Statement of
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Mr. Chairman and members of the committee, my name is Ray Scheppach, and I am the Executive Director of the National Governors Association. I appreciate the opportunity to appear before you today on behalf of the nation's Governors on the critical issue of long-term care.

Introduction

Increases in life expectancy and the aging of the baby boom generation are contributing to unprecedented growth in the population older than sixty-five. Similarly, improvements in medical technology are contributing to an increasing number of individuals with physical and other disabilities that are living longer, healthier lives. These growing populations are fueling an increasing demand for primary, acute, and long-term health care services. At the same time demographic and cultural changes are decreasing the availability of informal care. These factors will place a significant strain on our nation's current long-term care system, on beneficiaries and their families, and on current sources of public and private funding for these services.

One of the most important responsibilities of state and federal government is to protect and improve the health of our nation's citizens. The federal government, through Medicare and Social Security has been enormously successful in reducing the number of seniors living in poverty and in providing for some of the most basic health care needs of seniors and individuals with disabilities. However, there have always been significant gaps in Medicare's coverage. The most important gaps are for preventive care, prescription drugs, and long-term care. Additionally, there are significant beneficiary cost-sharing responsibilities. As a result, Medicare covers on average only about one-half of beneficiaries' health care costs.

Because Medicare does not fully address the long-term care needs of the nation, states (through Medicaid and state-financed programs) are facing an expanding range of long-term care challenges. Individuals and families, who already play a significant role in financing and delivering long-term care services, are under pressure to provide more assistance to their aging spouses and parents. There is a growing demand to increase the supply of long-term care providers and to develop new alternatives, services, and settings in long-term care. Moreover, there is an increasing need for government to integrate and streamline fragmented programs to be more client-friendly, cost-effective, and to assure quality service delivery.

Although these are significant challenges, we are confident that the answers are within our grasp. The Governors believe that greater flexibility for states and a new federal-state partnership are keys to developing innovative and improved systems of long-term care.

State Innovations in Long Term Care

To meet their long term care needs, states have undertaken a wide-range of innovations. The following sections will highlight certain categories of state innovation and initiatives in the area of long-term care and, where possible, identify examples of specific state programs and achievements.

Home and Community Based Care Waivers

Section 1915(c) of the Social Security Act, adopted in 1981, was intended to correct an "institutional

bias" in Medicaid services for the chronically ill by providing states an alternative of offering a broad range of home and community-based care services to persons at risk of institutionalization. Prior to this, the only comprehensive long-term care benefit in Medicaid was care in a nursing home.

For 20 years, states have made these waivers the backbone of the delivery of home and community-based care. There are more than 250 programs now in operation and every state operates multiple programs providing a broad range of medical and important social services for frail seniors and individuals with physical, mental and developmental disabilities. Many states offer programs for other populations such as individuals with traumatic brain injuries, persons with HIV/AIDS, or children with mental illnesses. Essentially everything we have learned at the state level about the provision of home and community-based care has arisen from our experience with these programs.

Congress did not, however, authorize the states to provide these services with automatic approval. States were forced to make a special application to the HHS for each of their specific programs. These programs were time-limited and were paperwork and resource-intensive. Although the federal government has worked very closely with states to ease these burdens, there is still much that needs to be done to make the system better. At the core of that discussion is to what extent it makes sense for programs that are cost-effective, highly desired by beneficiaries and their families, and have been in operation for 20 years to still require waivers to operate.

Overcoming Barriers to Care

Several state initiatives are aimed at overcoming barriers to care for the 6.4 million seniors and individuals with disabilities dually eligible for coverage under the Medicare and Medicaid programs. Innovations in this area are designed to integrate Medicaid's long-term care benefits with Medicare's acute care coverage. Two kinds of programs have been adopted by numerous states: the Program of All-Inclusive Care for the Elderly (PACE); and the Medicare/Medicaid Integration Program (MMIP) sponsored by the Robert Wood Johnson Foundation.

- ***PACE*** projects provide for a full-range of acute and long-term care services, often in an adult day care setting, using a Medicare and Medicaid capitated payment system. The Balanced Budget Act (BBA) of 1997 provided for expansion of PACE projects nationwide. Twenty-five PACE sites are operating in 14 states and are planned for an additional 10 states.

