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STATEMENT OF SHANNON BROUSSARD
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AND

MEMBER, NATIONAL ASSOCIATION OF AREA AGENCIES ON
AGING

SPECIAL COMMITTEE ON AGING
UNITED STATES SENATE

HEARING ON
“Long Term Care Services”
September 26, 2002 at 10 a.m.

Good morning Chairman Breaux and distinguished members of the Special Committee on Aging. My name is Shannon Broussard, and I am the Director of the Cajun Area Agency on Aging, Inc. in Lafayette, Louisiana. Thank you Chairman Breaux for inviting me to this important hearing on long-term care. My Board of Directors wants me to convey its appreciation for your interest in the long-term care needs of older adults. The Cajun Area Agency on Aging, Inc. is a member of the National Association of Area Agencies on Aging (n4a), the umbrella organization for the 655 area agencies on aging (AAAs) and more than 230 Title VI Native American aging programs in the U.S. and the following testimony includes information provided by n4a that reflects national trends concerning long term care services and AAAs.

The Mission of Area Agencies on Aging (AAA)

AAAs are most often the first place an older adult or their family member will turn when they need long term care services. Established in 1973 under the Older Americans Act (OAA), there are 655 AAAs across the country that provide a community-based structure for planning, service coordination, oversight and advocacy for supportive services for Americans aged 60 and over. The OAA also helps fund 232 Native American aging programs, known as "Title VI," to meet the unique needs of older American Indians, Aleuts, Eskimos and Hawaiians.

OAA services fall into five broad categories: information and access services; community-based services; in-home services; housing; and elder rights. These categories include support services such as congregate and home-delivered meals, home and personal care, caregiver support, transportation, senior centers, nursing

home ombudsman, employment and services for Native Americans and Native Hawaiians.

The Role of AAAs in Assisting Family Members and Older Adults in Identifying Long-term Care Resources

The wide range of OAA services administered by the aging network provides consumers with a broad range of service choices that best meet their individual needs. In particular, AAAs and Title VI agencies play a pivotal role in assessing their clients' needs and developing programs that respond to those needs. These agencies act as advocates for improved services for older persons and their families. They often serve as portals to care, assessing multiple service needs, determining eligibility, authorizing or purchasing services and monitoring the appropriateness and cost-effectiveness of services. AAAs provide direct services and contract with local providers to furnish other services in the community.

One of the greatest strengths of the Older Americans Act is the flexibility it allows AAAs and Title VI agencies to tailor services to the specific needs of older adults in their service area. While all AAAs and Title VI provide core support services as required by Title III of the Act, each adapts these services to appropriately, effectively, and efficiently serve their geographically, racially, culturally, and ethnically diverse local population.

The Cajun Area Agency on Aging, Inc.

My AAA, the Cajun Area Agency on Aging, Inc. serves eight, primarily rural, parishes (counties) in south Louisiana. There are more than 91,000 persons 60 years of age or older in our area. Because the Older Americans Act requires that we serve the *neediest elderly* first, and because there are so many older adults without family nearby to provide help of any kind, the older adults we now reach with in-home Older Americans Act services tend to be very frail and live alone; most are women, many are rural, and most are very poor. For those with family, the National Family Caregiver Support Program established in the recent reauthorization of the Older Americans Act, has allowed us to reach new constituents, the caregivers, who desperately need our assistance.

Thanks to advances in health care and medical technology, life expectancy has increased to an average of 76.9. However, with longer lives often comes the increased need for long-term care. Many older adults have only two options, institutional care or care provided by a family member. Though many older adults prefer receiving long-term care in their home, an institutional bias exists in Louisiana. Approximately 25,000 of Louisiana's impoverished older adults live in nursing facilities, where Medicaid subsidizes care. Medicaid is responsible for 80% of the nursing facility care in the state. For the most part, government-subsidized care is only available for nursing facility patients. Currently, Louisiana's Medicaid programs [Elderly & Disabled Adult & Adult Day Health Care Waivers] funds 1,804 in-home or community-based waiver slots for recipients [aged 65 or older] who would otherwise require institutional care.

Cajun Area Agency on Aging currently provides supportive and nutrition services to approximately 13,500 older adults, including home-delivered meals, light housekeeping, assisted transportation, and social opportunities for those who can attend community centers. These programs have been the salvation for many individuals who, in their absence, would have had to be placed in nursing facilities. These services, however, are non-medical in nature and many older adults also need in-home health services such as monitoring of medical devices and medication management. A high percentage of older adults who need this kind of assistance do not require twenty-four hour nursing care and can remain viable members of their communities, if they receive appropriate in-home assistance that meets basic health care needs.

As previously stated, most individuals who need long-term care services would much prefer or are desperate to remain in their own homes or in home-like settings, such as assisted living. For the past several decades, however, the bulk of public dollars for long-term care have supported services in nursing facilities. Additionally, the average family cannot afford the cost of assisted living facilities without some financial assistance.

Many consumers still assume that long-term care is covered under Medicare. The concept of purchasing long-term care insurance is relatively new and not really accepted or understood in Louisiana. The cost of such policies is also a barrier. Dual coverage policies that cover both institutional care and home care are now also available. However, these policies are very expensive and not a viable solution for low and even many middle-income individuals.

Consumer Questions

Louisiana

Throughout the state of Louisiana, family, friends and neighbors continue to be the main source of help for elderly community members, providing transportation and shopping assistance, social support and a wide variety of other services that successfully maintain older adults in the community. Even so, many older adults lack such support and depend on formal social services to meet critical needs.

At present, the majority of requests Cajun Area Agency on Aging receives for assistance have been for in-home care, such as sitter services, respite care and nursing care. Many calls are from individuals who do not qualify for government-subsidized care, and who need more critical services than typical social services currently provide. We do our best to refer older adults to services that will enable them to remain at home. All are advised to call the *Medicaid Request for Services Registry* and have their loved one's name placed on the waiver program waiting list, whether they are financially eligible [income limits – up to three times SSI amount - \$1,635] or not. Most individuals who are privately paying for home care will soon become eligible for Medicaid, due to the high costs of that care.

National - Eldercare Locator

One service that the Cajun AAA, Inc. and all AAAs use to connect older adults with needed long-term care services is the Eldercare Locator. Established in 1991 by the U. S. Administration on Aging, the Eldercare Locator is as a public service

administered by n4a and the National Association of State Units on Aging. The Eldercare Locator, a nationwide toll-free 800 number, provides individuals who call with access to more than 4,800 state and local information and referral (I&R) service providers, identified for every ZIP code in the country. The database also includes special purpose I&R telephone numbers for Alzheimer's hotlines, adult day care and respite services, nursing home ombudsman assistance, consumer fraud, in-home care complaints, legal services, elder abuse/protective services, information on Medicare/Medicaid/Medigap, tax assistance and transportation. In November 2001, the Eldercare Locator website was launched and currently receives approximately 25,000 hits a month.

Since its inception, the Eldercare Locator has fielded over 822,100 calls from individuals and their family members seeking answers to questions on long-term care services. In the period between October 2001 and August 2002, the Locator received over 111,500 calls. The most common information sought during this period include information on home care services (18,851 requests), financial assistance (10,358 requests), transportation (8,215 requests), and housing information (6,968 requests).

During this period there have also been spikes in calls on prescription drugs (April & May) and caregiving (June).

