Testimony before the
Pennsylvania Long-Term Care Commission

Philadelphia Public Meeting

July 14, 2014
Introduction
Good morning. My name is Kathy Cubit and I represent the Center for Advocacy for the Rights and Interests of the Elderly (CARIE). Thank you for the opportunity to present testimony and for traveling across the state to gather stakeholder input on the vital issue of how to improve the provision of long term services and supports (LTSS) in Pennsylvania.

Founded in 1977, CARIE is a nonprofit organization dedicated to improving the quality of life for frail older adults. CARIE’s focus of concern spans the long term care continuum from those who live at home to those who are living in facilities. Older adults with physical or psychological impairments are often a silent group with difficulty advocating for their needs. CARIE works to protect their rights and promote awareness of their special needs and concerns. CARIE provides a range of advocacy services to help older adults and their caregivers. Services provided include options counseling for older adults in need of long term care, problem resolution for consumers experiencing a myriad of difficulties such as with housing and transportation, and insurance and entitlement counseling. In addition, we provide extensive outreach and educational programming. We serve as the long term care ombudsman for part of Philadelphia and assist residents of nursing facilities, personal care homes, and domiciliary care as well as participants of LIFE and adult day programs with issues related to their rights and quality of care.

Overview
The Commission has a challenging task in creating a report that will lead to concrete actions Pennsylvania can take to implement real change to the current system. Ideally, Pennsylvania’s long term system would provide access to affordable, high quality long term services and supports that respects consumers’ choices and ensures their DIGNITY. In the case of older adults who depend on others for care, the loss of functioning is often coupled with a loss of dignity. It’s important to ensure a consumer’s dignity and avoid funneling people through routine processes and systems. Older adults deserve to age with dignity and independence in their own homes and communities. Pennsylvania ranked 37th in a national survey measuring support for home and community-based programs serving older adults. Pennsylvania can do better and should continue rebalancing efforts.

Aging is idiosyncratic and public policies should accommodate individual differences. Experiences are different because of individual health conditions, physical limitations, sensory impairments, the time of onset of illness or impairment, social supports and economic circumstances. Even though consumers and caregivers often need assistance with the challenges they encounter, there should always be a focus on autonomy and the empowerment of consumers to maximize their control and choices. In addition, public policy and planning typically overlook the fact that many older adults do not initially qualify financially for Medicaid but are not able to finance their long term care needs without eventually needing Medicaid. It is important to remember this group in the planning process. The state can save money by helping individuals avoid or delay nursing home care. This includes developing policies that support consumers who are not eligible for Medicaid.

Through CARIE’s work, we understand the importance of the following key values and principles that should be an integral part in the provision of LTSS:

- Ensure older adults and people with disabilities maintain their well-being and maximize their functioning so they can live with DIGNITY and remain in their homes as long as possible, if this is what they choose.
• Ensure access to high quality services and supports.
• Promote self-determination, choice, and respect to empower consumers and improve their quality of life.
• Provide culturally competent services that empowers a consumer regardless of race, gender identity, religion, ethnicity, or sexual orientation.
• Provide respite care and support for family caregivers so they can better care for their loved ones and themselves.
• Protect older adults from abuse and financial exploitation.
• Ensure a well-trained, stable workforce.

Recommendations
As the Long-Term Care Commission completes its final report, we hope you will consider the following recommendations:

1. Prevention and Caregiver Support:

Without the support of informal caregivers, our long term care system would not be able to meet the needs of all those who need assistance. The overwhelming majority of older adults who need long term services and supports do not live in facilities. They live in their own homes. Family members, neighbors and loved ones usually provide the care and services that keep them safe and supported. When consumers are being assessed for services, the needs of their caregivers should be assessed and the care plan should address their needs as well, whenever possible. Caregivers should be provided with basic information and training to provide care. As with older adults, caregivers should be treated with respect and dignity. The Commission’s recommendations should acknowledge and support caregivers in their vital role.

