

# Improving Health in an Aging Society

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Robert Wood Johnson  
Foundation

Chapter Two,  
excerpted from The Robert  
Wood Johnson Foundation  
Anthology:

**To Improve Health  
and Health Care  
Volume IX**



Edited by  
Stephen L. Isaacs and  
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*Published 11/2005*

## *Editors' Introduction*

The aging of the American population represents a significant social challenge, one that will increase over the next fifty years. From a strictly economic perspective, as the debates over Social Security and Medicare illustrate, retirement and health care commitments must be financed for a growing number of retirees. More broadly, society needs to decide how to make sure the elderly stay healthy as long as possible, lead productive lives, and receive access to good medical care.

What will challenge health providers, policy-makers, and families are the substantial inequalities that already exist within the elderly population and that promise to become even more pronounced in the future. Single, divorced, or widowed women as well as members of racial minorities—whose numbers will increase substantially—are especially vulnerable to debilitating chronic health problems, poverty, and unmet health and social needs as they age. As the older population grows, so will the number of vulnerable older people as well as the challenges involved in making sure that existing health, social services, housing, and environmental infrastructures have the capacity to serve them.

As Robin Mockenhaupt, Jane Isaacs Lowe, and GERALYN GRAF MAGAN have written in this chapter, an aging population is also an opportunity. They have set the Foundation's work in aging into a context of what society needs to do to promote the health and well-being of older adults. The chapter presents five propositions about how people can age in a healthy way. For each proposition, the authors present the research supporting the proposition and then discuss the relevance of various Foundation-supported programs to the proposition. Using this format, they are able to review the successes and failures of a broad range of initiatives and to suggest future paths that the Foundation might take.

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1. The authors would like to thank the following individuals who contributed to the development of various sections of the article: Jessica Siehl, Wendy Yallowitz, and Risa Lavizzo-Mourey.

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**D**eclining birth rates, aging baby boomers, and a series of life-extending medical and public health advances have contributed to a demographic change—the aging of the American population—that promises to have wide-ranging implications for all aspects of society. As one example, 20 percent of Americans are expected to reach retirement age by 2030, compared with only 4 percent in 1900.<sup>1</sup> Not only are older adults<sup>2</sup> especially vulnerable to debilitating chronic health conditions and unmet medical and social needs, but the substantial social and economic inequalities that already exist within the elderly population promise to become more pronounced.

This demographic shift is widely viewed as a growing crisis. Ordinary citizens and policy-makers alike often focus on fears that “greedy” older adults, who are wholly dependent on government programs, will deplete the nation’s financial resources at the expense of younger generations. These fears tend to divert public attention from a deeper question: What quality of life do we as a nation want to provide for our older citizens? How we answer this question will affect the quality of life for all Americans in the decades ahead. It will also raise a number of challenges.

Over the past twenty-five years, the Robert Wood Johnson Foundation’s efforts to address the health and supportive service needs of older adults have been driven by its concern that the acute care system has not been adequately meeting the complex needs of persons with disabilities and chronic illness. The Foundation has tried to improve systems of supportive services for older adults and persons with disabilities largely by making grants to improve home- and community-based services and to integrate health and long-term care services.

In the late 1990s, cognizant of the body of scientific evidence that behavioral strategies such as physical activity and tobacco cessation lead to improved health,<sup>3</sup> the Foundation made healthy communities and lifestyles a priority. This led to the development of programs for older adults that promoted physical activity, civic engagement, and elder-friendly communities. The Foundation has been able to use the program strategies at its disposal—including model development, convening, demonstrations, research, policy analysis, and communications—across the spectrum of aging from illness prevention and health promotion to civic engagement and long-term care.

The Foundation’s efforts to improve the quality of life of older Americans can be viewed in the context of the efforts of the federal government and of other foundations. The Administration on Aging (part of the Department of Health and Human Services), which was created in 1965 by the Older Americans Act, makes grants to states for community planning and services programs, research, training, and demonstration projects in the field of aging. Federally funded Area Agencies on Aging fund nutrition, health promotion and disease prevention, in-home care, and other services that are provided locally to low-income seniors. The National Institute on Aging (part of the National Institutes of Health) was established in 1974 to provide leadership in, among other areas, aging research, training, and the dissemination of health information.

Many regional, community, and family foundations have made aging a grantmaking priority. Grantmakers in Aging, made up of foundations working in the field, provides support to its members and to those interested in expanding into this field. Among national philanthropies, the Hartford Foundation has focused on aging and health for the last twenty-five years, with a primary emphasis on training of physicians, nurses, and social workers. For more than twenty years, the Retirement Research Foundation has been funding service programs and research that address aging and retirement issues. More recently, Atlantic Philanthropies has given priority to workforce issues and civic engagement in its program on aging and health. California's Archstone Foundation funds only programs affecting older adults, such as those to reduce falls and to improve care toward the end of life.

As awareness about the aging of the American population spreads, so too does the sense that an increasing older population represents a challenge rather than an opportunity. Health experts familiar with the latest statistics issue dire warnings about the veritable plague of frailty, chronic illness, and dementia that threatens to affect most, if not all, members of a future aging cohort. Similarly, policy-makers worry about the growing number of older people who will expect to receive Social Security checks each month, and those whose projected health care costs will overburden Medicare and Medicaid budgets.

Many concerns about the graying of America are warranted. After all, any population group that grows exponentially—whether that group comprises school-age children or eighty-five-year-olds—puts pressure on societal infrastructures. However, focusing only on the challenges has helped perpetuate the stereotype that old age has to be a time of disability and dependency. More important, it has diverted public attention from the fact that older people do continue to learn and grow after retirement, and that many continue to make significant contributions.

Drawing on the literature and on the Robert Wood Johnson Foundation's experience in the field, we have identified five propositions that can serve as a framework for discussions about aging and can help advocates, foundations, government agencies, and older consumers develop policies and programs that will promote the health and well-being of older adults.