Recommendations for Improvement to the Current System

The overwhelmingly preferred choice of older adults, as well as individuals with disabilities who need long term care services is for home and community-based care. Home and community-based care allows individuals to maintain their independence

and age with dignity in the comfort of their own homes, in familiar neighborhoods and communities.

Our federal policies do not adequately recognize that the most cost-effective form of long-term care is provided through home and community-based services. Older Americans Act programs and the services provided by AAAs are a major component of an array of federal, state, local, and private support services paid for through public and private financing. Moreover, despite the substantial role that family caregivers play in providing long-term care, the United States lacks a coherent set of policies to assist informal caregivers. Demographic changes, the aging of the 77 million baby-boomers, and increasing longevity will intensify current delivery and financing difficulties.

A comprehensive national policy that shifts the focus and funding of long-term care to community-based services is essential to meet the needs and address the desires of America's aging population. Independence, dignity and choice are strongly held values by all Americans, and individuals with physical or cognitive limitations and impairments are no exception. By shifting national policies toward home and community-based services, the quality of life of older adults will improve, taxpayers will be spared the cost of premature and expensive institutional care, and our nation's core values will be honored.

A sound home and community-based system of long-term care provides a coordinated and broad range of service that addresses the medical, social and

environmental needs of the individual. n4a has issued a series of policy papers on the nine components critical to a comprehensive home and community-based system of care, which include: Medicaid waivers for home and community-based services, Older Americans Act services, caregiver support, housing options, transportation services, nutrition and wellness programs, mental health services, adult protective services and a dependable paraprofessional workforce. The individual papers are provided as an Addendum to this testimony. Key recommendations from each follow:

- Increase the federal Medicaid match to states by 3% and dedicate the resulting savings in long-term care funds to home and community-based services;
- Reduce categorical funding barriers and support efforts to partner Medicaid waivers with other local, state, and federally assisted programs such as Older Americans Act services, federal housing programs, and community mental health services that provide home and community-based care;
- Promote greater coordination between the Medicare and Medicaid programs to address the interaction of acute and chronic care needs as a means of avoiding unnecessary hospitalization;
- Encourage approval of waiver proposals that integrate care for persons eligible for both Medicaid and Medicare;
- Increase funding for all OAA programs and services by a minimum of 10% above the FY 2002 levels;
- Double the initial \$125 million appropriation for the NFCSP to ensure that the much-needed benefits this vital program provides reach thousands more caregivers and their families;
- Maintain and enhance the flexibility of the OAA to enable AAAs and Title VI agencies to most appropriately and effectively respond to the specific needs of diverse populations of older adults in their communities;

- Offer a range of financial and other incentives, including tax credits/deductions and cash vouchers to all family caregivers, and affordable health insurance and guaranteed retirement security for individuals who leave the workforce to provide care to a family member;
- Increase financial assistance for home and community-based services on the federal and state levels to support aging in place for the majority of older adults who want to stay in their homes;
- Develop new residential models of housing that meet universal design standards, including new housing that is accessible, adaptable and affordable for the increasingly diverse older adult population;
- Enhance, coordinate and adequately fund the vast array of federal and state financed transportation services to provide viable and affordable options for the growing population of older adults who need services;
- Support increased funding for the Federal Transit Agency's *Section 5310* program, which funds transportation programs for older adults and persons with disabilities in the reauthorization of the Transportation Equity Act for the 21st Century (TEA-21) in 2003;
- Expand and revitalize community senior nutrition programs to better meet the specialized nutrition needs of an increasingly ethnically diverse population and individuals with multiple health conditions;
- Enhance resources to meet the increasing demand for home-delivered meals resulting from the growth of the 85 and older population which is expected to double by 2030;
- Increase collaboration among mental health services providers and streamline federal, state and privately financed mental health services to coordinate and strengthen existing service and delivery systems;
- Promote prevention and early intervention measures that increase collaboration among acute and long-term care providers;

- Provide adequate funding at the federal, state and local level to develop and enhance elder abuse prevention services;
- Continue to research the causes of abuse and neglect while acknowledging that many forms of domestic mistreatment are crimes and should be treated as such;
- Establish basic training in nursing skills and require the successful completion of a competency test for all paraprofessional personnel; and
- Encourage employers to provide higher wages and improved benefits for all paraprofessional staff through incentive programs.

ADDENDUM



Home and Community-Based Services

Introduction

As individuals age, and chronic conditions increase, the need for long-term care services grows. Long-term care refers to a broad range of services, paid and unpaid and provided in a variety of settings, for persons who need assistance with daily activities due to a physical or mental limitation. The availability of formal or informal support and services, an individual's needs and preferences and the ability to finance needed services all play a part in determining the setting in which an individual will receive long-term care services. According to a recent General Accounting Office (GAO) report, of the almost six million adults age 65 and over with long-term care needs, only 20 percent receive care services in a nursing home or other institutional setting, with the remaining 80 percent receiving assistance at home and in the community. Home and community-based care, which allows individuals to maintain their independence and age with dignity in the comfort of their own homes, in familiar neighborhoods and communities, is overwhelmingly the preferred choice of older adults, as well as individuals with disabilities.

Our federal policies do not adequately recognize that the most cost-effective form of long-term care is provided through home and community-based services. These services are currently provided through a fragmented and inconsistent array of federal, state, local, and private support services paid for through public and private financing. Moreover, despite the substantial role that family caregivers play in providing long-term care, the United States lacks a coherent set of policies to assist informal caregivers. Demographic changes, the aging of the 77 million baby-boomers, and increasing longevity will intensify current delivery and financing difficulties.

The 1999 Supreme Court *Olmstead v. L.C.* decision has accelerated the shift of national policy toward home and community-based services. In *Olmstead*, the Court ruled that the unnecessary segregation of individuals in long-term care facilities constitutes discrimination under the Americans with Disabilities Act (ADA). States are required, when it is appropriate and reasonable to do so, to serve individuals with disabilities in community settings rather than in institutions. The Court directed each state to develop a comprehensive, effective working plan to place qualified individuals in less restrictive settings and to assure that people come off waiting lists at a reasonable pace.

Olmstead affects those at risk of institutionalization as well as those currently institutionalized. Therefore, any reform efforts brought on by the decision must involve changes not only to the long-term provision of public health services (primarily Medicaid) but also to housing, transportation and other fundamental support services that are essential to fully integrate individuals with disabilities into least restrictive settings.

Executive Summary

A comprehensive national policy that shifts the focus and funding of long-term care to community-based services is essential to meet the needs and address the desires of America's aging population. Independence, dignity and choice are strongly held values by all Americans, and individuals with physical or cognitive limitations and impairments are no exception. By shifting national policies toward home and community-based services, the quality of life of older adults will improve, taxpayers will be spared the cost of premature and expensive institutional care, and our nation's core values will be honored.

A sound home and community-based system of long-term care provides a coordinated and broad range of services that address the medical, social and environmental needs of the individual. n4a believes the following principles must be adhered to for a home and community-based system to best meet the needs of those it serves, including the not-too-distant future needs of the baby boomer generation.

