

**CARIE Dorothy S. Washburn Legislative Committee
Older Americans Act (OAA) Roundtable Recommendations
June 9, 2010**

Introduction

The Center for Advocacy for the Rights and Interests of the Elderly (CARIE) is a non-profit advocacy organization that works to improve the well being, rights and autonomy of older persons through advocacy, education, and action. CARIE sponsored an Older Americans Act Roundtable on June 9, 2010. Nora Dowd Eisenhower, former Pennsylvania Secretary of Aging, facilitated a discussion among 25 leading professionals in the field of aging and older adults. CARIE coordinates the Dorothy S. Washburn Legislative Committee comprised of legal, health and human services professionals as well as older consumers who monitor legislative and regulatory developments at the local, state and national levels in an effort to promote the well being of older adults. The Committee continued discussions at its meetings to finalize the following recommendations. For more information, please contact Kathy Cubit, Director of Advocacy Initiatives, at cubit@carie.org or 267-546-3438.

Aging and Disability Resource Centers (ADRCs)

Recommendations:

With the emerging role of ADRCs, the Older Americans Act (OAA) should clarify relationships among Area Agencies on Aging (AAAs), Centers for Independent Living (CILs) and other agencies and ensure a “no wrong door” policy for accessing services. Secure centralized Internet based models should be developed for individuals to apply for multiple services through one application regardless of location.

Rationale:

Even with ADRCs, people still go to AAAs, CILs, and other agencies for assistance. Resources that are already stretched often seem to be spent on something new without examining and strengthening existing programs. Secure centralized Internet based programs can help ensure the “no wrong door” approach while reducing barriers to services and benefits.

Alzheimer’s Disease

Recommendations:

Alzheimer’s disease and other dementias should be elevated to its own stand-alone section in the OAA. Key partnerships should be developed such as with the Alzheimer’s Association and National Institute of Health (NIH). There should be a focus on early intervention and reducing the burden of caregiving. It is imperative to identify the extent of those with Alzheimer’s disease or related dementia who live alone with no family or responsible parties to assist them and to create a demonstration project to test models of care to address their needs. Implement an accreditation process for assessment centers that can address what consumers and families need when confronting these illnesses. Accreditation could also apply to providers such as adult day centers so families would know that they were equipped and trained to respond to the needs of consumers with dementia. All AAA staff, particularly assessment staff, should be trained to understand

that people in the early stages of dementia might appear to be highly functional but may actually need and benefit from services.

Rationale:

The projected growth of individuals with dementia and the cost to our society points to an epidemic and warrants a special focus. There are multiple challenges in educating the public as well as professionals. There are few “places of excellence” outside major cities to get a comprehensive assessment, pathways to treatment and options for care. Attached is a white paper about those who are “unbefriended” with Alzheimer’s disease or other dementia that provides more background information and specific recommendations.

Benefits Counseling

Recommendations:

The OAA reauthorization must focus on helping low-income seniors reach and maintain economic security. Application processes must be streamlined and simplified. Benefits access initiatives need to be better coordinated with a focus on a person-centered approach so that all multiple benefits can be obtained at one time. Funding channels need to support innovative methods to promote benefits access and to develop and sustain cost-effective methods to help low-income people gain access to benefits for which they are eligible. The State Health Insurance Program (SHIP) should be enhanced to support the addition of more professionals to the program to work along with volunteers in assisting eligible seniors apply for multiple benefit programs. The SHIP should be more involved in distributing understandable information to consumers, caregivers, and the professionals who serve them.

Rationale:

The majority of older adults in America cannot make ends meet without the important support of public benefit programs critical to helping them reach and maintain economic security. Unfortunately, many benefit programs are underutilized due to cumbersome and confusing application processes and the ineffectiveness of dated outreach strategies. SHIP staff and volunteers have the challenging task of staying apprised of complex and changing information related to Medicare and Medicaid. Some SHIP cases are complex and can take hours to resolve. When beneficiaries have questions, they often turn to trusted professionals at Senior Centers and others. The SHIP could broaden its impact by assisting eligible seniors apply for multiple benefits and by training and distributing helpful materials to trusted professionals who encounter seniors each day. These professionals could also benefit by receiving clear updates directly from AoA and CMS via email.