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**Proposition 1: Older Age Does Not Have to Be Characterized by Disability and Dependency; Older People Can Make Meaningful Contributions to Their Community and to Society**

**The Rationale**

Research suggests that while some older people face age-related declines, others continue to function as well as younger individuals; that many older people are healthy; and that age-related learning losses are often exaggerated and can be mitigated through intellectual stimulation and other strategies.<sup>4,5</sup> Research also suggests that old age doesn't have to be a time of isolation. In fact, most older people cope well with the losses that come with aging, despite conventional wisdom suggesting that the elderly are an isolated group for whom widowhood, retirement, and the departure of grown children brings about an irreversible loss of social attachments and community ties.<sup>6</sup>

Many older people are already making significant contributions to society. One-third of adults over age fifty-five work outside the home, and many provide valuable assistance to family members by raising 3.8 million grandchildren and providing child care to an additional 6 million families.<sup>7,8</sup>

Older volunteers—from well-known people like President Jimmy Carter to ordinary citizens who donate their time in soup kitchens and schools—are demonstrating that engaged older adults can make a difference. And research shows that active individuals are more likely to remain physically and mentally fit and that those who are not regularly engaged with others are more likely to be in poor health.<sup>9,10</sup>

Although many older people are involved in their communities, many more could be. Despite the potential for engaged older adults to make lasting contributions, the majority of seniors do not spend any significant time in service to their communities. The number of older volunteers has increased over the past few decades, but older Americans still volunteer less than any other age group. In part, this relative inactivity can be attributed to the fact that few communities have a formal infrastructure that effectively channels and manages the contributions of older people. Indeed, many public and private agencies and organizations across the country dedicate themselves to serving the elderly, but few agencies dedicate themselves to helping the elderly serve others.

While some older people find their fulfillment in volunteer activities, others remain active by staying on the job beyond normal retirement age. Eighty percent of baby boomers—those born between 1946 and 1964—say they plan to work at least part time during their retirement. About a quarter will work because they have to—they'll need the additional income to ensure their financial security. Thirty-five percent will work for the sheer pleasure of it.<sup>11</sup> The remaining percentage will structure paid employment to fit into their lifestyle and finances. This option may become less of a possibility once a worker reaches his or her late fifties. Despite the Age Discrimination in Employment Act, older workers throughout the nation continue to face both overt and subtle threats to their continued employment. Social Security and pension policies may force some older retirees to forego employment so they don't experience a reduction in their benefits. Employers may refuse to hire or promote older workers, encourage their early retirement, or target them if layoffs become necessary. Those who remain on the job may find themselves cut out of training opportunities or filling positions that seem to have fewer responsibilities with each passing year.

Policies and programs that encourage older people to volunteer or to remain in the workforce, though important, have been shown to be far more effective if they are combined with initiatives that encourage lifelong learning among older people. Such learning opportunities could provide supplemental training to help older workers remain competitive in their own fields or start second careers after retirement. Learning that is aimed at self-enrichment could lead to more frequent and meaningful interaction among older people, and increased community engagement through volunteering. Fortunately, the availability of technology means that the homebound elderly don't have to miss out on these learning activities as long as they have a computer. Finally, programs that teach older people how to maintain a healthy lifestyle—for example, by sharing strategies that promote physical activity, a healthy diet, and early detection of disease—could help more Americans achieve a vigorous old age.<sup>12</sup>

### Foundation-funded Programs

The Robert Wood Johnson Foundation has initiated several programs to help older people use their talents to address specific needs in local communities. The Experience Corps grew out of research conducted during the early 1990s by Public/Private Ventures—a nonprofit organization that works to improve the effectiveness of social policies—on the need to mobilize greater adult support for young people growing up in poverty. With funding from the Corporation for National Service and the Retirement Research Foundation, Public/Private Ventures and the late John Gardner led the team that launched the program in 1998, with five initial pilot sites. Civic Ventures was soon created to develop the Experience Corps into a national movement that would encourage older Americans to undertake public service in order to meet serious unmet community needs. Experience Corps members, most of whom give fifteen hours a week, work one-on-one with elementary schoolchildren who need intensive help learning to read. What began as a pilot program in five cities has grown—with funding from the Robert Wood Johnson Foundation, Atlantic Philanthropies, and many community funders—to include more than 1,500 volunteers in thirteen cities across the country. Such intergenerational mentoring programs have been highly effective in helping at-risk children avoid first-time drug use, improve school attendance, boost academic performance, and steer clear of violent behavior.<sup>13</sup> In addition to its benefits for students, the Experience Corps has also been shown to enhance the well-being of the volunteers. Physical, cognitive, and social activity increased in volunteers, suggesting the potential for Experience Corps and similar programs to improve health for an aging population while simultaneously improving educational outcomes for children.<sup>14</sup>

Similarly, Family Friends, an organization established in 1984 with funds from the National Council on the Aging, the Administration on Aging, and the Robert Wood Johnson Foundation, enlists older volunteers to help the families of children who have disabilities or suffer from chronic illnesses. It now operates at forty-three sites nationwide. Family Friends expanded this approach and now works with other groups, including the homeless and HIV-infected children, and at-risk children in poor rural communities. Adapting this model of intergenerational mentoring to teen pregnancy prevention, the Foundation funded Family Friends in 1998 to launch Generations Involved in Future Trust, or GIFT. It is the first initiative in the country to match older adults with young people with the idea of averting adolescent pregnancy.

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### **Proposition 2: The Chances for Aging Successfully Can Be Improved by Physical and Mental Activity, Community Involvement, and the Use of Preventive Health Services**

#### **The Rationale**

Summarizing eight years of research conducted under the MacArthur Foundation's Network on Successful Aging, John Rowe and Robert Kahn suggest that older people who are at low risk for disease and disease-related disability, and who have a high level of mental and physical functioning, are likely to weather old age better than those who don't enjoy these benefits.<sup>15</sup> The latter are at a greater risk of frailty and cognitive decline in their later years. Disability rates among older people fell during the 1980s, and a growing body of research shows that when people make certain lifestyle changes—like increasing their level of physical activity or taking advantage of preventive health care services—they reduce their risk of developing disabling conditions.<sup>16</sup> Communities can foster successful aging by ensuring that the design of the built environment and the services provided in communities promote physical activity and help older citizens live independent and productive lives.