Reform Medicaid

Medicaid, the largest public program financing long-term care, has an inherent bias toward institutionalization. Congress established the home and community-based service waiver in 1981 to attempt to reduce this bias. The Medicaid waiver program gives states the option to apply for waivers to fund home and community-based services for people who meet Medicaid eligibility requirements for nursing home care. A recent study by the Assistant Secretary for Planning and Evaluation with the U.S. Department of Health and Human Services found that average spending on the aged and disabled under the Medicaid home and community-based waiver saved money – providing for an individual under the waiver program costs \$5,820 a year compared to \$29,112 for nursing home care. Even so, nursing home care remains a basic service under Medicaid, while states still face a burdensome waiver process to offer home and community-based services.

Build Upon the Successes of the Older Americans Act

The Older Americans Act (OAA) has been the foundation of services for older adults throughout the country since its enactment in 1965 and forms the nucleus of a national system of home and community-based services. OAA funds, and the services they make possible, are augmented by leveraging state and local government funding, as well as private sector, foundation, participant and volunteer contributions. OAA funding has not kept pace with inflation or the growing population of individuals eligible for services. Significant increases in federal appropriations are crucial to assure the availability of services and programs that enhance the ability of older Americans to live with maximum independence.

Enhance Support for Family Caregivers

The majority of people of all ages with chronic disabling conditions rely on family members or friends as their primary source of care. Nearly one out of every four households (23 percent or 22.4 million households) is involved in caregiving to persons age 50 or older. Among older adults with long-term care needs, nearly 95 percent receive some or all of their care from informal caregivers who often suffer emotional, physical and financial hardships as a result of caregiving. Furthermore, cultural and demographic changes are reducing the pool of available caregivers just as the baby boomer generation approaches retirement age. The National Family Caregiver Support Program, enacted in 2000 as part of the Older Americans Act reauthorization, and numerous state programs provide support services for caregivers, but current federal funding is insufficient to meet caregiver needs.

Link Affordable Housing with Needed Support Services

Housing security is critical to the health and well being of older adults. The home and community-based system will not succeed without the provision of affordable and accessible housing for older adults. Greater coordination needs to occur between housing and service providers to guarantee that support services, such as meals, personal assistance and housekeeping, as well as health services, are readily available and easily obtainable. While policy initiatives are underway to increase existing assisted living facilities stock, convert existing public housing into accessible housing, and provide increased coordination of support and housing services, progress has been slow and more commitment to these efforts by policymakers is needed.

Develop Systems to Help Older Adults Retain Mobility

Mobility is essential for an individual to live at home and in the community. Transportation provides necessary access to medical care, shopping for daily essentials and the ability to participate in cultural, recreational and religious activities. Feelings of isolation and loss have been reported among older adults who can no longer use personal automobiles. Public policy must focus on the provision of safe, reliable and convenient alternative means of transportation for those for whom driving is no longer an option, as well as on efforts to help older adults retain their licenses and cars for as long as possible.

Design Responsive Mental Health Services

Good mental health is fundamental to the well being of older adults and has a major impact on quality of life and optimal functioning. Yet, as the U.S. Surgeon General's 1999 report on mental health points out, too many older adults struggle with mental disorders that compromise their ability to participate fully in life. Older adults underutilize mental health services, for both social and systemic reasons, and care professionals and social services personnel frequently fail to recognize the signs and symptoms of mental illness. Service gaps, lack of collaboration among service agencies, and shortages of trained personnel also contribute to a poorly functioning mental health service system. Policymakers must work toward resolving current challenges in the design and delivery of mental health services that affect quality of life for the older population.

Expand Nutrition and Wellness Programs

Good nutrition and daily physical activity both play important roles in preventing or forestalling the onset of chronic conditions as well as reducing the effects of existing conditions. Nutrition programs such as congregate and home-delivered meals, provided through the Older Americans Act and other government programs, not only improve participants' dietary intake but also provide a social outlet for older adults at risk of isolation. Unfortunately, long waiting lists for these meals programs exist throughout the country. And while fewer structured programs exist to promote physical activity, the social, economic and health benefits of daily exercise must be recognized. Greater emphasis needs to be placed on the development and expansion of programs that promote sound nutrition and increased physical activity at the federal, state and local level.

Increase Efforts to Prevent Elder Abuse and Neglect

The dependence on others for care and assistance whether at home or in a facility leaves older adults, especially the most frail, vulnerable to abuse, neglect and exploitation. Adult protective services are designed to reduce the incidence of abuse and neglect and are essential to making it possible for older adults to remain safely in their homes and communities. Many older adult victims do not report abuse and many cases are not prosecuted. Staffing shortages, poor training and heavy caseloads contribute to unsatisfactory protective services. Greater outreach and educational efforts and increased collaboration among service providers at the federal, state and local level are important measures that can be taken to prevent and decrease all types of elder abuse.

Collaborate on Solutions to Workforce Shortages

At a time when an increasing percentage of the population needs direct care services, our nation is facing a serious shortage of workers in this industry. Paraprofessional personnel shortages can be attributed to, among other things, low pay, inadequate employee benefits including lack of health insurance, insufficient training and minimal chance for career advancement. Moreover, health care agencies have a hard time maintaining employees due primarily to poor reimbursement rates from both public (Medicare, Medicaid) and private providers. Furthermore, the care that is provided by these workers is undervalued by society. Policymakers need to work collaboratively with workers unions, service providers and consumers to recruit and retain a stable, reliable workforce.



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Home and Community-Based Services for Older Adults: Medicaid Waivers

The Medicaid program is the major source of financing for long-term care, providing services for low-income individuals or those that become low-income as a result of paying for long-term care or medical needs. While Medicaid long-term care expenditures are still predominantly institutional, with nearly 70 percent of long-term care expenditures going to nursing homes and other institutional settings, there has been a growing trend toward home and community-based services that started with the implementation of the Medicaid Waiver program in 1981. The use of Medicaid waivers as an effective means of reducing long-term costs was highlighted in a recent study by the Assistant Secretary for Planning and Evaluation with the U.S. Department of Health and Human Services, which found that the annual cost for providing care for an individual under the waiver program is \$5,820 compared to \$29,112 for nursing home care.

Issue Background

Medicaid waivers are often an essential element in the establishment of comprehensive and coordinated service delivery systems for older adults that offer a broad range of choice of home and community-based long-term care services along with institutional care. Furthermore, the need to comply with the *Olmstead v. L.C.* Supreme Court decision to avoid inappropriate institutional care provides an additional impetus for expansion of Medicaid waivers to foster development of a wide range of home and community-based care options.

Sections 1915 (program waivers) and 1115 (research and demonstration waivers) of the Social Security Act allow states to apply to the federal government to obtain exemptions from certain Medicaid statutes. The 1915 (c) waiver is most relevant to home and community-based services because it allows

services to be provided to certain recipients at home or in other community-based settings rather than in institutional or long-term care facilities. The categories of eligible populations include the elderly, disabled, mentally ill and people with specific illnesses or conditions.

The waiver typically allows states to overcome statewide and comparability requirements. Also, the 1915 (c) waiver often includes a request not to apply the same income eligibility requirements throughout the state. The 1915 (c) waivers allow states to provide services beyond the scope of traditional Medicaid benefits to cover additional medical and non-medical services, including home health, case management, personal care, homemaker, adult day health, rehabilitation, and respite care. In addition, other services such as in-home support, transportation, and environmental modifications may be included if the state demonstrates they are necessary in order to avoid institutionalization.

