NASUAD
National Association of States
United for Aging and Disabilities

1201 15th Street NW
Suite 350
Washington, DC 20005
Phone 202-898-2578
Fax 202-898-2583
www.nasuad.org

Testimony of Martha A. Roherty
Executive Director, National Association of States United for Aging and Disabilities

Before the U. S. Senate Special Committee on Aging
Hearing on Assisted Living Facilities
November 2, 2011

On behalf of the National Association of States United for Aging and Disabilities, I would like to thank the Senate Committee on Aging for the opportunity to testify at this hearing on assisted living.

NASUAD was founded in 1964 under the name National Association of State Units on Aging (NASUA). In 2010, the organization changed its name to NASUAD in an effort to formally recognize the work that the state agencies were undertaking in the field of disability policy and advocacy. Today, NASUAD represents the nation's 56 state and territorial agencies on aging and disabilities, and supports visionary state leadership, the advancement of state systems innovation, and the articulation of national policies that support home and community based services for older adults and individuals with disabilities.

The Association's mission is to design, improve, and sustain state systems delivering home and community based services and supports for people who are older or have a disability and their caregivers. Our statement is based on the Association's mission to foster the development of state long-term services and supports systems (LTSS) that support individuals of all abilities and ages as well as their families.

While NASUAD member state agencies' roles vary from state to state, Association members develop and operate Medicaid-financed assisted living services in collaboration with their partners in the Single State Medicaid Agency (SSMA), oversee assisted living operations in the context of Medicaid quality monitoring strategies, lead or participate in affordable assisted living program development. Later in my testimony, I will discuss Medicaid Section 1915(c) Home and Community Based services (HCBS) waiver quality oversight in more detail. However, it is important to note that only a small portion of

assisted living is financed by Medicaid; the vast majority of assisted living is privately financed.

Related to the point above, NASUAD member state agencies provide assistance to people seeking Medicaid-financed assisted living and private pay assisted living. Specifically, NASUAD members provide resident advocacy services through Adult Protective Services (APS) and State Long-Term Care Ombudsman (SLTCO) programs, and also deliver information about assisted living as an LTSS option via information and referral (I&R) programs and Aging and Disability Resource Centers. With the exception of Medicaid – financed assisted living services program functions, including Medicaid Section 1915(c) waiver quality monitoring requirements and Medicaid waiver eligibility, most of these assisted living-related functions are performed for both private and publicly financed assisted living. States also license or certify assisted living settings, though the responsibility for licensure or certification is often located in a separate division within an umbrella health and human services agency, or in a separate department.

As outlined below, please find NASUAD's statement relating to the existing and potential funding sources for the State Long-Term Care Ombudsman Program and APS, as well as the opportunities for these initiatives to enhance the quality of life for residents of assisted living facilities, and the barriers to successfully doing so, as well as NASUAD's recommendations for improving the current system of assisted living.

Ombudsman Program Activities in Assisted Living Facilities

Often, the ombudsman program is only associated with advocacy for residents of nursing homes, despite the Older American's Act (OAA) requirement that all State Long-Term Care Ombudsman Programs serve residents in other settings, including assisted living facilities. In fact, ombudsman program advocacy on behalf of residents in assisted living facilities ranges from consumer education initiatives to complaint investigations.

Increasingly, long-term care residents live in residential settings other than nursing homes. While the number of beds and facilities in nursing homes have been steadily declining for several years, the growth of beds in other residential settings, including assisted living facilities, is steadily increasing. In 2005, there were 1.8 million beds in licensed nursing homes and 1 million beds in board and care and other settings. In the following years, these numbers trended downward and upward, respectively, so that by 2010, the most recent year for which data is available, there were 1.7 million beds licensed in nursing homes and 1.2 million in board and care and other settings.[1] Federal policy continues to accelerate the growth of home and community based long-term care services, and as the number of residents in other residential settings continues to approach the numbers of residents in nursing homes, the importance of the ombudsman's role in assisted living facilities will also increase. In many states, Medicaid funding provides services in these non-nursing home

[1] NORS Data for FY10, Table A-6

residential settings as part of the Home and Community Based Services array, often through a waiver.