Research studies have shown the powerful effect that regular physical activity can have on health and well-being. The Surgeon General of the United States reports that regular physical activity can reduce an individual's risk of developing coronary heart disease, hypertension, colon cancer, diabetes, depression, and anxiety, and that it can improve mood and enhance a person's ability to perform daily tasks.<sup>17</sup> Moreover, a regimen of physical activity can help increase levels of "good" cholesterol, improve balance, alleviate the aches and pains of arthritis, and save health care dollars.<sup>18, 19, 20</sup> In spite of these benefits, however, less than a third of older people follow the recommendations of the Centers for Disease Control and Prevention and the American College of Sports Medicine for a minimum of thirty minutes of moderate-intensity activity on most days of the week.<sup>21</sup> It remains to be seen how many older adults will follow the more recent guidelines from the Institute of Medicine on healthy eating and physical activity.

On the bright side, older people appear to be interested in increasing their physical activity, even though they haven't succeeded in doing so. A nationwide survey conducted by AARP found that 63 percent of people age fifty and older believe that exercise is the best thing they can do for their health. Nearly three-fourths of the 2,000 survey respondents said they are interested in learning how to exercise safely. Seventy-one percent said they want help staying motivated, and two-thirds expressed an interest in learning how to set realistic goals for physical activity.<sup>22</sup>

Many of the diseases that plague older adults could be prevented or delayed, or their seriousness could be diminished, through more widespread use of preventive health services. Yet fewer than half of Americans receive the preventive health services that are currently recommended by the federal Preventive Services Task Force, such as counseling for tobacco cessation, screening for vision impairments, and vaccinations against influenza and pneumococcal disease.<sup>23</sup> Depressive symptoms occur in approximately 15 percent of community residents 65 and older, yet depression often goes undiagnosed and untreated.<sup>24, 25</sup> In addition, some cognitive declines, such as memory loss, can be prevented through good nutrition, regular exercise, and continued engagement in certain leisure activities.<sup>26</sup>

Institutionalization can often be avoided if frail older people can find ways to stay in their own homes. But the desire of four out of five Americans to stay in their homes may be frustrated as long as American communities are designed only for young, able-bodied individuals. Suburban and rural communities—where 72 percent of the elderly now reside—often fail to provide the kinds of amenities that foster independent living.<sup>27</sup> For example, narrow doorways, long staircases, and second-floor master bedrooms—standard features of most residential dwellings—guarantee that even the most beloved family home will quickly become the homeowner's worst enemy when symptoms of frailty or disability appear. In addition, communities that fail to provide convenient public transportation, pedestrian-friendly streets, and shopping areas that are within walking distance of housing guarantee that older people who lose their driver's license will also lose their independence.

Elder-friendly communities anticipate and plan for the inevitable changes that occur as people age. They provide affordable housing designed for the entire life span and make it easy to walk or take a bus to needed services. At their best, they offer access to health care, clean, safe streets, good jobs and service opportunities, and a rich array of social and cultural activities.

### Foundation-funded Programs

The Robert Wood Johnson Foundation has taken several steps to help older people increase their level of physical activity. A major Foundation initiative, *Active for Life*, is testing two promising strategies for getting large numbers of adults age fifty and older to incorporate physical activity into their daily lives and maintain an active lifestyle. The first strategy uses group-based problem-solving methods. The second emphasizes participation in individually selected physical activities, with telephone and e-mail follow-up. Nine grantees—they include aging, health, faith-based, recreation, and educational organizations—fund local organizations to carry out programs using one or the other of the strategies. An evaluation is assessing the process of reaching large numbers of midlife and older adults in their communities, and learning how organizations adapt program models. To support Active for Life, the Foundation funds a communications initiative, coordinated by AARP, aimed at helping communities promote physical activity, develop resources to help older residents become more active, and campaign for the removal of neighborhood barriers to physical activity.

Two related initiatives—*Active Living by Design* and *Active Living Research*—encourage community design, public policies, and communications strategies that promote physical activity. Under Active Living by Design, twenty-five community partnerships (consisting of a variety of organizations in public health and other disciplines, such as city planning, transportation, architecture, recreation, crime prevention, traffic safety and education, plus some key advocacy groups) are working to develop community design, public policies, and communications strategies that will increase physical activity. Several Active Living by Design sites focus on older adult populations in their efforts to make land use, public transit, nonmotorized travel, public spaces, parks, trails, and architectural practices friendlier to physical activity. Active Living Research funds research that examines relationships among natural and built environments, public and private policies, and personal levels of physical activity. It is establishing a transdisciplinary research base on the environmental and policy correlates of physical activity.

Promoting physical activity is also part of a Foundation-supported Senior Wellness Project, a service of Senior Services of Seattle/King County, a research-based health promotion and disease management program. The project was created to provide accessible, low-cost health promotion programs to older adults with chronic conditions. Its Health Enhancement Program helps older people create a health improvement plan in partnership with a registered nurse, a social worker, a primary care physician, and a volunteer mentor who provides one-on-one counseling and encouragement. To help participants carry out their plans, the Health Enhancement Program's wellness sites offer a daily hot lunch, exercise programs, nutrition and health education, interest groups and classes, volunteer opportunities, and assistance with transportation. The Senior Wellness Project has been shown to reduce hospitalization days and the use of medications and to improve the quality of life, physical activity, and functioning.<sup>28</sup>

The *Vote and Vaccinate* program was piloted in fifteen communities in the fall of 2004. Building on a *Local Initiatives Funding Partners* grant to SPARC, a community-based program that develops local strategies for increasing access to clinical preventive services in New England, Vote and Vaccinate provides immunizations to older adults at polling places on Election Day.