The purpose of the 1115 waiver is "to experiment, pilot or demonstrate projects which are likely to assist in promoting the objectives of Medicaid." 1115 waivers can be used to waive a much broader set of Medicaid requirements than 1915 (c) waivers as long as program changes do not create additional federal costs or are budget neutral. These waivers typically permit states to expand eligibility or benefit packages by generating savings and reinvesting the savings into program expansion.

Proposed 1115 waiver programs must include a research component that provides new information on models that adapt Medicaid to specific state needs. Also, the proposed benefit package must not be less than the full coverage currently offered in the state.

Waiver Process

Medicaid waivers must demonstrate cost-effectiveness or budget neutrality. Proposed changes under a waiver request cannot cost the federal government more than the expected Medicaid costs for the traditional Medicaid program under the same time period. The Office of Management and Budget must determine that 1915 waivers are cost-effective and that 1115 waiver requests are budget neutral.

The evaluation of the cost effectiveness and budget neutrality of Medicaid waiver proposals should take into consideration potential cost savings not only for Medicaid but also for Medicare, Supplemental Security Insurance, and Social Security Disability Insurance. The current lack of coordination between Medicare and Medicaid exacerbates the fragmentation of acute and long-term care.

Policy Recommendations

Medicaid waivers will continue to play a critical role in the ability of states to develop comprehensive and coordinated service delivery systems for older adults that offer a broad range of home and community-based long-term care services. While Medicaid spending for home and community-based services is increasing, policymakers must work to make requirements less restrictive and Medicaid dollars more available to the states as the demand for home and community-based care continues to grow.

n4a urges policymakers to:

- **Increase the federal Medicaid match to states by 3% and dedicate the resulting savings in long-term care funds to home and community-based services;**
- **Reduce barriers for states and federally recognized Indian tribes to implement additional 1915 (c) waivers so they may offer increasing**

alternatives to institutional care for individuals with long-term care needs;

- **Reduce categorical funding barriers and support efforts to partner Medicaid waivers with other local, state, and federally assisted programs such as Older Americans Act services, federal housing programs, and community mental health services that provide home and community-based care;**
- **Promote greater coordination between the Medicare and Medicaid programs to address the interaction of acute and chronic care needs as a means of avoiding unnecessary hospitalization;**
- **Encourage approval of waiver proposals that integrate care for persons eligible for both Medicaid and Medicare; and**
- **Make financial incentives available from Medicare for Medicaid home and community-based long-term care providers who provide services that help reduce Medicare costs for dually- eligible consumers.**



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Home and Community-Based Services for Older Adults: Older Americans Act

The Older Americans Act (OAA) has been the foundation of services for older adults in the United States since its inception in 1965 and forms the nucleus of our national system of home and community-based services for older Americans. The OAA provides funding to states for a range of community planning and service programs to older Americans at risk of losing their independence. Since its enactment, the OAA has been amended fourteen times to expand the scope of services, increase local control and responsibility, and add more protections for the frail elderly.

Issue Background

The Aging Network

To develop and implement the wide array of OAA services, a system of federal, state and local agencies, known as the aging network was established. The core of the aging network is the U.S. Administration on Aging (AoA), State Units on Aging (SUA), and Area Agencies on Aging (AAA). The AoA and SUAs were established under the initial Act; AAAs were added in 1973 to respond to the needs of Americans aged 60 and over in every local community. The network also includes Native American aging programs, known as "Title VI agencies," service providers, and aging research, education, and advocacy organizations. Together these groups work to maintain the comprehensive and coordinated system of services that make up the national home and community-based care system for the aging. Currently, there are 56 SUAs, 655 AAAs, 236 Title VI agencies, and over 29,000 direct service providers throughout the United States.

OAA Programs and Services

The OAA services available through the aging network fall into five broad categories: information and access services; community-based services; in-home services;

housing; and elder rights. These categories include support services such as congregate and home-delivered meals, in-home services, caregiver support, transportation, senior centers, nursing home ombudsman, employment and services for Native Americans and Native Hawaiians.

The wide range of OAA services administered by the aging network enable it to direct consumers to service choices that best meet their individual needs. In particular, AAAs and Title VI agencies play a pivotal role in assessing community needs and developing programs that respond to those needs. These agencies act as advocates for improved services for older persons and their families. They often serve as portals to care, assessing multiple service needs, determining eligibility, authorizing or purchasing services and monitoring the appropriateness and cost-effectiveness of services. They also provide direct services as well as contract with local providers to furnish services in the community.

All AAAs and Title VI agencies support a range of home and community-based services, but services vary across communities. While there is much consistency in the types of essential home and community-based services available across the country, these services are customized to reflect local needs and caregiver resources.

Congress took an important first step toward recognizing the value and considering the needs of caregivers with the enactment of the National Family Caregiver Support Program (NFCSP), as part of the OAA amendments of 2000. The NFCSP provides grants to States to help hundreds of communities assist thousands of family members who are struggling to care for their older loved ones who are ill or who have disabilities.

Policy Issues

OAA appropriations provide funds to the AoA for administrative and program expenses for all titles of the OAA with the exception of Title V: the Community Service Employment Program, which falls under the jurisdiction of the Department of Labor. While the OAA has received incremental funding increases over the last several years, it has not kept pace with inflation or the growing population of individuals eligible for services. As a result there are unmet needs throughout the country. AAAs and Title VI agencies have skillfully managed care for vulnerable aging populations by maximizing private and public resources to ensure that essential services are available to millions of minority, frail and low-income older persons in need of comprehensive long-term care. However, as the aging population continues to grow — with more people living longer but facing chronic illness and frailty — the aging network will increasingly be unable to meet the demands for care without significant funding increases. This year, the President's budget request for FY 2003 includes \$1.34 billion in funding to AoA for OAA programs, an overall decrease of \$8 million from last year.

Policy Recommendations

The necessity for increased OAA funding will only continue to grow with the coming retirement of 77 million baby boomers and the demand for long-term care expected to more than double by 2030. Significant increases in federal appropriations are crucial to assure the availability of OAA programs and services and enhance the ability of older Americans to live with maximum independence.

n4a urges policymakers to:

- Increase funding for all OAA programs and services by a minimum of 10% above the FY 2002 levels;
- Double the initial \$125 million appropriation for the NFCSP to ensure that the much-needed benefits this vital program provides reach thousands more caregivers and their families;

- Ensure that the OAA is reauthorized on time when the current authorization expires in 2005, allowing for a seamless transition and avoiding a lapse in authorized funding which will be more important than ever as the elderly population and demand for services continue to skyrocket;
- Maintain and enhance the flexibility of the OAA to enable AAAs and Title VI agencies to most appropriately and effectively respond to the specific needs of diverse populations of older adults in their communities;
- Provide staff and technology resources within the aging network to track older adults and their caregivers together as they move through the home and community-based care system; and
- Encourage the AoA to begin planning for the 2005 White House Conference on Aging immediately and ensure that national aging advocacy groups have ample opportunity to provide input on the agenda and conference objectives.



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Home and Community-Based Services for Older Adults: Informal Caregiving

Family care of older adults is an important and valued role in our society, and one that is important to family preservation and well being. Most older adults with long-term care needs live at home, either in their own homes, with or without a spouse, or in the home of a close relative or friend. In this setting the major long-term provider is the family and, to a lesser extent, other unpaid "informal" caregivers. The overwhelming majority of non-institutionalized older adults with disabilities — about 95 percent — receive at least some assistance from relatives, friends and neighbors. Almost 67 percent rely solely on unpaid help, primarily from wives or daughters.

