

**Statement of Jane Isaacs Lowe, PhD
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Mr. Chairman and members of the committee, good afternoon. My name is Jane Isaacs Lowe. I am a senior program officer at The Robert Wood Johnson Foundation in Princeton, NJ, whose mission is to improve the health and health care of all Americans. Thank you for inviting me to testify this afternoon on the work the Foundation has done to improve long term care in America. I am pleased to share our experiences with long term care delivery systems and financing issues that may be of use to the committee.

Introduction

Let me begin by telling you about Mrs. K. Mrs. K lived by herself on a farm in rural Illinois where she raised six children, taught school, and cared for invalid relatives. At 85, she suffered from hearing and vision loss, and was increasingly confined to a wheelchair due to severe arthritis. An Illinois home care specialist visited several times a week as did several of her children, but she was slowly losing the ability to live independently without help. Although she resisted giving up her home, she was amenable to living in a senior apartment complex. However, the nearest facility was far from her hometown and also beyond her financial means. She feared that it was just a matter of time before she would have to go to a nursing home.

Mrs. K was lucky--an affordable assisted living facility was built ten miles from her home as a result of the Foundation's Coming Home Program, a national program designed to increase the number of affordable assisted living programs in rural America. Mrs. K was one of the first seniors to qualify for residence in Cache Valley located in an Illinois town of 550 people. Today, she has her own apartment filled with her furniture and adorned with prized possessions reflecting her long life. Mrs. K receives meals, and help with dressing, bathing and medications. As a result, Mrs. K feels more connected to others, and to quote her, "I have friends, my independence and help when I need it."

There are many people like Mrs. K who are living in rural, suburban and urban areas. They are alone and isolated, living with chronic illnesses and limited resources. Like Mrs. K, they need affordable housing and service options.

Mrs. K's story is just one example of our work to develop long term care programs for vulnerable and frail older persons and people with disabilities. The Robert Wood Johnson Foundation's work in this area is funded as part of our goal to improve care and support for people with chronic illnesses, which has been one of our principal programming goals since 1991. Since that time, the Foundation has awarded more than 3,000 grants totaling close to one billion dollars to improve long term care and care for people with chronic illnesses. Our strategies to advance long term care transcend any single approach--together with our grantees, we have developed many solutions to ensure that consumers have a voice in their own care, to build a flexible and responsive delivery system and to design and test a range of financing mechanisms.

It is apparent to observers from every perspective that the current health care and social service system do not meet long term care needs. The health care delivery system, which favors acute and institutional care over preventive and community-based care, and clinical services over supportive and enabling services, is often unresponsive to older persons and people with disabilities. Today, in the wake of the *Olmstead* decision, there are continued concerns about long term care coverage and costs, building community capacity for care, and the anticipated growth in the number of older Americans. As a result,

there is heightened interest in changing long term care systems at the national, state, and local level. Our experience with demonstration programs and our other grantmaking activities have particular relevance as policymakers seek to guide these changes.

What We've Learned

Through our grantmaking, we test new ideas and develop new models. These innovations necessarily fall short of broad-scale change, but with careful interpretation, provide valuable lessons. The three most salient lessons we've learned from our grantmaking are:

- Consumers and/or their families must be involved in decisions about their care.
- More alternatives to institutional long term care must be created.
- Financing must be more flexible in order to support these options.

Consumer Directed Care

One very promising model of care that the Foundation has supported in the past decade is consumer directed care. This model is based on the premise that control over the nature, extent and duration of services and supports that are available to people with disabilities and older persons should rest with the person receiving those services and their families.

The Robert Wood Johnson Foundation's involvement with consumer directed care began with Monodnock Developmental Services in Keene, New Hampshire. The goal of the project was to improve the lives of 45 individuals with developmental disabilities by improving the quality and cost effectiveness of their care. These consumers, with dollars instead of services, took charge of their own lives and selected and were able to pay family and professional caregivers alike for their care. And these arrangements were no more costly than the system they replaced.

Based on the success of the Monodnock program, the Foundation created a national program to test self determination in 19 states. We later applied the lessons learned from this demonstration project to support Independent Choices, a consumer directed program for older adults, and Cash and Counseling, a Medicaid consumer directed demonstration for older adults and persons with disabilities.

Our work on these programs suggests three further lessons. First, when consumers - to the extent they desire - control decision-making about their care, they experience improved quality of life, greater self confidence and personal autonomy, and improved access to services. Second, implementation of this model and its values requires a serious commitment to change. Successful implementation requires new clinical and financial incentives for providers, as well as cultural change within public agencies to ensure that decision-making rests with consumers and that services meet their needs. Third, supportive services are necessary to promote independence and are the keystone of this effort. Such services must be broadly defined, and they may range from providing at-home personal care to making it possible for a consumer to purchase a motorized wheelchair that will allow them to move more freely through their community and do their own grocery shopping.

Increasing the Availability of Alternatives to Institutional Care

Today, the only widely available service for most Americans with long term care needs is nursing home care. As a Foundation, we have worked to expand the number of options for all Americans, most

especially low income seniors. We have supported the expansion of affordable home and community based long term care options and have invested successfully in linking housing with services. Two Robert Wood Johnson Foundation programs for low income seniors, No Place Like Home and Coming Home, have worked extensively in this area.