The Commission should incorporate the recommendations, goals, and strategies of the Pennsylvania State Plan for Alzheimer's Disease and Related Disorders (ADRD) to the greatest extent possible in its final report. According to the plan, “Over 400,000 Pennsylvanians are likely afflicted with ADRD, and the toll of the disease extends beyond those affected to their families, friends, and communities. All told, one in 12 Pennsylvania families is affected by ADRD.” This epidemic cannot and should not be ignored. 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. It would be helpful to implement an accreditation process for assessment centers that can address what consumers and families need when confronting these illnesses. Special 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 intake and 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.

Many older adults do not initially qualify financially for Medicaid but are not able to finance their LTSS needs without eventually needing Medicaid. Providing lottery funded services to those who need LTSS but who are not eligible for Medicaid could help prevent or delay the need for more costly nursing facility care or Waiver services. It is important to adequately fund these programs before funds are moved out of the Lottery Fund. When people look for help for themselves or a family member, they may end up using more expensive or intensive services than is needed. Educational materials/resources should be available for all consumers so people are aware of alternatives to nursing home care and can spend their private resources
wisely. Pennsylvania should create incentives or develop a private-public partnership with home care agencies to make it financially viable to provide private home care on a limited basis. When a consumer or family member needs to hire a private aide, they typically must hire the aide for a four hour minimum even if only an hour or two is needed. From a business point of view, it is understandable why home care agencies have this policy. It would be helpful if a home care agency could provide less time for private pay cases in locations where they are already providing services for Waiver or Options consumers. Ideally, a consumer or caregiver could call a statewide number to identify a provider participating in this type of partnership in their area that may be able to serve them. This could help preserve a consumer’s resources before having to rely upon Medicaid.

Pennsylvania should help veterans and their spouses access Veteran’s benefits particularly the Aid & Attendance benefit that could ultimately help consumers meet their LTSS needs while saving state funds. CARIE recommends expanding educational awareness and support around Veterans benefits. Many veterans in need of long term services and supports are not aware of Veterans benefits, such as the Aid and Attendance pension, that could help finance their care or help them learn how to access these benefits. It would be helpful if Pennsylvania could develop an educational campaign and provide targeted outreach and assistance to help veterans and their spouses get the benefits they are entitled to receive. Increasing the participation of eligible veterans in these benefits could help meet their needs and reduce costs to the state.

2. Improve Access to Home and Community Based Services (HCBS):

Consumers in need of LTSS should be able to access HCBS as easily as nursing home care. The application, eligibility determination, and care planning process for waiver services, particularly Aging Waiver services, needs to be streamlined so eligible consumers do not have to wait months for services even in the absence of a waiting list. We recommend that the current policy of reviewing every individual service plan (ISP) be discontinued as it creates a backlog and inordinate wait times. It is our understanding that most ISP’s are approved. We would favor a process of quality control or monitoring using random sampling to review ISP’s.

An expedited enrollment process for the Waiver or any other future LTSS models should be created. CARIE recommends reviewing the Community Choice model for strategies to shorten the time needed for consumers at high risk of nursing home placement, such as those in hospital settings, or those at high risk of a loss to functional ability without services, to enroll and receive services so they may access HCBS services as quickly as they can receive services from a long term care facility. For example, allow the use of presumptive eligibility during the application process. An expedited enrollment process is needed now more than ever given how long it takes to apply and receive services.

Pennsylvania should complete an assessment to identify where there are gaps in services and a lack of qualified providers, and implement a plan to ensure that consumers can access needed services regardless of where they live. For example, not all consumers have access to an Adult Day program. Extermination services should be made available to Waiver consumers as this can be a barrier to LTSS and lead to premature institutionalization.

Pennsylvania should allow spend-down when a consumer’s income is over the $2,163 monthly Waiver income limit. Pennsylvania supports a nursing home bias by not allowing consumer’s in need of Waiver or LIFE services to spend-down their income using health and home care expenses. Changing this policy would save the state some Medicaid expenditures and help
support a consumer’s choice of where they want to receive services. Those who exceed the income limit often have no choice but to spend-down in a facility even if they could be cared for through the Waiver or LIFE program.