The AdvantAge Initiative, also funded by the Robert Wood Johnson Foundation, is developing a set of indicators to help communities assess how well they promote and facilitate independent living by older residents. Working initially in ten communities around the country, the AdvantAge Initiative surveyed older adults about how well their communities help them remain healthy, live independently, and lead productive and satisfying lives. In addition, to help other communities assess their ability to meet the needs of older residents, the initiative is providing assistance on collecting information, holding focus groups, and building coalitions. The initiative also profiled seventeen promising community efforts designed to maximize the potential for older residents to remain active, independent, and engaged. These include addressing the basic needs of older adults, such as housing and safety; encouraging physical activity and the use of preventive health services; promoting independence by improved caregiving and transportation; and advancing social and civic engagement, largely through volunteerism.

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**Proposition 3: Planning Early for Long-Term Care Can Give Older People the Security That They Will Be Able to Live Where They Choose as Long as Possible, Avoid Financial Ruin, and Have Health Care Decisions Made on the Basis of Their Own Preferences**

**The Rationale**

Over the next several decades, the number of Americans needing long-term care will increase dramatically. How easily older adults and their families will be able to obtain this care will depend on their ability to navigate a complex service delivery system, find the right providers and the right coverage, and finance the care they will need. What makes understanding long-term care so difficult is that there is no single authoritative source of information or single point of entry. Long-term care is delivered in communities. It is not a unified system but, rather, a constellation of individual parts.

Many middle-aged and older adults do not know how or where to obtain impartial information that can help them plan for later-life care. It often takes a medical crisis to create a sense of urgency that forces older adults and their families to think about long-term care options, which, by then, are often limited and more expensive. The AdvantAge Initiative's 2003 national survey of adults age sixty-five and older found that 20 percent of older adults did not know whom to call for information about long-term care and supportive services.<sup>29</sup> Furthermore, those with physical limitations or poor health were the least likely to know how to get information. A recent AARP survey found that more than 60 percent of Americans age forty-five and older indicated some familiarity with long-term care services.<sup>30</sup> Most respondents in both surveys underestimated the cost of a nursing home (whose existence makes advance planning seem less critical) or they overestimated the cost of long-term care insurance (which makes them reluctant to buy a policy).<sup>31</sup> In addition, many seniors believe—incorrectly—that Medicare will pay for long-term care.

**Foundation-funded Programs**

Recognizing that most older adults want to remain in their homes and communities, in 2001 the Robert Wood Johnson Foundation funded the *Community Partnerships for Older Adults*, or CPOA, an eight-year \$28 million initiative. The goal of this program is to build public-private community partnerships to improve long-term care and supportive services systems to meet the needs of older adults.

A key element of the program is the development of a model that provides reliable, up-to-date, and tailored information about long-term care services in the community. Each CPOA site is developing an information system that will allow older persons or their family members—especially recent immigrants and those who do not speak English, have limited health literacy, or confront other barriers to information and services—to make a single call to identify supportive services and determine eligibility. In nineteen locations across the country, CPOA grantees are educating members of their communities about long-term care and working to develop community-wide long-term care options. For example, through the Department of Aging and Adult Services, the San Francisco Partnership has launched SF-Get Care, a Web-based information and referral system that allows older adults and their families to locate in-home and community-based supportive services and other resources. In Hawaii, Maui Community Partnerships is using public access television to raise awareness about health care programs and services for older adults on the islands of Maui, Molokai, and Lanai.

Two other Foundation-funded programs help older adults learn more about long-term care: BenefitsCheckUp and Next Chapter (formerly Life Options). The BenefitsCheckUp program is an online service of the National Council on the Aging that helps people age fifty-five and older identify and apply for federal, state, and local programs. It provides information on prescription drugs, health coverage, payment of utility bills, volunteering, home-based services, and the like. Next Chapter, developed by Civic Ventures, is designed to help individuals nearing retirement answer the question, “What’s next?” The program provides information on a range of topics—from opportunities for paid or volunteer employment to financial and long-term care planning—in libraries and community colleges.

Long-term care can be expensive. Home health care ranges from \$12,000 to \$50,000 a year, and assisted living, other residential alternatives, and nursing homes can cost upward of \$80,000 a year. It should come as no surprise, therefore, that after paying for one year of long-term care, many older Americans find themselves impoverished and relying on Medicaid to cover the cost of their long-term care (as long as they qualify under the means test for the program in their home state).

Long-term care insurance is widely considered as a key component in guarding against the catastrophic costs associated with nursing homes, assisted living, and home health care. If purchased by enough people, long-term care insurance could also protect state Medicaid programs from carrying the entire long-term care financing burden of an aging population. Limited coverage and the high cost of long-term care insurance policies have, however, limited their appeal. Less than 10 percent of adults over sixty-five, and an even smaller percentage of those aged fifty-five to sixty-four, have purchased long-term care insurance.<sup>32</sup> The Health Insurance Portability and Accountability Act of 1996 took an important first step to making long-term care insurance more affordable by allowing purchasers of federally qualified long-term care insurance policies to deduct their premiums, up to a specified limit, on their federal income taxes.

Because of the high cost and the complexity of long-term care insurance, prospective buyers need objective information to help them decide whether this insurance is appropriate for them and, if so, which policy to buy. The Foundation has designed programs to help increase people's knowledge about both Medicare (which does not pay for long-term care but which enters into the consideration of long-term care options) and long-term care insurance (which does pay for long-term care). The Center for Medicare Education, funded in 1998 by the Robert Wood Johnson Foundation, has been an important resource for agencies and organizations that provide consumer education about the Medicare program. Likewise, the Medicare Rights Center, established in 1989 with funds from the Robert Wood Johnson Foundation and other foundations, provides free counseling services to people with issues concerning Medicare. Since its establishment, the Medicare Rights Center has helped more than a million people with Medicare-related issues through its counseling hotline, education sessions and materials, and technical assistance.