Issue Background

Long-term care of older adults by family members is central to the functioning of current social and health care systems and is therefore a critical policy issue. Informal caregiving has always been the dominant source of care to most individuals in need. Nearly one out of every four households (23 percent or 22.4 million households) is involved in caregiving to persons age 50 or older. In fact, caregivers now provide nearly \$200 billion in unpaid care. Without this essential component of care, the long-term care system and the Medicare and Medicaid programs would not be able to meet the needs of our older population. With the current system facing growing demands for support services, it is essential to provide family caregivers with the resources they need to provide this valuable care.

Research on family caregiving has not only consistently validated its significant role in long-term care, but has also illuminated the problems and needs experienced by informal caregivers which have been of increasing concern to both aging advocates and policymakers. The caregiver role frequently results in enormous emotional, physical, and financial hardships, even though it is willingly undertaken and often is a source of great

personal satisfaction. Caregivers commonly experience a sense of burden, fair-to-poor physical health and high rates of depression. Among caregivers who provide unpaid care for a family member or friend age 50 or older, some 15 percent report that they have experienced a physical or mental health problem due to their caregiving duties. Worries over paying for care especially plague middle income families, who are not eligible for public benefits, yet cannot afford the out-of-pocket costs of care.

Half or more of family caregivers juggle work, family and caregiving responsibilities, resulting in work disruptions and lost productivity. The cost in lost wages and benefits to family caregivers has been estimated to be \$109 per day, according to a report by the American Council of Life Insurers in March 2000. While the Metlife Mature Market Group in June 1997 estimated the cost of informal caregiving in terms of lost productivity to U.S. businesses to be \$11.4 billion annually.

Need for Overall Policy

Despite vast research on family caregivers, widespread awareness of the volume of family care, and general agreement that family care is necessary to balance the costs of long-term care, a comprehensive policy on family care of frail older adults has not emerged. A patchwork of family support programs of various kinds does, however, exist. These include community-based programs designed to help family members who are giving care, such as educational programs, support groups, and respite services. They also include long-term care services, usually for low-income people, that provide benefits directly to the older person and thus relieve family members to some extent.

In addition, many states support the family financially through tax incentives or direct payment. Taken together, these activities represent meaningful efforts to support family caregivers. In the last three to four years,

significant progress has been made at the national level with the advent of such policy initiatives as The Family and Medical Leave Act and The National Family Caregiver Support Program (NFCSP) under the Older Americans Act Amendments of 2000. In particular, the NFCSP enables local communities to connect families with information on caregiver resources and local services, provides counseling, training and peer support for caregivers, and provides services needed by older adults and their families, such as respite care, in-home services and adult day care.

- **Promote consumer direction in long-term care;**
- **Assure that family caregivers of adults with physical, as well as cognitive, impairments have a place to turn to for support; and**
- **Encourage the use of the Internet and other information technology to improve access to and information about caregiver support services and community resources.**

Policy Recommendations

As the home and community continue to be promoted as the preferred setting for the delivery of long-term care services to older adults and persons with disabilities, national policy must recognize and support the significant role that family members and other informal caregivers play in the provision of that care. The coming retirement of the baby boom generation and increased demand for long-term care will only intensify demands on family caregivers. A national policy on long-term care should provide services available in the recipient's preferred surroundings, be characterized by privacy, choice, and control over daily decisions, and maintain any self-selected mutually agreed upon relationships between caregiver and care recipient.

n4a urges policymakers to:

- **Double the initial \$125 million appropriation for the NFCSP to ensure that the much-needed benefits this vital program provides could reach thousands more caregivers and their families;**
- **Offer a range of financial and other incentives, including tax credits/deductions and cash vouchers to all family caregivers, and affordable health insurance and guaranteed retirement security for individuals who leave the workforce to provide care to a family member;**



Advocacy. Action. Answers on Aging.

Home and Community-Based Services for Older Adults: Housing

As home and community-based care continues to evolve as the preferred choice of older Americans for long-term care services, the important role that housing plays in the matrix of care must be recognized. A wide range of housing problems confront older adults and policymakers must identify and implement interventions to address them.

Issue Background

Housing provides a context for living that involves health, security and safety, privacy, neighborhood and social relationships, status, community facilities and services. Housing is the basis for independent functioning and is at the core of home and community-based services for older adults. The residential setting can either facilitate or inhibit an older adult's ability to age safely, independently, and with the dignity. Appropriate housing helps older adults remain longer in the preferred setting of the community and delays moves to more expensive institutional health care settings. The comfort and ease that comes with living in a familiar environment can help older adults cope with changes in physical and mental capacities that often accompany aging.

Despite being essential to well being, appropriate housing is unattainable for many older Americans. Current federal estimates suggest that the need for safe, affordable, accessible and suitable housing for older adults is not currently being met and will only increase as the nation's older population continues to grow. Older adults who are most likely to have housing problems include the frail, disabled, and rural older adults and those with low incomes. Millions of older adults live in housing that is in poor condition, is costly, or fails to accommodate physical disabilities. Some do not have access to the supportive services that can make the difference between continuing to live independently and being forced to live in an institution. Housing problems are endemic to both older adult

homeowners and renters. Housing issues for both groups include affordability, availability, suitability and overall housing quality.

Policy Issues

Older adults spend a disproportionately large portion of their incomes for shelter. Because older adults generally live on fixed incomes, they face the hardships of finding affordable rents, or maintaining a house and coping with rising costs, including mortgage payments, property taxes, repairs, and utilities. The insufficient supply of affordable housing and excessive costs are especially threatening to older adults with incomes at or below the poverty level. Despite efforts to increase the supply of publicly subsidized housing, only a small portion of the housing needs of older adults are currently met.

As the older population lives longer, there is a greater likelihood of disability resulting from chronic illness. For frail older adults, the integration of supportive services with suitable physical housing can forestall or prevent the need for institutionalization or more extensive home care. Both subsidized and private housing developments are finding growing numbers of older adult residents "aging in place" and experiencing greater difficulty with activities of daily living as a result of increased limitations. Services are needed to maintain quality of life and support continued residence in housing. In the absence of critical supportive services, including meals, housekeeping, and social services directed by qualified service coordinators, individuals are at greater risk of relocation, typically to more restrictive living situations, such as nursing homes. Service-rich housing has been found to reduce both the number of hospital and nursing home admissions and the number of days spent in such facilities.

Policy Recommendations

Given the critical importance of housing to the success of home and community-based care for older adults, the provision of suitable living facilities for older Americans needs to be a major public policy goal. The focus must be on providing housing that both meets the needs of independent older adults and addresses the supportive service needs of frail older adults. The future challenge is to develop new models of supportive housing and provide a range of residential settings and portable services to increase the choices for frail older adults.

n4a urges policymakers to:

- **Increase financial assistance for home and community-based services on the federal and state levels to support aging in place for the majority of older adults who want to stay in their homes;**
- **Develop new residential models of housing that meet universal design standards, including new housing that is accessible, adaptable and affordable for the increasingly diverse older adult population;**
- **Support the conversion of public housing for older adults into supportive housing and increase the number of service coordinators provided in housing facilities; and**
- **Encourage more helpful household arrangements through incentives for making home modifications that help older adults remain independent in their homes.**



Advocacy. Action. Answers on Aging.