- ***MMIP*** projects seek to integrate Medicaid's long-term care services with Medicare's acute services through managed care for the dually eligible. MMIP projects are currently underway in 13 states.

Addressing Workforce Issues

To address the ongoing shortage of nursing home and home health aides who are critical to meeting the long term care populations, states have undertaken a range of initiatives. Some examples of these efforts include:

- ***Iowa's*** Certified Nursing Assistant (CNA) Recruitment and Retention Project. Passed by the legislature and approved by the Governor, the project was conducted at eight nursing facilities. Its purpose was to reduce CNA turnover by providing programs and services that responded to the needs that direct care workers identified. Interventions were implemented at some facilities while other nursing homes served as a control group.

- ***Michigan's*** dedication of $1.7 million in tobacco tax funding to state innovation grants, formation of a

state stakeholder commission, and funding for staff positions designed to address workforce capacity and quality issues.

• ***Oregon's*** ballot initiative mandating a commission to examine home care workforce issues.

"Cash and Counseling" and Family Caregiver Support Programs

Related to the home health and nursing home aide shortages, are consumer directed care and family caregiver support programs. To provide people of all ages with long-term disabilities with greater choice in selecting their own personal assistance workers, states have undertaken a variety of initiatives. Several states are involved with projects sponsored by the U.S. Deportment of Health and Human Services and the Robert Wood Johnson Foundation known as "Cash and Counseling projects." Additionally, to support caregivers providing ongoing long-term care assistance to family members, states have implemented a wide range of caregiver support programs.

• ***Cash and Counseling Programs*** exist in three states, Arkansas, Florida and New Jersey, and enable persons with long-term care needs to hire and retain their own personal care attendants. As part of the program, persons with long-term care needs are provided with a direct cash allowance to hire personal assistance workers (which may include friends and relatives) and are provided with counseling regarding bookkeeping and services management.

• ***Family Caregiver Support Programs*** exist in or are being planned for almost every state as a result of the enactment of the National Family Caregiver Support Program -- part of the Older Americans Act reauthorization last year. In addition to these federally supported programs, many states have initiated family support programs using state general fund or tobacco tax revenues. Among the larger and older programs of this kind are family support programs operating in California and Pennsylvania. California's program provides information, education and support to caregivers of adults with a wide range of cognitive impairments. Pennsylvania has a similar program that also allows caregivers under the age of 60 to purchase new services or supplies to assist them in their caregiver responsibilities. For example, these supplies might include materials to make home modifications.

State Funded Program Innovations

To supplement federal/state funded programs such as Medicare, Medicaid and Older Americans Act programs that provide long-term care services, states have also implemented programs funded only with state and/or local revenue. Generally, state/locally sponsored programs offer a wide variety of long-term care services that enable individuals who need assistance to remain in their homes. They also provide services to individuals that would otherwise not qualify for means-tested programs like Medicaid. States have used a variety of state funding sources to finance these programs including general revenue, county property taxes, tobacco settlement funds, and state lottery funds. Examples of these kinds of programs can be found in California, Florida, Indiana, Ohio, and Pennsylvania.

State Pharmacy Assistance Programs

In response to the need to provide senior citizens in their states with assistance in meeting the high cost of pharmaceuticals, states have been leaders in developing pharmaceutical assistance programs. Almost half of the states have pharmaceutical assistance programs in operation, and many other states are developing programs. The majority of state pharmaceutical assistance programs provide benefits through direct subsidy or discounts. There are other options, however, including tax credits or measures that reduce retail prices, such as bulk or cooperative purchasing programs and drug buying pools. More

recently, states are experimenting with Medicaid waivers (under Section 1115 of the Social Security Act) to provide the Medicaid prescription drug discount price to other residents, such as those eligible for Medicare.

In operation since the 1970's and 1980's, New Jersey, New York, and Pennsylvania's programs are three of the largest and oldest state-only pharmacy assistance programs. In 1999, enrollment in these three programs accounted for 71 percent of all state assistance program enrollees. All three states provide coverage to low to moderate-income beneficiaries age 65 or older through direct subsidy programs. Eligibility income levels range from $14,000 to $35,000 for singles and from $17,000 to $50,000 for married couples. While seniors are generally pleased with each program, they cover large populations and carry an annual cost of almost $400 million.