Medicaid Waiver

Most states use one or more Medicaid Home and Community Based Services waivers (1915(c)) to help older adults and individuals with disabilities continue to live independently in their homes and communities. Under Medicaid waivers typically serving older adults, individuals must meet the state's nursing home level of care, and waivers may not be used to pay for room and board in residential settings such as assisted living. Whether or not a person's care needs can be adequately met in an assisted living setting is handled on a case-by-case basis, and individuals who are eligible for waiver services typically have a case manager assigned to assist them with accessing needed services.

Some states use Home and Community Based (HCBS) waivers that provide services to individuals in residential care settings as part of a larger initiative to transition individuals out of nursing facilities, or to provide individuals who are at risk of institutionalization with options for remaining in their communities. A 2005 report, Quality in Medicaid Waiver Assisted Living: The Ombudsman Program's Role and Perspective, highlights the way assisted living waivers work in different states, ombudsman program activities in assisted living, and quality of care in assisted living, by focusing on the experiences of seven states using such waivers for these purposes.

A 2007 overview of residential care and assisted living policy found that 42 states had the option of using Medicaid funds to provide services for individuals in residential care settings, including assisted living facilities. The majority of these states, 28, covered assisted living services through a Medicaid waiver, while seven used the Medicaid state plan, and six states used a combination of waivers and the state plan.[2] Two years later, in 2009, a report on State Medicaid Reimbursement Policies and Practices in Assisted Living found that in that year, 37 states used 1915(c) HCBS waivers to cover services in residential settings, 13 states used the Medicaid state plan services, four included services in residential settings under 1115 demonstration program authority, and six states used state general revenues.

Concerns about quality and oversight have been raised as growth in assisted living has outpaced states' efforts to define and regulate the industry in many states, and ombudsmen continue to be called upon to resolve complaints about quality of care and residents' rights on behalf of assisted living residents**.** With respect to Medicaid HCBS waivers, the role of the ombudsman in assisted living facilities may be to inform consumers of waiver services within the context of providing information about long-term care options, while others also coordinate with agencies that administer Medicaid waivers.[3] In FY10, the ombudsman program nationwide handled 51,163 complaints on behalf of residents in assisted living and

[2] Residential Care and Assisted Living Compendium: 2007
[3] Quality in Medicaid Waiver Assisted Living: The Ombudsman Program's Role and Perspective

similar type facilities, a slight seven percent decrease from 55,029 in FY09. In comparison, complaints against nursing homes decreased by about ten percent from 176,083 in FY09 to 157,962 in FY10.[4]

In Section 1915(c) Home and Community-Based Services (HCBS) waivers, states are required to develop quality improvement strategies for all services delivered under the waiver, including assisted living. CMS has designed and adopted an evidence-based approach to HCBS Waiver program quality. The evidence-based approach is premised on the expectation that states have first-line responsibility for program monitoring to ensure the waiver operates as it was designed, and that the health and welfare of program participants are protected. States, on a periodic basis, must provide CMS with evidence that the program is indeed operating as specified in the approved waiver and that participants' health and welfare are maximized. The evidence CMS requires is tied to the six statutory assurances that states pledge to CMS as a condition of approval of a waiver. CMS' role is to review the evidence the state submits, along with other information about the waiver's performance, and render a determination about the Waiver's compliance with the federal assurances. [5] For several of the assurances CMS has articulated sub-assurances which operationalize CMS' interpretation of what assurances mean, further define the assurances, and are intended to ensure that states monitor the aspects of the program CMS deems fundamental.