Capacity Building of the Aging Network

Recommendations:

Standards should be developed for State Units on Aging (SUAs) for the oversight and administration of AAAs to ensure consistency and accountability. However, the standards should allow some flexibility to be able to respond to unique needs of communities or neighborhoods. Standardized evaluations/assessments can provide comparative data for analysis. The Administration on Aging (AoA) should offer

technical support to both SUAs and AAAs to ensure effective state and area planning. Potential conflict of interest issues related to service delivery can impede the AAAs ability to be an effective advocate and should be addressed.

Rationale:

AAAs are at the core of the aging network and should be supported in this vital role particularly since resources are limited. As the AAAs have evolved to deliver more services, the potential for conflicts of interest has increased and the function of evaluating and planning for the needs of the community has become a lower priority, even perfunctory.

Recommendations:

The AoA should support the aging network in creating a defined role in health care reform implementation and rebalancing efforts. The AoA should strengthen partnerships with the Centers for Medicare & Medicaid Services (CMS), the Veterans Administration (VA), and other federal agencies to help create state and local partnerships to foster a more coordinated streamlined approach for service delivery and possible opportunities for additional funding. The AAA network should help link aging services with health care whenever possible. One example would be to provide support for chronic disease self- management. AAAs could help impact such issues as health literacy. AAAs could also be a vehicle to bring “research to the people,” using evidence based models as a start.

Rationale:

The aging network has been on the front lines providing services with limited resources for many years. The AAAs should be supported in maximizing opportunities created through health care reform and rebalancing efforts.

Recommendation:

The AoA should consider increasing its capacity to work with the states and local communities by maintaining a presence in all regional HHS offices.

Rationale:

AoA provides an important leadership role and can provide support to local and state entities. However, in the 1990s, offices were consolidated and some communities lost important connections to the agency. Currently in Region 3, the only AoA official on the ground is based in New York City with responsibility for a region that runs from Massachusetts to West Virginia. The current broad swath of the regional offices creates perceived and actual distance from the programs they administer.

Caregivers

Recommendation:

When older adults are being assessed for services, the needs of their caregivers should be assessed along with the clients and the care plan should address their needs as well whenever possible.

Rationale:

The overwhelming majority of older adults who need long term care assistance do not live in facilities. They live in their own homes in communities in urban, suburban and rural settings. Family members, neighbors and loved ones usually provide the care and services that keep them safe and supported. The importance of supporting caregivers is well documented and care plans should reflect their needs. The well-being and economic needs of caregivers should be addressed to support them in this vital role.

Consumer Choice and Control

Recommendation:

The prevention of fraud and abuse should be addressed in the consumer directed model, especially for clients who are reluctant or unable to report their family member or caregiver when there are problems with the provision or lack of care.

Rationale:

Consumers in the community are often isolated and dependent upon caregivers for their needs. As the consumer directed model grows, it is important to address the potential for abuse and neglect that may occur.

Demonstration Programs

Recommendation:

Create a demonstration program for a neighborhood or community-based program, whether called a village, NORC or something else, particularly in economically challenged areas that do not have the resources or infrastructure to support their aging population. Demonstration programs supporting innovations in sustainable models should be identified for all communities. Outcomes such as hospital readmission rates and overall institutional care referral rates should be analyzed with an eye towards expanding models that improve quality of life for all members of a neighborhood or community.

Rationale:

Models should be created by community-based participation in high poverty areas to define the needs from the community's perspective and develop a response or plan on how to utilize limited resources.

Diverse Populations

Recommendation:

The OAA should better address diverse populations such as minorities, veterans, LGBT, and people with disabilities who are aging by creating opportunities, recognizing and integrating the needs of special populations throughout the OAA, and helping to create "culturally competent" programs.

Rationale:

Currently, Americans are aging into a more diverse and challenging population to serve. It is important to have targeted programs for diverse populations to address their unique

needs and circumstances and support them as they age. In addition, it would be helpful if their needs were more broadly integrated throughout the OAA whenever possible.

Elder Rights

Recommendations:

The OAA's recognition of legal assistance as a priority service should be reflected in the provision of adequate funding in every state. "Adequate funding" should be defined consistent with the statutory recognition of legal services as a priority service. At the same time, maintenance of effort requirements should be instituted to retain non-AoA funds currently available to fund legal services. States should be required to create a statewide strategic plan that identifies elder rights issues and needs throughout the state, and addresses those needs systematically and in a coordinated fashion. States should be required to develop a coordinated implementation process to most effectively and efficiently deliver legal services that meet the most critical needs. Statewide coordination of technical assistance, training and other supportive functions to legal services providers, as well as to ombudsmen and other elder rights advocates, should be a part of this implementation process. States should be required to collect qualitative and quantitative statewide data to measure the impact of services and to provide consistent information about the efficacy of Title III-B funding in meeting individual and systemic advocacy goals. This data should also be collected, evaluated and reported at the national level.