Retirement Planning Efforts

Several states have engaged in efforts to encourage their citizens to plan to meet their own retirement needs. These efforts include Partnerships for Long-Term Care and individual state efforts.

• ***Partnerships for Long-Term Care*** are programs that exist in Connecticut, Indiana, California and New York that represent public/private alliances between state government and insurance companies to create long-term care insurance programs.

Originally sponsored by the Robert Wood Johnson Foundation, the programs use two approaches: the "Dollar for Dollar" model and the "Total Assets" model. Under the Dollar for Dollar model used in Connecticut, Indiana, and California, long-term care policies of varying length and scope are covered by the state's insurance division. Policies must provide at least one year of coverage at the time of issue. Once benefits under the private long-term care policy are exhausted, an application for Medicaid can be made using special eligibility rules. Every dollar paid out by an insurer through a certified policy is deducted from the resources counted toward Medicaid eligibility. Under the Total Assets model used in New York, once policies are certified by the state, they must cover three years in a nursing home or six years of home care. Once benefits under the private policy are exhausted, the Medicaid Eligibility process will not consider assets at all. While total asset protection is provided, individual income must be devoted to the cost of care.

While successful, current federal law prohibits the expansion of these programs beyond these four models.

• ***Individual State Efforts*** such as those undertaken in Michigan are aimed at increasing understanding of long-term care needs and the necessity to save for them. Michigan has dedicated $3 million in tobacco tax funding annually toward this goal. Accordingly, beginning in September, 2001, a media campaign including radio, TV, print media, a new web page and a toll-free telephone number will be launched to provide citizens aged 35 to 65 with information about a range of long-term care financing vehicles including long-term care insurance, annuities, and medical/retirement accounts.

Single Point of Entry Programs

A number of states have instituted single point of entry or "no wrong door" programs designed to assist seniors in obtaining the services they need regardless of income levels or where they first go to obtain help. For example:

• ***South Carolina's*** legislatively mandated Senior Access program provides a single point of entry

system for seniors in 9 of 46 counties in need of long-term care services. Local Councils on Aging serve as the Senior Access agency receiving intake information on people seeking in-home services. Via an automated referral system, financial eligibility for Medicaid waiver services is determined. Nurses make in-home functional assessments. If eligible, clients are enrolled for Medicaid waiver services. If ineligible, the council on aging enrolls clients for other appropriate federal and state funded services such as personal assistance and chore service.

• ***Indiana's*** single point of entry program utilizes the 16 Area Agencies on Aging covering all 92 counties in the state. Funding for this program that integrates 11 separate federal, state, and local funding streams has increased from $98.5 million to in 1995 to $237 million in 2001. Assessments are made for all in-home and nursing home services. Long-term care services are based on individual need and are available to people of all ages. If an individual can afford to pay for all or a portion or the cost of services they do so in accordance with a sliding fee scale. Developed in 1992, the infrastructure for this comprehensive approach is updated periodically to account for changes in law.

Increasing Assisted Living/ Housing for Low and Moderate Income Seniors

Several states have engaged in efforts to increase the number of available assisted living and senior housing units available to low and moderate-income persons. Innovations in this area include:

• ***Iowa's*** Senior Living Trust Fund, which provides financial assistance to nursing facilities to convert nursing home beds to assisted living programs. Participating facilities must serve at least 50% Medicaid clients and give up a certified nursing home bed for each assisted living bed created. Development grants are also available to any type of provider for developing alternative services (other than assisted living) such as adult day care, respite, home health, transportation and PACE. Grantees must demonstrate goals of providing alternative services to underserved populations and underserved areas of the state. In the first year, 76 applications were received, with $20,000,000 in funding available in the second year.

• ***Maine's*** state funded assisted living program, which supports 210 units of assisted living statewide. The program requires cost sharing by participants and takes into account not only income, but assets as well. Program costs run approximately $325,000 per unit, and $15,000 per person annually.