It is important to note that these quality oversight requirements only address Section 1915(c) Medicaid waivers. While CMS has indicated long-term plans for its quality approach to cut across Medicaid HCBS program authorities such as the Medicaid Section 1915(i) State Plan Option and Section 1115 Research and Demonstration Waivers, such requirements do not apply to private pay facilities or residents.

In recent years, the number of sub-assurances and methods of addressing Section 1915(c) continuous quality improvement has been problematic for states. As a result, NASUAD and its sister association, the National Association of State Directors of Developmental Disabilities Services (NASDDDS), transmitted a letter to CMS communicating these concerns. In response, CMS is working with NASUAD and NASDDDS to convene a work group composed of state officials (e.g., aging and physical disabilities, intellectual and developmental disabilities, and state Medicaid agency), national association staff, and CMS. The workgroup is ongoing, and met virtually for the first time in September 2011 to re-conceptualize how quality is monitored and reported to CMS.

---

[4] NORS Data for FY10, Tables B-1 and B-6

[5] The six statutory Medicaid waiver assurances are: 1) Level of Care: Persons enrolled in the waiver have needs consistent with an institutional level of care; 2) Service Plan: Participants have a service plan that is appropriate to their needs and preferences, and receive the services/supports specified in the service Plan; 3) Provider Qualifications: Waiver providers are qualified to deliver services/supports; 4) Health and Welfare: Participants' health and welfare are safeguarded; 5) Financial Accountability: Claims for waiver services are paid according state payment methodologies specified in the approved waiver; and 6) Administrative Authority: The State Medicaid agency is actively involved in the oversight of the waiver, and is ultimately responsible for all facets of the waiver program.

Medicaid Administrative

Historically, State Long-Term Care Ombudsman Programs have had agreements with their state Medicaid agencies to carry out "activities the Secretary finds necessary for proper and efficient administration of the state Medicaid plan."[6] According to Section 1903(a) of the Social Security Act, State Medicaid agencies may claim federal Medicaid funds for activities which further the "proper and efficient" administration of the state plan, which is generally for expenses related to providing approved services to Medicaid-eligible recipients as well as Medicaid administrative functions. Administrative activities can include, but are not limited to, outreach activities undertaken to identify and enroll Medicaid beneficiaries; education and engagement of Medicaid members; quality assurance; and providing access to appropriate services at the appropriate time from the appropriate provider at the appropriate setting for the appropriate reimbursement.

The state does not have to link specific activities to Medicaid eligible individuals in order to claim federal Medicaid funds, but they must calculate the administrative costs of a particular service, such as the ombudsman program, which can reasonably be attributed to Medicaid. In 2007, 13 states were drawing Medicaid administrative funding to carry out a variety of activities which assist the Medicaid agencies in administration of the state plan and assist Medicaid residents in ways which are not included in the ombudsman program functions outlined in the OAA.[7] The sustainability of these endeavors is expected to be clarified by CMS in forthcoming guidance.

Home Care Ombudsman

As established by the Older Americans Act (OAA), Long-Term Care Ombudsmen are advocates for residents of nursing homes, board and care homes, assisted living facilities, and similar adult care facilities. In this capacity, they work to resolve problems of individual residents and to bring about changes at the local, state and national levels that will improve residents' care and quality of life. All states, the District of Columbia, Puerto Rico, and Guam have an Office of the State Long-Term Care Ombudsman, and these statewide programs are federally funded under Titles III and VII of the OAA, as well as by other federal, state and local sources.[8]

Under the OAA and its appropriations, the role of the Long-Term Care Ombudsman does not extend to non-institutional settings, despite the growing number of complaints made by consumers receiving home care. According to the National Ombudsman Reporting System (NORS), in FY10, 1,055 home care complaints were made to ombudsmen, an increase over the 774 similar complaints made in FY09, and the 907 made in in FY08.[9]

---

[6] Section 1903(a) of the SSA
[7] Unpublished NASUAD survey data
[8] AoA Fact Sheet: Long-Term Care Ombudsman Program
[9] NORS Data, Table B-10

