

Center for Advocacy for the Rights and Interests of the Elderly (CARIE)  
 Comments Regarding House Bill 1152  
 An Act Establishing the Department of Aging and Long-Term Living  
 May 21, 2009

Introduction

House Bill 1152 (HB 1152), to create a new Department of Aging and Long Term Living, is of vital importance to consumers, many of whom are unable to speak for themselves, and caregivers represented by CARIE. As this legislation with significant impact on the future of aging and long term living services is considered, we would like to share our concerns, recommendations and questions.

The Mission

**The new department should have a clearly defined mission, vision and values that encompass all of its responsibilities to Pennsylvania’s seniors, persons with disabilities and those needing long term living supports and services.** Section 2 of HB 1152 describes the objectives of the new department. However, that section does not address the current functions of the Department of Aging. **It is important for all stakeholders including consumers, caregivers, providers, members of the legislature, and the public to be involved in the process of creating a new department.**

Finally, there should be a more detailed description of how programs or protocols will be redesigned or the process that will be used for system change to meet the stated objectives. Without a roadmap to serve as a guide to get from where we are today to the new vision, there is the risk the new department will simply be implementing current programs with little or no improvement.

Preservation of Lottery Funds

Older Pennsylvanians are fortunate to benefit from many programs and services funded through the Pennsylvania Lottery. Currently, the Department of Aging uses some lottery dollars to fund its administrative costs. Not all Administrations have utilized lottery dollars in this way. Since the administrative costs of the new department will grow exponentially, there is serious concern that, particularly during difficult economic times, the Lottery Fund will be relied upon more heavily for administrative costs leaving fewer resources for the programs and services older Pennsylvanians have come to rely upon. The current Administration has also started the troubling trend of using lottery dollars to fund the Medicaid long term care budget that is mostly directed toward institutional care. Continued reliance on nursing facilities is antithetical to the administration’s position on balancing long term care and will exacerbate Medicaid long term care costs decreasing resources available for home and community based programs. **Traditionally, Lottery funded programs and services have helped older**

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**Pennsylvanians avoid or delay nursing home placement and it is essential that this critical resource be directed to the programs and services it was intended to fund.**

This Administration has stated that it will not use additional lottery dollars to fund the administrative costs of the new department. However, future administrations could take great latitude in determining how to distribute lottery funds under the guise of benefiting older Pennsylvanians. A new direction for lottery dollars could have an inadvertent outcome of diminishing the ability of the current lottery programs and services from assisting those older Pennsylvanians who desperately need help. **HB 1152 should include language to ensure the Lottery Fund is preserved for PACE as well as home and community based programs and services, and has restricted use for administrative costs with the establishment of a new department.**

Independence of the Ombudsman Program

The Long Term Care Ombudsman Program provides a vital service to older Pennsylvanians who use nursing facilities, personal care homes, assisted living, adult day programs and Domiciliary Care. In 1978, Congress enacted an Older Americans Act requirement that state agencies on aging establish an ombudsman program. The ombudsman program is resident driven and serves as an advocate to resolve problems. As the new department assumes additional responsibilities within the long term care system, safeguards must be put into place to ensure there is no conflict of interest or even a perception of such conflict with the ombudsman program. The 1992 reauthorization of the Older Americans Act clearly states that the state agency may not enter into a contract with an agency that has programmatic, licensing, or certification responsibilities. To ensure the integrity of the Long Term Care Ombudsman Program, it needs to be independent of any government entity that regulates, creates policy for, or reimburses providers. **We suggest that Pennsylvania consider removing conflicts or even perceptions of conflict by relocating the Ombudsman Program.** Pennsylvania might look at the practices of states including Vermont, Maine, Wyoming, and Rhode Island for other models – some operate the program out of the Governor’s Office or a Consumer Advocates’ office and/or it may be contracted out to a private entity.

Inclusion of All Older Adults

While the purpose of HB1152 is clear in its intent to create a more thoughtful, better coordinated approach for long term living in Pennsylvania, the Department of Aging has other important functions that should not be lost if it is replaced by the new department. The focus of the current Department of Aging is to serve all older Pennsylvanians. **There needs to be a strong statement added to the legislation that will ensure that the new department works to safeguard the well-being of all older Pennsylvanians.** There should also be language to describe how the new department will work and coordinate with other government entities that interface with older adults such as behavioral health.

Senior centers play a critical role in providing services and support to older Pennsylvanians. **Senior centers should be included in the list of definitions in Section 3 as well as the list of “system development activities in Section 4(12). The definition of long term living services should be expanded to include health promotion and preventive care. Section 5(f)(2), should be expanded to include, “and to ensure culturally competent services are being provided.” In addition the bill fails to mention critical programs such as the Family Caregiver Support Program, APPRISE, Options, meal/nutrition programs, and hospice.**

#### Consumer Choice and Autonomy

Consumer choice, dignity and autonomy should be at the foundation of all long term living services. The terms consumer choice and dignity are mentioned in the bill; but, the term autonomy is notably missing. **We recommend adding the word “autonomy” to the list found on page 2, Section 2 (3). Descriptions of in-home services include the clause “which shall include consumer-directed services” on pages 7, 17, and 18. For older adults, consumer choice is what needs to be emphasized and this language should be added to these descriptions.** Consumer-directed services should be one of many available long term living services.