Home and Community-Based Services for Older Adults: Transportation

Transportation is the vital link between home and community. It connects individuals of all ages to the places where they can fulfill their most basic needs — the grocery store for food, the worksite for employment, friends' homes and recreational sites for social interaction, and houses of worship for spiritual sustenance. But, these resources in the community are only beneficial to the extent that transportation can make them accessible to those who need them.

Issue Background

The core values of Americans, autonomy and independence, are reflected in the fact that most prefer and rely on the convenience of their own automobile to access the outside world. However, as individuals age, they eventually lose the physical or financial ability to maintain a car. When they stop driving, older adults can experience a drastic decline in mobility.

In suburban and rural areas, home to nearly 80 percent of the older adult population, destinations are often too far to walk, public transit is poor or unavailable, taxis are costly, and special services are limited. In particular, distance from public transportation presents a major barrier as less than half of households in urban and suburban areas are within a half-mile of a transportation stop or station. In rural areas, the situation is more difficult, with only one in eight households being within a half-mile of public transportation.

Transportation problems are closely correlated with poor income, self-care problems, isolation and loneliness. Reduced mobility puts an older person at higher risk of poor health, as the ability to obtain the goods and services necessary for good health and welfare is reduced. In addition, independence is stifled and loss of self-sufficiency can fuel depression.

Policy Issues

Older adults who drive their own car experience few transportation problems. However, the picture is vastly different for non-drivers. Those who stop driving usually rely on family and friends, but asking for and accepting rides can be difficult, particularly for those raised in a tradition of self-sufficiency. As a result, non-drivers take fewer and shorter trips, and rides are taken around the schedules and convenience of others. Older non-drivers take only two trips per week compared with six trips per week of older drivers.

For some older adults who have relied on an automobile, learning to use public transportation, if available in their community, can be very difficult. Routes may be geared to commuters and not to the places where seniors frequent. Walking to and from pick-up points can be tiring and dangerous as roads and walkways are not always pedestrian-friendly. It has been reported that more than one-fifth of individuals age 50 and older see the lack of sidewalks and resting places as a major barrier to walking.

Access to public transit, both fixed-route and paratransit systems, needs to be enhanced for older adults with cognitive disabilities. Some older adults with cognitive disabilities may need the additional assistance of "through the door" services to reach their destinations safely. Sensitivity awareness training also should be provided for drivers in how to interact with passengers with dementia and other special needs.

The number of older adults will continue to grow. While many of these older Americans will be healthy and mobile, many others, particularly the "old-old," will need to utilize alternative modes of transportation. Since the passage of the Americans with Disabilities Act (ADA) in 1990, availability of paratransit

services to older adults has been declining as operators adhere more tightly to ADA criteria in the face of financial constraints. As a result, transportation options for some older adults have declined.

Policy Recommendations

Mobility is essential for an individual to live at home and in the community, yet policymakers have focused little attention on how to help older adults retain their mobility. Efforts are needed to help older adults keep their licenses and cars as long as possible, as well as to provide safe, reliable and convenient alternative means of transportation for those for whom driving is no longer an option.

n4a urges policymakers to:

- **Enhance, coordinate and adequately fund the vast array of federal and state financed transportation services to provide viable and affordable options for the growing population of older adults who need services;**
 - **Support increased funding for the Federal Transit Agency's *Section 5310* program, which funds transportation programs for older adults and persons with disabilities in the reauthorization of the Transportation Equity Act for the 21st Century (TEA-21) in 2003;**
 - **Examine and expand existing public transit systems to improve accessibility and availability to older adults especially in suburban and rural communities where fixed route services are less accessible;**
 - **Promote the provision of non-emergency medical transportation as an allowable expense under Medicare;**
 - **Provide training to ensure public transit drivers are sensitive to the special needs of older adults;**
- **Encourage greater coordination and communication between community transportation providers and social service providers; and**
 - **Promote a pedestrian and transit user friendly environment and develop standards to be incorporated into local building and zoning regulations.**



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Home and Community-Based Services for Older Adults: Mental Health

Mental health is fundamental to the well being of older adults, and has a major impact on quality of life. Yet, the 1999 report by the U.S. Surgeon General on mental health points out that too many older adults struggle with mental disorders that compromise their ability to participate fully in life. The cost of this loss of vitality to older adults, their families, their caregivers, and the country is staggering. Despite substantial numbers of older persons with mental health difficulties, the role of mental health in the continuum of care is largely neglected. There is considerable evidence that many of the problems of older Americans caused by poor mental health could be avoided if treatment and prevention resources were enhanced. Because chronic mental disorders are over-represented in long-term care populations, planning and providing for essential services presents an important health and long-term care policy challenge.

Issue Background

Mental Health and Aging

Most older adults enjoy good mental health, but nearly 20% of those who are 55 years and older experience mental disorders that are not part of normal aging. The most common disorders, in order of prevalence, are anxiety disorders such as phobias and obsessive-compulsive disorder; severe cognitive impairment, including Alzheimer's disease; and mood disorders, such as depression. Schizophrenia and personality disorders are less common. Mental disorders can range from problematic to disabling to fatal. The rate of suicide is higher among older adults than any other age group. Older adults with mental illness vary widely with respect to the onset of their disorders. Some have suffered from serious and persistent mental illness most of their adult lives, while others have had periodic episodes of mental illness. A substantial number of older adults experience mental health disorders or problems for the first time

late in life — problems frequently exacerbated by bereavement or other losses which tend to occur in old age.

Minority populations are expected to represent 25% of the older adult population by 2030, up from 16% in 1998. With the expected jump in this population, there is a need for mental health interventions that are effective for ethnic minority older adults. At present, members of ethnic minority groups are less inclined than whites to seek treatment, despite higher rates of poverty and greater health problems. In addition, there is an insufficient number of mental health professionals from ethnic minority groups, which leads to language barriers and inadequate services in mental health programs.

Delivery of Services to Older Adults in Community Settings

Older Americans under utilize mental health services. A number of individual and systemic barriers impede the provision of adequate mental health care to older persons. These include the stigma surrounding mental illness and mental health treatment; lack of outreach to older adults; denial; access barriers; fragmented and inadequate funding for mental health services; lack of collaboration and coordination among primary care, mental health, and aging services providers; gaps in services; and shortages in professional and paraprofessional staff trained in the provision of geriatric mental health services. While mental health services for older adults are provided in diverse settings, far greater emphasis should be placed on community-based care, provided in homes and in outpatient settings, and through community organizations.

Initiatives in Mental Health and Aging

A number of notable initiatives have been undertaken to address issues surrounding mental health services. Among these are

efforts to: encourage collaboration in the delivery of mental health and supportive services; organize consumer advocacy groups; increase public education of mental health issues; support research specific to older adults with mental health needs; and expand and better educate the geriatric mental health workforce. These efforts provide an excellent foundation for confronting critical challenges in mental health and aging.