To address this growing need, some states have looked to other funding sources to expand the scope of their existing OAA-created Long-Term Care Ombudsman Programs so that they may advocate on behalf of consumers who receive home and community based care. As of 2007, 12 states either authorized or mandated under state law that their ombudsman programs serve consumers who receive home and community based care.[10]

A survey of eleven of these programs, supported by the U.S. Administration on Aging (AoA) and compiled in the Home Care Ombudsman Programs Status Report: 2007 identified variances and commonalities in the scope, funding and administration of these programs from state to state.

Scope. Though the full array of services covered by the surveyed Home Care Ombudsman Programs differed, the majority of state programs reported that they were responsible for handling complaints concerning Home and Community Based Services funded by Medicaid waivers, a significant trend given the emphasis on the use of waiver services in states' long-term care rebalancing efforts, including nursing facility diversion and transition activities. Notably, since 2007, two additional states, Georgia and Delaware, have expanded their Long-Term Care Ombudsman Programs to provide in-home ombudsman services through the Money Follows the Person demonstration.

In addition to Medicaid waivers, the most frequently covered services included state funded home care, home health agency services, OAA home care programs, and private pay home care. The programs also signaled that the majority of home care complaints related to issues of access to service, staffing problems, and abuse and exploitation.

Funding. The OAA defines the scope of ombudsman services to include nursing facilities, skilled nursing facilities, board and care and similar adult care homes. Accordingly, funds authorized or appropriated under the OAA for the State Long-Term Care Ombudsman Program may not be used for ombudsman services in settings other than those listed in the act.[11]

Since home care is outside the scope of the ombudsman's duties as enumerated in the OAA, State Long-Term Ombudsmen who advocate for individuals receiving home and community based care must rely on non-OAA dollars to support their work in this area. A majority of the surveyed programs named state general revenues as their single funding source, while five states reported multiple funding sources, including Medicaid waiver funds, Medicaid administrative funds, facility-based provider fees, and state funds dedicated to home care advocacy.

Administration. The majority of states surveyed allowed any ombudsman program staff member to investigate home care complaints, rather than dedicating specific staff to this task, and seven states required ombudsman program staff to receive training on home care

[10] Home Care Ombudsman Status Report
[11] OAA Section 102(a)(32)

advocacy prior to investigating home care complaints. The survey also revealed that Home Care Ombudsman Programs coordinate both formally and informally with other state agencies regarding home care issues, including with Adult Protective Services agencies for the referral of home care complaints, and with the state agency that licenses and certifies home care providers and Medicaid waiver programs.

Adult Protective Services

While the role of State Long-Term Care Ombudsmen in preventing, reporting and investigating abuse in long-term care facilities varies across the country, Adult Protective Services (APS) is the principal public agency responsible for investigating reported cases of elder and vulnerable adult abuse, and for providing victims with treatment and protective services regardless of setting or service funding source. Although most APS agencies also handle adult abuse cases (ages 18-59), nearly 70 percent of their caseloads involve elder abuse, as APS caseworkers are generally the first responders to such reports.

Scope. APS are those services provided to insure the safety and well-being of elders and adults with disabilities who are in danger of being mistreated or neglected, are unable to take care of themselves or protect themselves from harm, and have no one to assist them. Interventions provided by APS may include, but are not limited to, receiving reports of adult abuse; exploitation or neglect; investigating these reports; as well as case planning, monitoring, and evaluation. In addition to casework services, Adult Protection may provide or arrange for the provision of medical, social, economic, legal, housing, law enforcement or other protective, emergency, or supportive services.

Funding. With no federal funding stream dedicated to the provision of APS, the funding sources for APS varies from agency to agency. According to a 2009 APS State Budget Cuts Survey administered by the National Adult Protective Services Association (NAPSA), 85 percent of APS programs are funded with state funds, 60 percent receive county or tribal funds, while 30 percent are funded with SSBG dollars and another 30 percent rely on Medicaid funds.