#### Quality Assurance

What are the benchmarks or outcome measures that will be used to determine the progress or success of the new department? What information will be collected to measure quality specific to the design and functioning of the new department? **There should be performance audits required during the transition and for the next few years to gauge the success of the new department and identify areas that need focus and improvement.** Ideally, the new department will result in an increase in quality and access to services while reducing costs. The PA Medicaid Policy Center reports in terms of public spending for older Pennsylvanians, “...for every \$1 spent on community-based services nearly \$12 is spent on institutional care.” There should be a clear shift in balancing efforts from moving public spending for long term living toward home and community based care and away from institutional care. The use of the Lottery Fund in relation to the new department should also be monitored. **Outcomes should be measured and used to make any needed changes to the infrastructure or policies of the new department and all data should be made public.**

#### Advisory Council Representation

HB 1152 describes the composition of the Council on Aging and Long Term Living. It can also be assumed that should a new department be established, there will be a review concerning the efficacy and need for the various existing advisory groups related to long term care issues. **It is essential that the composition of the new Council on Aging and Long Term Living as well as any other advisory group include advocacy organizations representing older adults.** Advocacy groups can represent the experiences of many older adults who would otherwise not have a voice. For example,

those with Alzheimer's disease or other dementia and those whose disabilities make them homebound and unable to participate in meetings should still have a voice which they can have through representation by an advocacy group. Individual consumers provide helpful and compelling perspectives about the long term care system and should be an integral part of any advisory committee. They have valuable insight and information to share.

Advocates that represent large groups of consumers are also important in that they can confirm whether the experiences expressed by individual consumers are reflective of the aggregate or somewhat unique to that individual. Advocates are often in a better position to identify trends and systemic problems. Caregivers of older adults also provide a needed unique perspective that should be part of any advisory committee. The significant role caregivers play in our long term living system should not be overlooked. **We recommend that the Administration describe the process it will undertake to streamline its numerous advisory committees and provide this information to the legislature and public. HB 1152 should be amended to include the addition of at least two advocacy groups for older adults as well as at least two caregivers to the composition of the Council of Aging and Long Term Living.**

#### Transparency of Information

It is essential that the new department be required to provide information about program policies and regulations to the public in a clear and timely way. Current long term care related programs and services have multiple complicated rules, policies, requirements and procedures that consumers, their families, and the professionals who serve them need to understand. All regulations, policy changes, program directives, memos, bulletins, etc. need to be made public and posted online in an easily accessible and timely way. New and revised information should also be distributed in a timely way to anyone who requests to be notified of such changes. The website should have the information well organized by categories and dates, should be able to be searched, and should have an ongoing separate listing of new information and directives. **HB 1152 should require that all policy, rules and regulatory information be made public in a clear and timely way.**

#### Safety Net during Transition

It would be helpful if the Administration could describe its plan for an effective transition to the new department. What is the plan and timeline for getting from where we are today to the vision of the new department? **There should be a safety net of services for consumers during the transition to the new department.** The creation of this new department will involve major reorganization and shifts in systems. No consumer should lose services, be significantly delayed in getting services, or be denied access because of glitches that occur during times of transition. **There should be an expedited procedure in place to review any situation when a consumer loses or is denied services that appear to be a result of a problem related to the transition process.** This procedure needs to be identified and communicated to the public.

## Conclusion

How will the new department effectively serve as advocate for two populations throughout the Commonwealth? We realize that there is a similarity between the needs and interests of older adults as well as adults with disabilities in regard to long term living and that it is logical to have program integration and pair them within one department. However, it is unlikely that there will be a 100% symbiotic relationship between the two groups. In these instances, the department would probably serve the role of a mediator to reconcile differences and therefore would no longer be an advocate for either group. How will the function of advocacy be preserved when there is a conflict between the two populations being served within the same department?

While we understand the interest in enacting the changes that began with the creation of the Office of Long Term Living before the end of this Administration, we hope that the desire to pass something quickly will not take priority over crafting thoughtful legislation. Any oversights may have immediate serious implications for older Pennsylvanians as well as in the future as elections of new Governors and cabinet changes often bring changes in priorities and focus. **We need to make certain that adequate provisions are in place to guide this administration and future administrations in serving the needs of those who are aging, those with disabilities and those who require long term living supports and services.**

We realize that all of our questions and comments are not appropriate to be included in enabling legislation but nonetheless, hope that the questions will be answered and concerns addressed before any legislation is passed. **Thank you for considering our concerns and recommendations.**