• ***The Coming Home Program*** of the NCB Development Corporation, in partnership with the Robert Wood Johnson Foundation, which provides three-year grants of $300,000 to nine states willing to make regulatory and reimbursement changes necessary to foster affordable assisted living for low-income seniors - usually in rural areas. Grantees are provided with technical assistance on state policy issues, a revolving loan fund, and assistance to local sponsors who wish to develop affordable assisted living.

• ***Michigan's*** Affordable Assisted Housing Project undertaken by Area Agencies on Aging, a two county regional center (both entities being designated to implement waiver services) and the State Housing and Development Authority. The project demonstrated the benefits of coordination between the Home and Community Based Waiver program and the Section 8 Rental Assistance program. Initial program participants were waiver clients on the state's waiting list for Section 8 rental assistance vouchers. The average value of combined public subsides was $1,540 per month, including $320 in housing vouchers and $1,220 in waiver services. Of elderly participants, the average age was 77 -- with most choosing to remain in their existing homes.

Self-Sufficiency Efforts

Several states have encouraged seniors to remain physically self-sufficient through health promotion and disease prevention projects and via positive aging initiatives. Examples of these kinds of programs include:

• ***South Carolina's*** In-Home Prevention Services for Seniors (IHPSS) program, which targets seniors in 13 rural counties aged 65 and over who are willing and cognitively able to respond to individual health promotion and disease prevention plans. Public Information/Volunteer Coordinators provide community outreach and Registered Nurses (RNs) conduct in-home assessments and develop a plan of individually tailored priorities for the clients. Human Services specialists monitor clients and provide support through home visits. Volunteers provide assistance such as installing grab bars and helping clients exercise. Client evaluation occurs at the Department of Health and Environmental Control.

• ***Florida's*** Positive Aging and Self-Care Initiative media campaign, which encourages senior citizens to live life to its fullest, rather than focusing on disengagement. The campaign motto is "Aging in Inevitable. Living Life to Its Fullest Is an Option". This new program is aimed at encouraging learning new skills and participating in activities; taking responsibility for growing old well, accepting illness as a means of adapting to limitations and continuing to pursue life's pleasures, finding satisfaction in life-long experiences and accomplishments, and remaining eager to continuing to contribute. The campaign will feature Florida State football coach Bobby Bowden as spokesperson and will showcase role models who are proactive in managing the way they age.

Implications of the Olmstead Decision

The Supreme Court's decision in the L.C. v. Olmstead case addressed the issue of whether a state government discriminates against individuals with disabilities by treating people in an institution when it is determined that treatment in a more integrated setting in the community is "appropriate". The decision acknowledged that states must provide community placements when that can be "reasonably accommodated". States are not required to "fundamentally alter" any services or programs in order to meet this requirement. Importantly the court also ruled that a state's budgetary constraints and the resources available to the state and the needs of others must be taken into account.

The Olmstead decision therefore does not constitute a mandate for complete and immediate deinstitutionalization. Instead Olmstead actually reaffirms what states have been doing for the past 20 years - moving individuals out of nursing homes and into the community - where doing so is appropriate. The Supreme Court decision clearly left states wide latitude in determining how to proceed with expanding home and community-based care. It required states to make "reasonable accommodations", and states are now in the process of meeting with providers, advocates and communities to develop plans to move people with disabilities into the community and to help those in the community stay out of institutions.

States cannot bear the burden of these decisions alone, and will need more assistance from the federal government. There are many things that our federal partners can do to assist states in assuring that the requirements of the Americans with Disabilities Act (ADA) are met. Congress and Federal agencies such as the Departments of Health and Human Services, Housing and Urban Development, and Labor can help with the housing, workforce shortage, and funding issues that remain.

NGA's Health Care Reform Proposal

One of the most important actions that the federal government can undertake in this area is to act on the health care reform proposal adopted by the National Governors Association in February. That policy

(HR-32) calls for a number of improvements that will enable the states and the federal government to better anticipate, identify, and solve the long-term care challenges in this country.