No Place Like Home provided technical assistance and grant support to help state and local housing finance agencies finance and deliver supportive services for older people living in subsidized housing developments. For many people, receiving supportive services in their housing environment can make the difference between institutionalization in a nursing home and aging in one's own apartment or home--what we in the field call "aging in place."

The second program, Coming Home, demonstrates another way to link housing with supportive services, in this case within affordable assisted living facilities. This program combines real estate development with Medicaid coverage for supportive services within assisted living facilities.

Beyond the two housing programs that I have described, we have supported innovations by providers delivering community care services. Three examples of this work include Building Health Systems for People with Chronic Illnesses, the Program of All-Inclusive Care for the Elderly (PACE) and the Partners in Caregiving Program.

Building Health Systems focused on the difficult challenge of better coordinating the delivery of medical services and supportive services for people with long term care needs. This program supported the development of 24 models throughout the country to overcome fragmentation of services, financing barriers, and the prevalence of episodic care.

In the early 1990s, Robert Wood Johnson funded the development and replication of the PACE Program. Based on the On Lok model, PACE integrates Medicare and Medicaid financing streams and acute and long-term care services within a single delivery system. The PACE program continues to evolve, as PACE sites experiment with greater use of home-based services.

Adult day centers, which RWJF has supported through its Partners in Caregiving program since 1986, provide formal day services for aging adults with long term care needs. Adult day centers are of tremendous help to family caregivers, because they provide crucial services during work hours, when many family members are not able to look after their loved ones. In that way, they allow people with long term care needs to continue living at home by taking the daytime burden off their families.

Financing

Any discussion of long-term care reform would be incomplete without addressing financing questions. Financial support for a variety of services is obviously critical to the viability of the service delivery systems and other models we have funded. A number of our programs use existing money in new ways, such as combining housing funding with Medicaid funding, or integrating acute and long-term care benefits from a combination of public insurance programs. However, demonstration programs cannot, on their own, solve the underlying questions about the sources and nature of financing for long term care services.

At the same time, our demonstration experiences do suggest lessons about the use of long-term care dollars. For example, we have learned that funding sources should cover a variety of services, and a range of medical and social services, in order to make consumer choice a reality. We have also learned that the ability to leverage multiple funding sources, such as creating inter-relationships between

housing and supportive services, best enables older Americans to age in place.

Future Directions

As we move forward, the Foundation's work will be driven by our nation's need to prepare for the significant increase in the number of older adults, which will have a profound effect on our health care and social services systems as well as our broader culture. The Foundation's program efforts will focus on:

- a) Assisting family caregivers and strengthening the paid workforce;
- b) Encouraging communities to design, build and strengthen their capacity for providing long term care services;
- c) Promoting changes in public policy to increase consumer choice and to improve the coordination and financing of supportive services.

Some of these efforts are still on the drawing board--such as our interest in enhancing the workforce--and others have been underway for some time. For example, the Foundation recently received letters of intent from 450 communities seeking to participate in Community Partnerships for Older Adults, an effort to improve local infrastructure for delivering long-term care services and social supports to vulnerable and frail elders and their caregivers. We believe that these new community efforts will provide inspiration to other communities struggling with similar concerns.

The Robert Wood Johnson Foundation recognizes that reforming the system must be complemented by a national effort to improve the health of older members of our society. To encourage this work, the Foundation is supporting numerous efforts. A new program, Increasing Physical Activity Among Mid-Life and Older Adults will work to encourage more older adults to remain or become physically active. The Foundation is also committed to improving clinical services for people with chronic illness, and improving public awareness of issues related to chronic illness and disability. This rich portfolio will certainly evolve over time.

We also hope to assist Federal and State policymakers as they consider a variety of issues through improved information and research, through technical assistance, and through the development of policy options. For example, we have funded a three-year project at Georgetown University to nurture a range of ideas for improving long-term care financing at the national level. This project will generate new creative proposals related to the financing and delivery of long term care as well as provide policymakers with thought-provoking ideas as they contemplate policy changes. We also provide technical assistance and mentoring support for state-level officials working on home and community-based long-term care programs.

Our work suggests that long term care reform will need to incorporate the Federal, State and community perspectives in order to find solutions to the most pressing issues confronting vulnerable older Americans and their caregivers.

Conclusion

The Robert Wood Johnson Foundation's decades of experience in this field demonstrate the formidable challenges of improving America's long-term care system. Our experiences also highlight many opportunities and provide significant lessons for the nation as we embrace this challenge. We will need

to develop delivery systems, service capacity and financing streams that provide vulnerable and frail elders and people with disabilities with choices about how to live their lives and receive the care they need. We will need to pay particular attention to supportive services and housing issues, which determine whether these individuals can maintain the autonomy and independence they desire. The Foundation will continue to work with providers, public agencies, consumers, researchers and others to refine the models we have, test new ideas, and build capacity within our communities and our nation to meet these challenges. We'd be happy to connect you with projects in your state in your state that are grappling with these issues. I thank you for your attention, and look forward to your questions.