The *Program to Promote Long-Term Care Insurance for the Elderly* was funded between 1988 and 1998 to provide states with resources to organize partnerships of long-term care insurance companies and state Medicaid programs. The partnerships protect beneficiaries against losing everything if they need expensive long-term care. Instead, the costs are paid initially by a private insurance company and, if coverage runs out, by Medicaid. Even after support from the Robert Wood Johnson Foundation ended, public-private partnerships in California, Connecticut, Indiana, and New York continue to operate. By 2000, more than 95,000 partnership policies had been sold in these states, and more than 30 percent of the participants reported that they would not have purchased long-term care insurance without the partnership program. An independent evaluation found that the strict regulations governing the policies sold under the Program to Promote Long-Term Care Insurance for the Elderly resulted in higher-quality long-term care insurance coverage than was previously available in the states.<sup>33</sup>

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**Proposition 4: A More Efficient and Responsive Health and Supportive Care System Requires Better Coordination of Services and Information**

**The Rationale**

Older people with complex health conditions often receive health and long-term care services from a number of providers, including primary care physicians, specialists, nurses, home health aides, social workers, and physical therapists. In fact, nearly a third of people with serious chronic conditions see four or more doctors at a time.<sup>34</sup> Many chronically ill people receive their care in a variety of settings: doctors' offices, hospitals, assisted-living locations, skilled nursing facilities, and their own homes. Many move from one setting to another in the course of a year.

This plethora of providers and settings makes care of the chronically ill extremely difficult. Health care providers and informal caregivers find it challenging, and sometimes impossible, to ensure that an individual's long-term care plan follows him or her from one setting to the next. Lack of communication among an individual's health care professionals can exacerbate the difficulty that patients encounter when they make these transitions. Moreover, older adults living in the community may not know what services they need or how to find the ones they want. Those who require services from different agencies may find it overwhelming to keep straight the programs' varied eligibility requirements and their unique sets of service providers and financing systems. These challenges,

taken together, often keep chronically ill older people from receiving a full range of home- and community-based services.

Navigating the maze of programs and services can be hard for both rich and poor. A low-income person, for example, may qualify for publicly funded long-term care services but may have no idea that such services are available or how to learn about them. Persons with higher incomes may correctly assume that they can't take advantage of public services but may have little idea about how to find the ones they need, at an affordable price, in the private sector.<sup>35</sup>

### **Foundation-funded Programs**

To help improve the coordination of services for older people living in the community, the Foundation has supported the development of programs that sought to integrate housing, health, and social services by placing these services in a single location or by integrating the way they were financed. In the mid-1980s, several Foundation programs integrated social services for frail elders into federally subsidized housing for seniors. This concept was expanded to include incorporating social services into housing in naturally occurring retirement communities—housing developments, apartment buildings, and neighborhoods in which residents had aged in place and that had high concentrations of older people. The *Coming Home* program, for example, developed a model of affordable assisted living that combined housing and social services for older adults in small towns and rural areas in ten states.

In addition, the Foundation supported several programs that integrated Medicare and Medicaid financing in order to create a seamless system of health and social services integration for frail older adults. The Program of All-Inclusive Care for the Elderly, or PACE, provides team-managed care that integrates acute and long-term health services in both inpatient and outpatient settings for elderly people. “Social health maintenance organizations,” developed in the 1980s, were viewed as a way of improving care for frail elderly people by combining managed care and expanded home- and community-based services. The *Medicare/Medicaid Integration Program* is a fourteen-state demonstration that tests the operation and design of delivery systems that integrated long-term and acute care services under combined Medicare and Medicaid capitation payments for elderly patients.

In 1992, as the Robert Wood Johnson Foundation developed a more formal funding strategy for its grantmaking in chronic illness care, it applied lessons from these earlier programs to a new program, *Building Health Systems for People with Chronic Illnesses*. This program funded demonstration projects designed to overcome the fragmentation, financing barriers, and episodic care that characterized existing systems of care for older adults, people with physical and mental disabilities, and children with special needs. Six of the thirty-two demonstration projects focused on frail older adults. These projects sought to link acute and long-term care services for older adults who might otherwise be in nursing homes but were residing in their own homes or in personal care homes.

Community Partnerships for Older Adults, referred to earlier, also supports efforts to develop coordinated service systems. For example, the Atlanta Community Partnerships program, Aging Atlanta, has developed Care Options, an online care coordination system that will allow for electronic updates of changes in a client's needs.

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**Proposition 5: Successful Aging Will Require a More Highly Trained and Qualified Workforce of Paid and Unpaid Caregivers**

**The Rationale**

Most of the country's long-term care services are dispensed by informal caregivers such as family members and close friends in individual homes. As more long-term care is provided at home and in the community rather than through institutions, reliance on family and informal caregivers will continue to grow. Providing this support is no small feat, given the sheer numbers of relatives and friends who care for older people. Nearly one out of every four households—about 22 million—is involved in caring for a person aged fifty and older, while 5 million households care for an older person with dementia.<sup>36</sup> Sixty percent of these caregivers either work or have worked while providing care, and have had to make some adjustments to their work life, from reporting late to work to giving up work entirely. Although this arrangement saves the nation billions of dollars a year, informal caregiving does not come without a price. Nearly a third of those caring for persons age sixty-five and older describe their own physical health as fair to poor. As many as 11 million informal caregivers may suffer from the symptoms of depression.<sup>37</sup>

Informal caregivers lack information, training, and support. The need to strengthen and sustain families in their caregiving role is becoming a key issue in our society. Caregivers who receive support, such as education and skills training, counseling, and respite care for themselves and coordinated services for their care recipient, tend to have better health than those who do not receive such support. Caregivers who take their loved one to an adult day care center, for example, experience less stress and better psychological well-being than those who don't.

Beyond nonpaid caregiving, a trained and qualified paid workforce is essential to providing quality care. Yet there is a shortage of frontline workers, such as home health aides, companions, nursing assistants, and community health workers, that threatens to compromise the ability of health care systems to respond to the growing need for personal care among older adults. Although the number of elders who need help with daily activities will more than double, to 11 million from 5 million by 2050, the supply of elder-care workers is expected to decline during the same period.<sup>38</sup>

Annual staff turnover rates of 45 percent for nursing homes and 10 percent for home health programs are a big part of the problem. High turnover rates can result in poor quality and unsafe care for patients, higher levels of stress for workers who remain in understaffed workplaces, and increased pressure on family members who often must fill in the care gaps. They also cost health care providers millions of dollars in recruitment, training, and lost productivity.