Rationale:

Legal assistance is critically important to seniors as they face more complex rules governing crucial public programs, deal with increasingly complicated financial institutions and practices, and are targeted for predatory scams and elder abuse. Title III-B legal services ensure that elders are able to obtain and maintain: Social Security, Medicare, Medicaid, SSI and other benefits and entitlements; housing; financial security; autonomy and protection under the law in the face of diminished capacity, abuse, violence, exploitation, or fraud; planning for health care, independence and financial stability; and, essential services such as in-home care. Now an "adequate proportion" standard is used to designate funds for legal services but the term is not clearly defined.

In addition to resolving the legal problems of individuals, Title III-B legal assistance identifies and remedies systemic problems that harm thousands. Although the OAA makes legal assistance to elders a priority, there are many funding and structural limitations in the current system that prevent the goals of Title III-B legal services from being fully achieved for all. For example in Pennsylvania, the availability of Title III-B legal services is inconsistent from area to area. The proportion of Title III-B funding expended for legal services is very small throughout the state. In some counties, no Title III-B legal services are available at all.

Recommendations:

Elder rights protection programs such as legal services, protective services and ombudsman programs clearly need more funding. The new national ombudsman position should be added to the OAA. The state legal services developer position also needs to be funded.

Rationale:

Funding continues to be an issue for legal services. OAA funds for legal services go to the AAAs where it is often used ineffectively and inefficiently with little or no oversight. Funding also is an issue for the ombudsman, as some areas do not have a full-time ombudsman. Protective services are inconsistent and poorly funded with some AAAs having few substantiated complaints. The potential for abuse with guardianship, particularly since there is little oversight, is also of concern. Unless the new national ombudsman position is formally added to the OAA, it could be eliminated during a future administration. The Act currently provides that the legal services developer is to provide leadership and coordination in the provision of legal assistance; arrange technical assistance and training for AAAs, legal services providers, ombudsmen and others; and ensure the state's capacity to aid elders in understanding and exercising their rights. The role is demanding and requires a great deal of skill and knowledge of legal services and institutions. Yet currently, many state developers have little or no legal training. In Pennsylvania, as in many states, the legal services developer has little authority to promote advocacy initiatives and cannot devote significant time to these critical tasks because of the demands of many other unrelated duties. As a result, there is little state-level coordination of elder rights advocacy and no OAA-supported training for legal services providers, and the availability and quality of Title III-B legal services is extremely uneven in the state. In the absence of dedicated funding, this situation appears unlikely to change.

Recommendation:

The OAA should authorize and fund statewide legal hotlines. ABA standards should be used for the collection of quantitative and qualitative data. Statewide Senior Legal Hotlines/Helpines should be supported, as an important part of an integrated, statewide legal assistance delivery system, involving local legal aid providers and state legal assistance developers, among others.

Rationale:

Legal Helplines provide free legal advice, information, referrals, advocacy and a variety of additional services cost-effectively to Americans 60 and over, enabling more seniors to maintain healthy, independent lives, free from the threats of poverty, exploitation or abuse. They are also a model of service delivery that addresses the needs of older adults in rural areas, with disabilities and who are socially needy or isolated from friends, neighbors and families. Legal hotlines are necessary to help reduce disparities in accessing legal services especially for those with limited income or living in rural areas.

Recommendations:

The OAA should work to reduce and prevent guardianship abuse. Representation of alleged incapacitated persons should be a priority. A public guardianship system should be developed, properly funded and monitored.

Rationale:

There should be funding for representation since the older adult is typically not represented by counsel and may not even be at the court hearing. Guardianship abuse is widespread and has been a problem for many years.

Recommendations:

The OAA should be expanded to include ombudsman services for consumers of home and community-based care and senior housing particularly given increasing need and the shift from an institutional bias. Due to potential conflict of interest with the AAA providing or coordinating services, there is a need for an independent ombudsman that is not employed by the AAA.

Rationale:

Many consumers of home and community-based care are by definition as clinically needy as those in facilities but they are often more isolated. Consumers may transition among the various long term care alternatives and do not always have access to an ombudsman should the need arise. Residents of Continuing Care Retirement Communities (CCRCs) particularly need an advocate as they typically invest their life savings and then have little control over where they receive their services.