The same NAPSA study highlights the degree to which the economic downturn continues to impact the provision of APS, with over half of APS state administrators reporting budget cuts of 13.5 percent in 2009. Troublingly, two-thirds of the respondents also said that abuse reports to APS have increased by 24 percent, leaving vulnerable adults increasingly at risk. These results support the data in NASUAD's joint report with AARP and HMA, Weathering the Storm: The Impact of the Great Recession on Long-Term Services and Supports, which captures a significant and disturbing trend since the beginning of the economic downturn: the large number of states that experienced increased calls for APS in state fiscal years 2010 and 2011. Of these states, 25 reported that financial exploitation was the number one cause of such calls, and an additional 20 states reported that neglect was a factor in the calls. Despite an increase in the number of APS calls, only two states increased funding for APS over this time period, while the rest either flat-funded or decreased state appropriations.

The ongoing efforts of state APS agencies to absorb these cumulative budgetary cuts highlight the need for federal funding to support these programs. Prior to the passage of the Elder Justice Act (EJA) as part of the 2010 Patient Protection and Affordable Care Act (ACA), few federal laws authorized funding to states and local agencies for identification, prevention, or remediation of elder abuse. Currently, the EJA authorizes funding in several areas, including grants to enhance the provision of APS by state and local agencies, as well as grants to support Long-Term Care Ombudsman Programs and funds to develop best practices to improve investigations of elder abuse that are reported in long-term care facilities. Although the EJA is now law, no funds have been appropriated to implement its provisions. Given the grave economic outlook for state and locally-funded APS agencies amid increasing service requests, a strong federal investment is needed in order to successfully move forward with the promise of the EJA.

Administration. All fifty states and the District of Columbia have statues that authorize and regulate the provision of services in cases of elder abuse. These statutes set up systems for reporting and investigating suspected elder abuse and for delivering services to victims. These laws vary widely from state to state, including on such characteristics as eligibility, the definition of abuse, reporting requirements, and investigation procedures. For example, eligibility for APS services is typically based on a statutorily defined disability, vulnerability or impairment, not solely on the age of the adult. Some state APS laws only apply to vulnerable citizens who are living alone or with family what is called "domestic abuse," while others go further and protect individuals who live in nursing homes and other long-term care facilities in instances of "institutional abuse." The ABA Commission on Law and Aging has developed detailed charts on threshold eligibility criteria for adult protective services, including a comparison chart of criteria by state and an age-specific comparison chart.

In addition to these regulations, approximately 15 states have separate statutes that address abuse, neglect, and exploitation of residents of long-term care facilities and other settings. The ABA Commission on Law and Aging has compiled a list of such statutes, titled Adult Protective Services, Institutional Abuse and Long Term Care Ombudsman Program Laws: Citations by State.

NASUAD Recommendations

Currently, the only federal requirements for state oversight and monitoring of assisted living facilities exist in the context of Section 1915(c) HCBS waivers and under the new Section 1915(i) and related quality assurance requirements. Significantly, Medicaid licensed units comprise only a small portion of the marketplace and no federal guidance exists for the oversight and monitoring for private pay assisted living, which makes up the majority of assisted living. At the state level, all states differ in their assisted living regulations, and the variation in state oversight is tremendous. To aid states in linking state licensure and survey agency roles and responsibilities more cohesively with Medicaid HCBS waivers, APS, and Long-Term Care Ombudsman efforts, NASUAD suggests the development of a

federal template framework for an Assisted Living Bill of Rights and an Assisted Living Disclosure Statement, as well as increased funding for options counseling and resident advocacy services. Educating people about their assisted living options, rights in assisted living facilities, and resources to aid them when problems arise is critical. Accordingly, NASUAD respectfully supports:

Federal guidance on standard requirements for a Resident's Bill of Rights and Disclosure Statement. Building on the 2003 Senate Special Committee on Aging Assisted Living Work Group recommendations, federal guidance on a framework for a Resident Bill of Rights and Disclosure Statement is needed. The only minimum federal expectations or requirements for state oversight and monitoring of assisted living are in the context of Section 1915(c) waivers and under the new Section 1915(i) and related quality assurance requirements. In a 2007 study commissioned by the DHHS Assistant Secretary for Planning and Evaluation, researchers found that about 21 states have requirements for Resident's Rights, while requirements for Disclosure Statements are included in virtually all states, but the content varies considerably. A federal framework for a Resident's Bill of Rights and Disclosure Statement, along with a suggested tool for states to ensure compliance, would help to standardize this need among assisted living residences nationwide and offer all prospective assisted living residents a consistent format for comparing assisted living options.

Increased federal funding and for options counseling, including such counseling services delivered by I&R staff and ADRCs. This is necessary in order to educate potential residents on their rights, options, and long-term affordability of both public and private assisted living residences, as well as their options if spend down to Medicaid occurs. Additionally, potential residents, particularly individuals and families of low to middle income who could quickly exhaust their resources and turn to Medicaid, need objective, third-party assistance with understanding their assisted living options, including what they can afford and for how long. Options counseling could be extremely helpful to this population, but additional federal dollars are needed, as states currently do not have the funding to meet such demand.

Increased federal funding for state programs that provide resident advocacy services, including Adult Protective Services and State Long-Term Care Ombudsman. More resources for APS and State Long-Term Care Ombudsman services would also be helpful, since private sector assisted living is only subject to state licensure and not Medicaid-financed assisted living oversight. Through a regular presence in assisted living facilities, the ombudsman program provides both a quality monitoring system and a voice through which residents can address individual concerns about quality of care and quality of life. A stronger federal investment in APS and ombudsmen would allow these initiatives to leverage their existing authorized access to assisted living facilities and better protect residents through friendly visits, as well as random, surprise inspections, during which they would have the opportunity to determine if there is any evidence of patient neglect or abuse. Additionally, the ombudsman program is strategically positioned to provide Medicaid waiver programs with valuable information about the quality of care in these facilities, and increased funding could allow State Long-Term Care Ombudsmen to

supplement the work of state licensure agencies, which generally survey assisted living facilities only once per year unless a complaint is submitted.

Full Funding for the Elder Justice Act. As more consumers age and require a wide array of services, including assisted living, there will also be a need for further protection and advocacy for those who are most vulnerable. In addition to the state and local ombudsman, adequate funding needs to be provided to improve the quality, quantity and accessibility of information and resources regarding long-term care, including assisted living. The Elder Justice Act provides for various safeguards and protections, but does not provide a dedicated funding stream to carry out the duties it assigns. Without federal appropriations and guidance for these important provisions, many of the enhancements outlined in the Elder Justice Act will not be implemented.

Broad Federal Definition. A federal definition based on the 2003 core principles of assisted living (i.e. efforts to support the autonomy, choice, privacy and dignity of residents) rather than a definition that includes specific housing elements (i.e. private bathroom, kitchen and lockable door to single-occupancy room) is needed. There is tremendous variation among state assisted living definitions, therefore any federal definition must be broad enough to address the array of state models, including housing with services, small assisted living facilities structured similarly to Adult Foster care, as well as larger settings. Components of the definition should address autonomy, choice, privacy, and dignity of residents.

Thank you again, Senator Kohl, Senator Corker, and Senator Nelson, for your leadership on these important issues and for the invitation to testify here today. I welcome your questions and comments, and I look forward to continuing to work together to improve the quality of life for older adults and individuals with disabilities, in whatever place they call home.

1201 15TH STREET, NW, SUITE 350
WASHINGTON, DC 20005

P: **202.898.2578** | F: **202.898.2583**
www.nasuad.org