High turnover rates are due, in part, to the low pay, difficult working conditions, and high demands on those caring for elderly people. The typical paraprofessional is a single mother with a high school degree or less, who earns between \$6.50 and \$8.50 an hour. Many of these people hold two jobs, and most live below the federal poverty level.<sup>39</sup> Few receive employer-paid health insurance, and

supportive supervision is rare. On top of this, inadequate training leaves most paraprofessionals ill-prepared to provide the level of care required by the chronically ill patient. Medicare requires that nursing home assistants receive only seventy-five hours of training, with only sixteen hours of that training devoted to supervised, hands-on work. Some states set additional standards for training, but the rigorousness of these training standards varies widely.

### Foundation-funded Programs

It would be difficult to overstate the importance of neighborhood volunteers in supporting caregivers and providing services to older people living in the community. Neighbors and other community members who befriend chronically ill elderly people and their caregivers help lessen the isolation that older people experience, offer vital services that help them remain in their communities, provide respite for family members providing care, and save health care dollars by reducing the need for paid service providers. The *Faith in Action* program, initially funded in 1992, brings together volunteers of many faiths to provide assistance with daily activities to those with long-term health needs. It has provided seed grants to more than a thousand interfaith coalitions in communities across the United States.

From 1992 to 2001, the Foundation supported the development and expansion of *Partners in Caregiving*, a program that allows older adults with dementia or chronic illness (or both) to continue living at home yet receive the care they need in adult day centers. These centers, in communities in thirteen states, provide health, social, and support services for adults with impaired physical, mental, and social abilities. At the same time, they allow family caregivers a much-needed respite, and also allow them to continue working if they need to earn a living. In 2000, a Foundation-funded study of adult day services documented the need for more centers.

Through its *Cash & Counseling* program, the Foundation has given home-bound disabled people the option of choosing whom to pay for their home care. Many have decided to pay family members or other informal caregivers who otherwise would have had to volunteer their time or not be able to do it at all. The program began as a two-state demonstration and was expanded to eleven states in 2004. As a result of this program, the federal Centers for Medicare & Medicaid Services now supports state Medicaid demonstrations to develop consumer-directed options for beneficiaries who receive long-term care.

Another program that focused on advancing consumer choice in long-term care was *Independent Choices*. It was designed to complement the Cash & Counseling program by supporting smaller-scale demonstration projects and research. Individual projects were chosen to address diverse populations and to test alternative approaches to the cash option for empowering consumers of long-term care. For example, several research projects explored older adult preferences for consumer-directed care, and the demonstration projects ranged from expanding available options for those who receive Medicaid long-term home care services to developing emergency backup services for people with disabilities.

Recent Foundation efforts have focused on finding ways to increase the number and the expertise of paraprofessional caregivers. The *Better Jobs, Better Care* program, jointly funded by the Robert Wood Johnson Foundation and Atlantic Philanthropies, is designed to create changes in policy and practice through demonstration and research grants that will lead to the recruitment and retention of high-quality direct care workers in both nursing homes and home and community settings. During 2003, five state-based coalitions consisting of providers, workers, and consumers were awarded grants of up to \$1.4 million each to strengthen practices and policies in order to attract and retain high-quality paraprofessionals. The demonstration project in North Carolina, for example, aims at developing a special licensure designation for home care agencies and for residential and nursing facilities. The project in Pennsylvania is establishing a statewide nonprofit entity to promote policies, such as wage increases, mentoring, and the adoption of uniform training standards across all long-term care settings, that can improve the quality of care and retention of workers. In addition, Better Jobs, Better Care awarded grants of up to \$500,000 to eight university-based researchers and nonprofit organizations to examine programs and policies thought to be successful in recruiting and retaining high-quality long-term care workers.

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## Future Directions

It is evident that the time has come to change the images, stereotypes, perceptions, and the language around aging and to develop new approaches to healthy aging. At present, images tend toward two extremes—the eighty-year-old running the marathon or the eighty-year-old tied to a chair in a nursing home. The reality is that aging, unlike child development, is incredibly variable and does not meet an expected set of milestones. It is the lack of predictability in aging that results in many different pathways from midlife to the end of life. The continuum of aging from well to chronically ill to frail is not linear, and older adults frequently move among these categories. The propositions presented in this chapter can serve as guideposts for transforming how aging is viewed, for supporting the active participation and contributions of older adults in society, and for creating services that support and empower frail older adults and their families. Individuals, professionals serving older people, organizations, and society need to examine their stereotypes and create new images that support meaningful and productive living in the second half of life.

The twenty-first century will continue to see the rapid growth of an aging population. The number of people living beyond eighty-five will continue to increase. As a result, there are likely to be more people in their fifties and sixties who have surviving older relatives and therefore increased responsibilities for their care. Women will continue to become the majority of the oldest old, and they will face significant health, social, and economic problems, including living alone, increasing needs for supportive services, and higher levels of poverty. Finally, as illustrated in the report, *A Tale of Two Older Americas: Community Opportunities and Challenges*, the “fortunate majority” of older adults are thriving and experiencing good health, strong social connections, and adequate resources, while the “frail fraction” are in poor health and with inadequate financial security.<sup>40</sup> These two groups can reside in separate neighborhoods or live within the same apartment building. It is this second group—those with incomes below 200 percent of the poverty level, with less than a high school education, and with poor health status and limitations in daily activities—that needs attention.

Within the frail population are many minorities and immigrant groups, reflecting the increased diversity in the older adult population. The challenge for those concerned with healthy aging is to develop a set of programs and interventions that will reach the increasingly heterogeneous older adult population, and especially the frail fraction.

Research has shown that healthy aging results from physical activity (which can be done by almost all adults, even the frail), mental activity, preventive care, connecting with others, engaging in meaningful activities, and knowing where and how to get supportive services. There is a need to translate research findings into practices that are accessible to older adults regardless of income, living situation, or culture. Although few organizations and communities are currently equipped to provide them, services can and should be designed to meet the needs of a culturally, linguistically, and educationally diverse older population.