The policy adopted by the Governors calls for strengthening the collegial and cooperative mindset between the states and the Health Care Financing Administration (now the Centers for Medicare and Medicaid Services). States have a unique role as funders and administrators of the Medicaid program, and it is critical to the health and well being of all 40 million beneficiaries that collaboration with our federal partners be encouraged. A stronger state-federal partnership acknowledging state flexibility will allow innovative programs to be implemented faster and in a more widespread fashion.

After twenty years of experience with home and community-based care waivers, we know that it no longer makes sense for good public policy to be implemented through the waiver process. Although HCFA has worked closely with states to improve the process, the greatest improvements would come through acknowledging that home and community-based care is best administered through the state plan process, and not through paperwork-intensive waivers.

In addition, in the Medicaid reform principles laid out in HR-32, there are important components for improving the long-term care system in this country. Under current law, Medicaid is essentially an all-or-nothing program. Financial and functional conditions will trigger eligibility for all the services currently offered by the program, but until those conditions are met, Medicaid is not allowed to pay for any services at all. States know well that the provision of a few targeted services, such as respite care, home modifications such as a wheelchair ramp or bathtub railings, or personal care attendants can often maintain a high level of functioning in seniors or individuals with disabilities. These targeted services often prevent catastrophic events, prevent slow declines in functioning, and are a cost-efficient and critical component of good public health policy.

Unable to provide such targeted services through Medicaid, many states have taken to developing such programs with 100% state dollars. Allowing the federal government to partner in these types of programs would encourage some states to begin such programs, and allow the rest to expand and enhance what they currently provide. I've described some of the types of programs currently underway at the state level; it is critical that we as a nation find ways to encourage the continued to development of such programs. Furthermore, understanding that these state funded programs provide long-term savings for both Medicaid and Medicare, it is easy to see why allowing Medicaid to partner with the states is an important policy objective.

Our policy also calls on Congress and the Office of Management and Budget to relax the very stringent "budget neutrality" requirements that often serve to impede state innovation and the development of quality long-term care programs for seniors. We know that early intervention services in Medicaid are responsible for preventing hospitalizations for the elderly, thereby saving the Medicare program from additional costs. Similarly, state-funded respite care can prevent nursing home placements, thereby saving money for the Medicaid program. Funding for protease inhibitors for people who are HIV-positive will prevent the onset of AIDS and provide savings to a number of other health and social welfare programs. Currently, states are unable to factor in such cost savings when applying for Medicaid waivers. The flexibility to consider budget neutrality across federal programs would enable the Medicaid program to help people with disabilities return to the workforce, integrate and coordinate care for seniors, and prevent the onset of AIDS in people infected with HIV.

Finally, our policy acknowledges that there must be a reevaluation of the funding partnership in the Medicaid program. For the first time in its history, the combined federal state budget of the Medicaid program has exceeded the Medicare budget. This is due to a number of factors, but most importantly because Medicaid is increasingly being asked to carry burdens never dreamed of when the program was

first created. In 1965, the Congress never could have imagined that Medicaid would become the single largest payer of long-term care services in the country, nor could they have foreseen the enormous budgetary pressures of providing prescription drug coverage, or even that one-third of the entire Medicaid program would be devoted to health care services for Medicare beneficiaries.

Given how the program has changed since its inception; given that Medicaid spending is growing faster than state per capita incomes and state tax revenues; and considering that so much of Medicaid spending is for Medicare beneficiaries, it is critical that some reevaluation of the funding nature of the program take place. The funding changes called for in our policy create a simple, yet elegant balance that will simultaneously help states that are facing severe fiscal crises but also provide sufficient incentives for states to expand eligibility and benefits to those who currently have nothing.

Conclusion

As you can see, Governors have been and will continue to be active in responding to the health and long-term care needs of the citizens in their states. Without a comprehensive national framework, however, it is likely that future services will be under funded and implemented on a state-by-state basis. This is why it is critical that states and the federal government commit now to developing a vision for long-term care in the 21st century. The most important thing that we can do is to create a comprehensive long-term care benefit at the federal level. Until then, the Governors have developed a plan that will enable the states to better meet the needs of seniors and individuals with disabilities.

Thank you Mr. Chairman and members of the Committee for this opportunity and I look forward to answering any questions you may have.