Recommendation:

Each state ombudsman should be a vocal and independent advocate for all long term care consumers. This position should be located in a separate office that is protected or insulated from political forces of a SUA. State ombudsman should be able to provide testimony or speak freely about issues affecting long term care consumers without the filter or discretion of state government. Regulations should be promulgated about conflicts of interest and require independence in local programs. (Title VII, Subtitle A, Chapter 2, Section 713)

Rationale:

Since many state ombudsman programs are now located in the same agency that regulates providers and coordinates adult protective services, there are numerous potential conflict of interest issues that may impede the effectiveness and ability of the ombudsman's resident centered approach. Likewise, in many instances local programs are under the authority of government or service entities that often have real or perceived conflicts.

Recommendation:

Improve services to older victims of crime and abuse to ensure their safety, independence and well-being.

Rationale:

Services for older victims are very limited and non-existent in many areas. Current victim services and domestic violence agencies are typically not equipped to address many of the unique needs of older victims.

Home and Community Based Care

Recommendations:

Develop strategies to engage all governmental agencies and others to help create “livable” communities and the infrastructure needed to help people age in place including such needs as transportation and crosswalks. Community supports and services should be made readily available especially for those transitioning from nursing facilities. Increase Title III funding for neighborhood based supports and develop opportunities to mobilize neighbors to help with activities such as transportation. Strategies should be identified and implemented to prevent and reduce isolation of older adults. Encourage the use of assistive technology to supplement and replace personal care services. Create a demonstration project to study the cost savings of using technology.

Rationale:

Older adults almost always prefer to remain in their own homes and communities as they age and yet many communities were created when the population was younger and had different needs. In order to insure that communities age appropriately, there must be a focus on planning with agencies and community groups beyond the aging services network. This may help insure that services and supports will be readily available for those who are homebound. Public policy and planning typically overlook the fact that many older adults do not initially qualify financially for Medicaid but are also not able to finance their long term care needs without eventually needing Medicaid.

Recommendation:

The OAA should provide funding for the modernization and upgrade of senior centers to keep pace with the changing needs of older adults, attract people as they age into the service network and respond to the changing needs within a community. The provision of meals also should also be modernized to offer tasty and healthy options that respect the preferences of diverse populations as they age.

Rationale:

Senior centers are still a focal point for many older adults. Many important services and activities are offered such as congregate meals, health and wellness programs, and volunteer and educational experiences. Senior centers can serve a key role in NORCs and help all older adults in a neighborhood age in place.

Home Repair and Modification

Recommendation:

The OAA should focus on home repair and modification to help older adults remain in their own homes and prevent people from becoming trapped in their homes by creating more accessible and affordable housing and retrofitting existing housing stock to meet the needs of an aging population.

Rationale:

Many older adults are on a fixed income and do not have the resources to pay for needed repairs or home modifications. The success of rebalancing efforts of the long term care system will hinge on a more effective response to these problems.

Housing

Recommendation:

The OAA should encourage stronger partnerships with HUD to improve coordination of housing and services. Service coordinators in HUD housing should be professionalized and more available. (They are often part-time with low wages.) The housing needs of grandparents raising grandchildren should be addressed and accommodated.

Rationale:

Issues related to affordable and accessible housing as well as modifying and repairing existing housing stock has been a problem that continues to exacerbate. The success of balancing the long term care system is directly linked to improving housing. There are increasing numbers of grandparents raising grandchildren and their needs, particularly concerning senior housing should be addressed.

Mental Health Services

Recommendation:

The funding of mental health services should be expanded beyond serving those with persistent serious mental illness to address the mental health needs of older adults. Funding should be expanded to include outreach and education, prevention programs, screening and detection, and support groups. Cross-cultural issues should be addressed and programs that provide in-home services should be expanded and more readily available.

Rationale:

Pennsylvania is like most states in that a significant number of older adults regardless of whether they are living in their own homes or in facilities are not receiving needed mental health services. It is important to increase the availability of mental health services so that older consumers can access care regardless of where they reside.

Transportation

Recommendation:

The role of AAAs should be expanded to provide a greater role in coordinating transportation and mobility management.

Rationale:

The availability of reliable, accessible and affordable transportation is imperative to older adults particularly as many lose the ability to drive safely. The AAAs are well positioned to play a key role in mobility management.