By increasing both paid and volunteer opportunities for service, later life could be a time when older people, both the fortunate majority and the frail fraction, make their most lasting impact on their families, their places of work, and their communities. The Older Americans Act of 1965 helped raise the public's awareness of aging issues and made possible a range of programs, organized by the Administration on Aging, that continue to offer important services and opportunities. A similar national policy on the employment of older workers and an initiative on volunteerism would increase understanding of the importance of providing older people with options for meaningful activities. Individual organizations, both public and private, are already playing an important role in promoting opportunities for paid work and volunteerism among the elderly, but they can't do it alone. To be most successful, such a promotional effort should be rooted in a strong national organization that could gain the attention of both the public and private sectors.

Elderhostel and programs like it have been extremely successful in demonstrating that one is never too old to learn new things or enjoy new adventures. These programs should be replicated and expanded so that opportunities for growth and intellectual stimulation will be widely available to all older people, regardless of income or ability to travel. Because of their unique status within the senior community, senior centers may be able to play a central role in this effort. In addition, technology, which is bringing learning opportunities to homebound and other older people, should be expanded. Colleges, universities, and other learning institutions should be encouraged to develop learning materials that can be shared with older adults through the Internet.

Traditionally, health, housing, and social services have been divided into distinct professional and service sectors. Yet as people age, this separation does not make sense; health, housing, and services ought to become indistinguishable. For example, many older adults with limited financial resources live in an aging housing stock. It is often difficult to differentiate a housing crisis (for instance, no railings in the bathtub) from a health crisis (such as a broken hip). Partnerships of public and private funders, housing developers, the aging services network, and government need to work together to expand and refine community models that integrate or coordinate health, housing, and other services. These integrated systems of support save money, improve health outcomes, and decrease the frustration, confusion, and stress among older people and their caregivers. A great deal can be

learned from emerging models of supportive housing such as shared housing arrangements, senior housing, intergenerational housing, and new forms of assisted living.

Finally, strong partnerships should be developed to create communities for all ages. What older adults want in their communities—affordable housing, safe neighborhoods, transportation, recreation spaces, access to work or volunteer activities—is what families and younger adults want as well. These partnerships may involve unlikely partners, such as transportation, land use, health, recreation, and children’s organizations. The challenge is combining the interests of these divergent community groups to reach common goals. This can happen through increased dialogue between organizations and individuals about important community and societal values.

The five propositions on aging can become a reality so that all older adults, their families, and their neighbors can support and safeguard their health and their independence.

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## Appendix: Examples of Major Robert Wood Johnson Foundation Programs on Aging

### Building of Organizational and Community Capacity

*AdvantAge Initiative* (1999–2001, \$200,000) is a community-building effort focused on creating elder-friendly, or “AdvantAged,” communities that are prepared to meet the needs of older adults. This initiative began as a multifoundation collaborative to create benchmarks for elder-friendly communities. Using these benchmarks, ten communities across the United States tested and developed strategies to address the needs of their older adults.

*Building Health Systems for People with Chronic Illness* (1992–2002, \$13 million) encompassed a broad range of initiatives covering the medical, mental health, and supportive services needs of frail elders, people with disabilities, children with special needs, and people with severe mental illness. Each project used a broadly inclusive definition of health and the health system, sought to reduce fragmentation in service delivery and financing, and included consumer-directed principles in the design and implementation of health and supportive services systems.

*Community Partnerships for Older Adults* (2000–2010, \$26 million) fosters community partnerships to improve long-term care and supportive services to meet the current and future needs of older adults. This program provides funds for both development and implementation grants for thirty community grantees ([www.partnershipsforolderadults.org/](http://www.partnershipsforolderadults.org/)).

*On Lok Senior Health Services* (1983–1987, \$649,930) began as a neighborhood-based alternative to nursing home care. It provided mobile support services in the home as well as centralized off-site care at an adult day health care center, and created a fully integrated model of acute and long-term care for low-income seniors that blends Medicare and Medicaid financing.

*Program of All-Inclusive Care for the Elderly (PACE)* (1993–1996, \$1.2 million) was a replication of On Lok. PACE programs provided and coordinated all needed preventive, primary, acute, and long-term care services so that older individuals could continue living in the community.

*Program for Health-Impaired Elderly* (1979–1986, \$7.7 million) was developed to address an intrinsic defect in the provision of services to the elderly—the absence of mechanisms or strategies to coordinate and prioritize services needed for health-impaired elderly people residing in the community.

*Teaching Nursing Home Program* (1981–1987, \$6.7 million) was designed to improve the quality of nursing home care and the clinical training of nurses by linking nursing schools with nursing homes. Grants were made to eleven university nursing schools.

### **Civic Engagement and Physical Activity**

*Active for Life* (2001–2007, \$17 million) is a national program to encourage adults fifty and older to increase their activity levels. The program replicates and expands models demonstrated to be effective in increasing levels of physical activity.

*Active Living by Design* (2001–2008, \$15.5 million) is a national program that attempts to harness community design and livable community initiatives as a vehicle for making communities more activity-friendly.

*Active Living Research* (2000–2007, \$12.5 million) supports research to identify environmental factors and policies that influence physical activity. Findings from this research are used to help inform policy, the design of the built environment, and other factors to promote active living.

*Experience Corps* (2001–2006, \$6.8 million) is an intergenerational project testing a well-developed model for making matches between children and older adults in public schools.

*Health Enhancement Program* (1999–2002, \$194,000) was a participant-directed program for seniors to change health behavior, supported by a nurse–social worker–peer health mentor team and complemented by courses in exercise and self-management of chronic conditions. The program was offered to seniors in low-income, multi-ethnic public housing facilities and an African American senior center.

*Expansion of a Senior Wellness Program* (2001–2003, \$750,000) entailed expansion of the Health Enhancement Program. This program integrated three critical elements of health enhancement for older adults—self-management of chronic disease, physical activity, and social support—in a variety of settings.

*Improving Physical Activity Levels of Mid-Life and Older Adults* (2001–2005, \$4.3 million) has been a national program housed at AARP that aims at replicating programs shown to be effective in encouraging adults fifty and older to increase their levels of physical activity.

