of work in long-term care, the Robert Wood Johnson Foundation hopes that lessons learned as a result of our programs can help to shape public policy and move the long-term-care reform debate forward in a useful and informed way.

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