Policy Recommendations

A national crisis in geriatric mental health care is emerging and policymakers, practitioners, and researchers are facing many challenges in meeting the needs of a diverse and growing aging population. Careful consideration must be given to confronting these challenges, especially in light of the expected increase of older adults in our population and their need for a wide range of mental health services. The crisis will require partnerships across service systems and disciplines to address the mental health needs of older adults.

n4a urges policymakers to:

- **Increase collaboration among mental health services providers and streamline federal, state and privately financed mental health services to coordinate and strengthen existing service and delivery systems;**
- **Promote prevention and early intervention measures that increase collaboration among acute and long-term care providers;**
- **Aggressively recruit and train geriatric mental health professional and paraprofessional personnel needed in the fields of medicine, mental health, and social services;**
- **Increase public awareness and education campaigns to reduce the stigma surrounding mental illness and the resulting underutilization of mental health services;**
- **Increase mental health and aging research to improve understanding of the biological, behavioral, social, and cultural factors related to mental illness, especially for at-risk and underserved populations;**
- **Encourage greater consumer advocacy and involvement in issues of access, range, and quality of mental health services that depend in large part on consumer and family involvement, participation, and advocacy; and**
- **Ensure that mental health professionals acquire adequate knowledge of the cultural background and values of the ethnic minorities they serve, which will enable them to determine the service approaches that best meet their mental health needs.**



Advocacy. Action. Answers on Aging.

Home and Community-Based Services for Older Adults: Nutrition and Wellness

An essential component of an effective home and community-based system of services for older adults is the promotion of healthy aging through nutrition and physical activity programs. Current research shows that it is never too late to begin to make good eating and exercise choices for healthy aging. Good nutrition is essential to maintaining cognitive and physical functioning and plays an essential role in the prevention or management of many chronic diseases such as heart disease, cancer, stroke, diabetes, and osteoporosis. Research has also indicated that the substantial protective effect of physical activity persists even to advanced old age. In fact, some community-based wellness programs, which may feature exercise classes, chronic condition self-management classes, and personal health action plans, have resulted in a significant reduction of hospital use by older adults.

Issue Background

Nutrition

Adequate nutrition is critical to healthy functioning and quality of life. Current nutrition programs and education have been the cornerstone of the Older Americans Act and aging network programs, improving the nutritional intake of older adults and decreasing social isolation. Available to seniors age 60 and older, these programs are targeted to those with the greatest social and economic need. But, while 3.2 million older Americans participate in senior meal programs each year, an estimated 4 million more older Americans suffer from food insecurity or the inability to afford, prepare or gain access to food.

The provision of nutrition services is especially important to ethnic minority older adults, who tend to have a higher incidence of chronic disease. Culturally appropriate meal programs are the entry point for improved nutrition and community engagement. For immigrant or

refugee groups who may have limited English language skills, senior nutrition programs help address cultural isolation, augment diet choices limited by fixed incomes, and bring needed services in a culturally supportive setting.

One program that has been of particular benefit to older adults who lack adequate nutrition is the Seniors Farmers Market Nutrition Pilot Program. The program awards grants to States, U.S. Territories and Indian tribal governments to provide coupons to low-income seniors for use at farmers markets, roadside stands, and community-supported agriculture programs. According to the U.S. Department of Agriculture, in 2001, fresh, nutritious, locally grown fruits, vegetables and herbs were available to 3,700 seniors at 929 farmers markets as well as 542 roadside stands and nearly 90 community supported agriculture programs through this important program.

Physical Activity

While social service providers offer some fitness programs for older adults, these programs need to be recognized as an essential partner to healthy aging and significantly expanded. Fitness programs offer older adults instruction on how to exercise safely and effectively, as well as information regarding access to convenient fitness programs. Researchers have found that exercise by older adults even in their mid-nineties can greatly increase overall muscle strength as well as bone density. Exercise can also improve an older adult's balance and ability to walk, resulting in maximum independence and a decreased incidence of falls.

Wellness/Health Promotion

Health promotion programs designed to meet the special needs of older adults can lead to improved behaviors and health status. Current health promotion and disease

prevention activities funded under the Older Americans Act include health risk assessments and screenings, nutrition screening and educational services, physical fitness, and health promotion programs on chronic disabling conditions.

The Medicare program has also made great strides in recognizing the importance of health promotion in healthy aging by covering preventive services, such as mammography, pap tests and other cancer screenings, bone mass measurements, diabetes monitoring and self-management, influenza immunizations, and pneumococcal vaccinations. In addition, the Centers for Medicare and Medicaid Services (CMS) is taking steps to actively promote Medicare clinical preventive services that contribute to a healthy aging experience. Under the Healthy Aging Project, CMS, in collaboration with other federal health agencies, is exploring Medicare's role in reducing behavioral risk factors, which account for 70% of the physical decline that occurs during aging. This project has focused on identifying interventions that increase Medicare-funded preventive services and promote behavioral change such as smoking cessation, proper diet and exercise among older adults.

Policy Recommendations

Good nutrition and daily activities that lead to overall wellness are integral components of an effective home and community-based service system for older adults as they play important roles in preventing or forestalling the onset of chronic conditions as well as reducing the effects of existing conditions. The benefits of, and need to expand, programs that promote sound nutrition and increased physical activity must be addressed at the federal, state and local level.

n4a urges policymakers to:

- **Expand and revitalize community senior nutrition programs to better meet the specialized nutrition needs of an increasingly ethnically diverse**

population and individuals with multiple health conditions;

- **Enhance resources to meet the increasing demand for home-delivered meals resulting from the growth of the 85 and older population which is expected to double by 2030;**
- **Support efforts to expand on the Seniors Farmers Market Nutrition Pilot Program by building on collaborative efforts between local service providers and farmers to improve access by older adults to healthy and nutritious foods;**
- **Promote and integrate support for physical activity throughout the aging network so that all older adults and aging network providers are aware of the health benefits of even moderate physical activity; and**
- **Advocate that public health funding be available for senior wellness programs, as well as Medicare preventive health coverage, to promote healthy aging and reduce future disease-related costs.**



Advocacy. Action. Answers on Aging.

Home and Community-Based Services for Older Adults: Adult Protective Services

Adult protective services provide an important safeguard for frail older adults. Individuals who are severely disabled and unable to meet their basic personal needs are generally dependent on family members, friends, and paid caregivers for care and support. Their physical or mental impairments and resultant dependency make them extraordinarily vulnerable to mistreatment and neglect. These situations have high potential for abuse, neglect and exploitation, and measures to protect the rights and interests of the frail and impaired in domestic settings are essential.

Issue Background

Elder Abuse among the Older Adult Population

In its common usage, the term "elder abuse" represents all types of mistreatment or abusive behavior toward older adults. This mistreatment can be an act of commission (abuse) or omission (neglect), intentional or unintentional, and of one or more types: psychological, physical, or financial. While elder abuse occurs in domestic and institutional settings alike, it is more prevalent in domestic settings, where the majority of disabled older adults live. Older adults living at home are also isolated and largely invisible to the rest of the community, which puts them at greater risk for mistreatment and neglect.

Researchers have offered various theoretical explanations of why elder abuse occurs: an overburdened caregiver, a dependent elder or perpetrator, a mentally or emotionally disturbed perpetrator, and a childhood of abuse and neglect. Others theorize that structural forces such as the imbalance of power within relationships or the marginalization of older adults within society have created conditions that lead to conflict and violence.