*National Blueprint on Physical Activity Among Adults Age 50 and Older* (2001–2005, \$670,000) was an effort led by six partner organizations (AARP, American College of Sports Medicine, American Geriatrics Society, the Centers for Disease Control and Prevention, National Institute on Aging, and the Robert Wood Johnson Foundation) to create a national framework for planning, collaborative action, and social change among organizations and agencies involved in physical activity, aging, or both.

### **Education and Advocacy**

*Center for Medicare Education* (1998–2002, \$5.4 million) has been a resource for public agencies and private organizations that provide consumer education about the Medicare program and its health plan options. The center is part of the Institute for the Future of Aging Services, a policy research institute within the American Association of Homes and Services for the Aging.

*Creation of a Counseling and Assistance Program for People with Medicare* 2002–2003, \$100,000) was initiated by the Medicare Rights Center, a Medicare counseling and assistance system that helps New Yorkers with Medicare obtain the Medicare benefits and health care services they need quickly and easily.

### **Financing and Policy**

*Cash & Counseling* (1995–2008, \$12 million) provides funding for elderly and disabled people that enables them to choose the people who provide their care and to pay them directly.

*Independent Choices* (1995–2000, \$3.3 million) was designed to complement the Cash & Counseling program by providing funding for small-scale demonstrations and research designed to develop and test other approaches to empower consumers of long-term care.

*The Medicare/Medicaid Integration Program* (1996–2006, \$4.5 million) addresses the financing and policy changes necessary to integrate these two funding streams for disabled older adults. This demonstration program tests the operation and design of delivery systems that integrate long-term and acute care services under combined Medicare and Medicaid capitation payments for elderly patients in fourteen states.

*Program to Promote Long-Term Care Insurance for the Elderly* (1988–1998, \$12 million) was created to provide states with resources to plan and implement private-public partnerships that would join private, long-term care insurance with Medicaid to offer high-quality insurance protection against impoverishment from the costs of long-term care. Eight states received initial planning grants and four received implementation grants.

*Promoting Long-Term Care Policy Development and Debate* (2001–2004, \$3.4 million) was created to renew interest in financing and policy change by establishing a broader understanding of the financing of long-term care, developing a range of potential policy solutions, and analyzing the costs of the newly created proposals. Based at Georgetown University, the program was seeking different answers to the question of how to cope with long-term care and its service needs.

*Service Credit Banking Program for the Elderly* (1986–1990, \$1.1 million) was designed to assist consortia of community groups to expand the concept of service credit banking, under which elderly individuals volunteered to provide services to other elderly people and, in return, received credits that were redeemed for similar services at a later point.

*Service Credit Banking in Managed Care* (1994–1999, \$600,000) provided technical assistance and information for the replication of service credit banking programs and sought to demonstrate the feasibility of establishing a service credit banking project within a managed care organization.

*Social Health Maintenance Organization* (1983–1994, \$1 million) was created to reduce the cost and improve the quality of care for the elderly. This was to be achieved by combining the services of the fragmented health and long-term care systems into a single social HMO entity. (This was before the passage of legislation allowing for the development of Medicare managed care organizations.)

*State Solutions* (2001–2006, \$4 million) has been a national program working to increase enrollment in and access to the Medicare savings programs, which are directed to low-income older people. State Solutions provides technical assistance and direction to grant recipients and disseminates information about innovative and promising practices throughout the nation.

### **Housing with Services**

*Coming Home: Integrated Systems of Care for the Rural Elderly* (1992–2005, \$13 million) has had as its goal the development of affordable assisted living as an integral part of the long-term care system for low-income elders in rural areas. Coming Home operates through a revolving loan fund managed by the NCB Development Corporation, which acts as a fiscal and technical assistance intermediary to organize community partners, make loans and grants for site analyses and predevelopment costs, and help arrange for long-term financing through NCB or other commercial lenders.

*The Green House Model* (2002–2006, \$1 million) has sought to create an environment in which the frail elderly could receive medical assistance without being required to live in a large institution. Each Green House facility is designed to be a home for eight to ten people. Though technically licensed as a health care facility and not as private housing, this model expands the boundaries of what can be considered supportive housing.

*Supportive Services Program for Older Persons* (1985–1991, \$8.5 million) was designed to promote the expansion of nontraditional health and health-related services to the elderly, including services such as respite care, housekeeping, home repair, and transportation. This led to a shift in policy that allowed for the inclusion of services in Section 202 subsidized housing.

*Supportive Services in Senior Housing* (1987–1995, \$3 million) sought innovative approaches to financing and delivering supportive services to people who lived in subsidized housing projects for the elderly.

### **Informal and Formal Caregiving**

*Better Jobs, Better Care* (2002–2006, \$8 million) is a research and demonstration program created to improve the recruitment and retention of quality nursing assistants, home health aides, and personal care attendants who care for elderly people with chronic diseases or disabilities. It is funded by the Robert Wood Johnson Foundation and Atlantic Philanthropies.

*Faith in Action* (Phase I, 1992–1999, \$36 million; Phase II, 1999–2007, \$50.5 million) has the primary goal of helping communities care for the growing number of people with chronic illness and disability who wish to remain in their own homes but need some assistance with daily activities. It makes grants to local interfaith groups that provide volunteers to care for their neighbors with long-term health needs.

*Family Friends* (1985–1991, \$3.7 million) was a demonstration program based on a successful pilot project in Washington, D.C., conducted by the National Council on the Aging, with Foundation support. The program was designed to match older volunteers (age fifty-five and older) with chronically ill or disabled children and their families. Volunteers worked with children and their families in the families' homes. The goal of the program was to demonstrate the feasibility, value, and sustainability of the Family Friends model in different geographical locations under different types of organizational sponsorship.

*Partners in Caregiving: The Dementia Services Program* (1992–2001, \$4.2 million) built on the lessons from an earlier adult day care program, the Dementia Care and Respite Services Program, which the Foundation funded between 1988 and 1992. In expanding the scope of that earlier program to all fifty states and the District of Columbia, Partners in Caregiving demonstrated that the adult day care model could be used for older adults with other chronic illnesses.

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