Pennsylvania should ensure a strong LTSS infrastructure. Low reimbursement rates make it difficult to recruit and retain professional caregivers which can impact access to care. It is important to support a qualified, stable workforce. Thirteen Area Agencies on Aging (AAAs) have dropped out of providing service coordination for the Aging Waiver. More will be forced out if rates are not increased. The AAA network has been a vital resource for older adults and caregivers, and their role should not be diminished. We are pleased to see the modest 2% increase in the personal assistance services (PAS) rate under the HCBS waiver programs in the recently approved state budget. It is important that provider reimbursement rates are set at an amount that ensures consumer access to quality service providers.

Lesbian, gay, bisexual and transgender (LGBT) community and people living with HIV/AIDS often feel unwelcome at health or human services organizations and more needs to be done to ensure their inclusion and access to care.

3. Improve Quality Care and Accountability:

All consumers of LTSS and future LTSS models of care should have access to an ombudsman to help resolve problems and complaints as do residents in long term care settings and adult day programs. Ombudsman services are an essential component to ensure accountability and quality of care. Pennsylvania has long mandated the provision of an ombudsman for older consumers receiving home and community based care. However, even with this mandate, the program has not been funded or fully implemented. While having access to a care manager and the utilization of consumer satisfaction surveys are important components to a quality assurance system, more needs to be done to assist consumers who are having problems or complaints with their services. 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. To help empower consumers to remain in the setting of their choice, the need for a community ombudsman to advocate for and with consumers is critical. We therefore recommend that consumers have access to an independent ombudsman. Whether an appeal needs to be filed or an inappropriate discharge from services needs to be prevented, an advocate can make a real difference to ensure a successful outcome to the problem.

As Pennsylvania has worked to expand providers so consumers can have “choice,” it has created a problem for consumers in terms of distinguishing which provider could best meet their needs. For example, consumers are given a list of service coordination agencies with phone numbers. There is no quality or background information given to help a consumer sort through the list of names. Pennsylvania should collect and provide background and quality related information so consumers can make a real choice versus a random selection from a list of names. This information should also be posted on a website so consumers, families, and professionals who help older adults can access the information. In addition, particularly with the proliferation of service coordination agencies, Pennsylvania should be vigilant in monitoring how
Protecting the most vulnerable among us should be a top priority. Increasing attention to preventing and identifying elder abuse and financial exploitation, and responding to allegations in a timely way, would help older adults preserve their resources and ensure their well-being. These resources should be used for their daily or long term care needs and not to benefit criminals. Fighting elder abuse requires a multidisciplinary approach but unfortunately, systems are not adequate to address all the needs. Informing the public about how to prevent elder abuse in their lives and families is a good first step. We must not let our loved ones live in isolation and we must encourage older adults and their families to talk and plan for the potential of incapacity. Older adults should be taught how to be good consumers and to reach out for help when needed. Whenever possible, we must also try to better incorporate abuse awareness into the aging, law enforcement, legal rights, mental health, and disability rights networks. We all must work to balance autonomy, privacy, and safety of older adults when confronting elder abuse.

It is important to improve the Department of Health’s enforcement of nursing home residents’ rights and quality of care. The Department of Health is particularly lax in enforcing regulations that prohibit inappropriate discharges from nursing facilities. They are failing to cite facilities who are discharging consumers as soon as their Medicare coverage ends without regard to whether the consumer needs additional care at the facility.

**Conclusion**
CARIE hopes Pennsylvania will create a system that promotes independence and dignity across the long term care continuum by empowering consumers to control and choose their services and how those services are delivered. Informal caregivers should be valued and supported in their role and a well-trained, stable work force should be supported. Ideally, consumers should be able to easily access high quality services that meet their needs when they need them.

We hope that regardless of the Commission’s recommendations, that the Administration will have a transparent process that includes stakeholder input and discussion before formalizing or implementing any recommendation or plan to change the delivery of LTSS in Pennsylvania.

Thank you again for the opportunity to comment and for sponsoring today’s hearing.