It is difficult to estimate the prevalence of domestic mistreatment of older adults or its

level of severity. Community surveys conducted in the last decade show that 4 to 6 percent of older adults report experiencing incidents of domestic elder abuse, neglect and exploitation. According to the National Elder Abuse Incidence Study (NEAIS), mandated by Congress in 1996, the number of reported cases of domestic abuse nationwide increased steadily from 117,000 in 1986 to 296,000 in 1996. The study estimated that 449,924 persons ages 60 and older living in domestic settings were abused, neglected, or exploited. While for each new incident of elder abuse, neglect, or self-neglect reported four or five incidents went unreported.

Little is known about the consequences of elder abuse because of the difficulty in disentangling the effects of the aging process, disease, and abuse. Researchers have found that abused older adults include higher proportions of people with depression or other mental distress, a history of physical abuse, and financial difficulties than are found among their non-abused cohorts. Clinicians suggest that other effects of elder abuse include feelings of learned helplessness, alienation, guilt, shame, fear, anxiety, denial, and posttraumatic stress syndrome. These findings underscore the need for more research, not only on the psychological and physical consequences of mistreatment, but also on the effectiveness of current intervention strategies.

Elder Abuse and Public Responses

Law enforcement, medical, nursing, health care, social work or other professionals in the community are the first line of defense for victims of neglect or abuse. All 50 states and the District of Columbia have enacted legislation to provide adult protective services for victims of abuse. These mandates usually provide for intervention, advocacy, and mandatory reporting of suspected abuse or neglect to a specific agency, some at the state level, but most often at the county or city level. These laws generally require various licensed

professionals to report incidents of abuse and neglect. After a report is received, a designated agency is obligated to investigate within a set time frame and if the mistreatment is verified, the investigation may involve the police, courts, social services or other community agencies. When the form of mistreatment is passive neglect, those affected can receive services, such as financial assistance, physical and mental health assessments, home maintenance, home health care, meal preparation, counseling and other interventions.

Many states use Social Services Block Grant (SSBG) funds for the protection of adults and children. Federal support for protective services is also provided through the Older Americans Act, which funds legal, guardianship, ombudsman, as well as more traditional nutrition and supportive services such as transportation, meals and personal care.

Policy Issues

With the growth of awareness of the problem of abuse and neglect of older adults has come an increased concern over the inadequacies in our adult protective services systems. Shortcomings in both policy and services seriously compromise the ability of the frail elderly to live in the community. Multiple factors most likely contribute to the ineffectiveness of protective services, including the victim's reluctance to accept help and the inadequacy of services offered. In addition, protective service agencies cannot refuse cases, and are routinely placed in the unenviable position of receiving those cases that other voluntary agencies find too difficult to handle. Burdened by heavy caseloads, insufficient staffing and inadequate training for staff, protective services in some locales have become stigmatized by other agencies and by the public.

Policy Recommendations

For protective services to succeed in the context of long-term care, several changes are required. The most important of these involve networking across service systems, amending state laws, and improving resources for adult protective services.

n4a urges policymakers to:

- **Provide adequate funding at the federal, state and local level to develop and enhance elder abuse prevention services;**
- **Continue to research the causes of abuse and neglect while acknowledging that many forms of domestic mistreatment are crimes and should be treated as such;**
- **Increase community awareness and understanding of elder abuse through a nationwide public education campaign;**
- **Encourage training and education to combat elder abuse for a wide range of professionals, particularly those working in adult protective services and law enforcement;**
- **Establish neighborhood watch programs and similar initiatives designed to provide assistance and referrals; and**
- **Promote recruitment, continued training, and support for the network of volunteers serving in the adult protective services system.**



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Home and Community-Based Services for Older Adults: Workforce Shortage

The services provided by home health care agencies and nursing home facility workers are a critical component of the health care and long-term care industries. While the need for these paraprofessional workers — home health aides, nursing home aides, unlicensed assistance personnel, certified nursing assistants, personal aides, personal assistants, and home health assistants — is increasing, current recruitment and retention efforts are not sufficient to overcome shortages and secure minimum needed personnel. Employers continue to face high turnover rates and lack of available staff. This coincides with a demand for personal care and home health aides that is projected to grow by 58 percent between 1998 and 2008, according to the U.S. Department of Labor, Bureau of Labor Statistics.

Issue Background

There are several significant factors that contribute to the scarcity of paraprofessional personnel who provide direct care to the frail and elderly in their homes or nursing facilities. The high turnover and shortage of paraprofessional personnel results from such factors as low pay and status, poor benefits, high emotional demands, few options for training, high proportion of young and part-time workers, and limited potential for advancement.

Paraprofessional personnel often have burdensome workloads and too many patients to be able to provide adequate care. Chronic under funding by Medicaid and Medicare and a regulatory system that focuses on fines and penalties, often for failing to provide adequate personnel, also contribute significantly to the workforce shortage. The pool of younger workers for entry-level positions continues to diminish while at the same time seniors are living longer and their numbers are increasing.

The nursing home and home health industries are not providing sufficient and appropriate wages, benefits and training for paraprofessional personnel positions. In 1998, according to the Bureau of Labor Statistics, home health and personal care aides made a median wage of \$7.58 an hour, while nursing home aides made a median wage of \$7.99 an hour. A year later, the median wage of home health care aides was \$9.77 an hour, and the bottom 25 percent of home health aides earned just \$8.12 an hour, according to the National Association of Home Care/Hospital and Healthcare Compensation Service's *Homecare Salary & Benefits Report 2000-2001*.

Making the picture even worse is the fact that home health aides normally do not receive pay for their travel time between jobs. And, while nursing home aides may receive benefits, home health aides usually do not. Moreover, although some employers give slight pay increases with experience and added responsibility, training options and advancement opportunities are undefined and inadequate.

Consequences of Shortages

Of all staff caring for patients, paraprofessional personnel have the most contact with clients and provide most of their care. They are responsible for bathing, feeding, hydrating, and ensuring that patients do not acquire bedsores and other conditions stemming from poor mobility. In some cases, paraprofessional personnel are the only or main source of human contact. In this demanding environment, staff shortages can contribute to quality of care issues and circumstances in which workers may become prone to neglectful and abusive behavior.

Policy Issues

A number of states are now tackling the shortage of paraprofessional personnel in various ways. Some states are experimenting with new programs to establish increased wages and benefits, such as health insurance and payment for transportation costs, and improved training designed to recruit new workers to the ranks of paraprofessional personnel. For example, as of November 2000, 16 states have implemented "wage pass-through" legislation that requires that some portion of Medicaid payment increases to long-term care providers be used to increase wages and benefits for nursing aides.

- Introduce comprehensive guidelines to encourage home health care agencies and nursing homes and their paraprofessional staff to meet and exceed minimum quality assurance standards; and
- Promote recognized safety guidelines for paid caregivers and their clients.

Policy Recommendations

While state efforts to develop a more qualified, stable frontline workforce are encouraging, decisive federal action must be taken to effectively address the national workforce shortage which will likely worsen over time as demand continues to increase.

n4a urges policymakers to:

- Establish basic training in nursing skills and require the successful completion of a competency test for all paraprofessional personnel;
- Encourage employers to provide higher wages and improved benefits for all paraprofessional staff through incentive programs;
- Support research and demonstration programs to find solutions to the paraprofessional workforce shortage, and assess the feasibility of applying successful state efforts at the national level;
- Train paraprofessional personnel in ethnic sensitivity, addressing language barrier issues, and ethical care and compassion;