

## 2008 PA Department of Aging State Plan Town Meeting Discussion Guide Comments

Submitted By:

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### Introduction

Thank you for sponsoring town meetings for the 2008-12 Pennsylvania Department of Aging State Plan and for adding a Philadelphia site to your schedule. There are a number of critical issues that were not discussed at the Philadelphia town meeting that we hope you will consider incorporating into the final plan. Our comments and recommendations reflect issues highlighted under each goal area as well as some general concerns.

### Goal #1

*Empower older Pennsylvanians and their families, including those from diverse communities, to make informed decisions on their health care and long-term living options.*

In order for older consumers and their caregivers to make informed decisions, they need to be able to easily access helpful consumer information. As the Department develops and updates its consumer brochures and materials, a prime focus should be on creating documents that can be understood by those with low literacy levels. There is also a lack of useful consumer information that describes the Options and Aging Waiver programs including major gaps in the information provided on the Department of Aging's and Department of Public Welfare's websites. Consumers and their caregivers are often confused about or unaware of their options. This lack of information can cause delays or barriers to consumers and their caregivers from seeking the help that they need. We recommend developing and distributing comprehensive, easily understood public educational materials about the Options and Waiver programs. This information should also be posted online.

Another public education need is related to the rules surrounding estate recovery and the Aging Waiver program. While we understand that the Department does not control the estate recovery regulations, the Department can improve upon how the information is communicated to clients as well as fund legal services to serve as a resource for consumers since there are clients who continue to refuse Aging Waiver services out of fear of losing their homes. For example, some fear that if they leave their home for any reason such as a hospital stay, the home will be taken away from them. Others want a caregiver to be able to live in their home after the consumer's death. There are some older adults who refuse services who would meet the postponement or hardship waiver requirements but these exemptions from immediate estate recovery are not well understood by older adults, AAA staff, and other professionals involved with their care. Without clear assurances from the state, older adults are not willing to assume the risk. Care managers are not in the position of providing legal advice but should make referrals to local legal services for individual consultation. This is one of the many areas of unmet need for legal assistance which should be addressed. However if clear guidance and assurances could be developed by the Departments, care managers could pass the information onto consumers and their families. Unfortunately the current brochure when first developed was

reviewed by focus groups of seniors as unappealing and unlikely to be picked up from a display rack. Perhaps when it is reprinted the brochure and particularly the photos could be more engaging and consumer friendly. CARIE therefore recommends that the Departments of Aging and Public Welfare and the Office of Long Term Living work together to develop and distribute clear information about estate recovery for consumers. Care managers should also receive training and supervisory support about how to advise clients about estate recovery.

There appears to be a significant problem related to program transparency and in communicating changes in definitions and guidelines even though these changes have triggered major consequences for older consumers, their families and the professionals who serve them. For example, the clarification related to the “NFCE” (nursing facility clinically eligible) definition was not readily communicated and had tremendous negative implications for many consumers. Changes in the Level of Care (LOC) assessment and reassessment practices have also presented similar problems. When older clients and the professionals who serve them are not aware of new rules or policies, or new interpretations of policies, it is difficult to understand or assess whether reductions or elimination of service plans are being fairly implemented without knowing the specific guidelines. The following case example highlights some of the problems Aging Waiver participants are experiencing. We received a call on our CARIE LINE from the son of a 77 year old woman (a double amputee who suffers from diabetes) who had been receiving Aging Waiver services since September 2006. A year later, she received a letter stating she was being terminated from Waiver services because “her condition was improved.” She was told that she was no longer medically eligible for Waiver services. This came as a surprise to her and her son who is in the process of helping his mother appeal the decision. According to her son and her family physician of 30 years, her condition has actually worsened since she was initially admitted into the Waiver program in 2006.

We recommend that the Pennsylvania Department of Aging make the rules, policies and procedures of the Aging Waiver and Options programs transparent and readily available to consumers, their families and the professionals that serve them. Consumer friendly materials should be developed and also posted on the Department’s website. In addition, the website should include information about consumers’ rights and responsibilities. Professionals and interested consumers should be able to access online outcomes and performance measures for Waiver and Options programs, as well as any correspondence to and from CMS in regard to the Aging Waiver.

#### Goal #2

*Enable older Pennsylvanians, including those from diverse communities, to remain in the setting of their choice, improve their quality of life, and to take individual economic responsibility via the development of needed infrastructure and provision of home and community-based services, including supports for family caregivers.*

CARIE appreciates the strides that have been made in Pennsylvania’s struggle to shift away from the institutional bias in the provision of long term care services; however, Pennsylvania still has a long way to go to balance its system. CARIE is a member of the Pennsylvania Senior Support Coalition that is advocating for increased funding for Options services and senior centers. While Aging Waiver services are critical, Options services are an

important component of Pennsylvania's service system. Options services help prevent or delay the need for Aging Waiver or nursing facility care and should be fully funded to eliminate the waiting lists for care. The Department should also begin to maintain waiting list information about consumers who are waiting for additional services to be added to their care plans. The Nursing Home Transition program is an effective response to address the problem of paying for higher levels of care than is needed. However, planning should include the impact of not paying enough for necessary care, even at a nominal level. Having both the waiting list for consumers who need services along with a list of those who need additional services would provide a more accurate picture of the overall service gaps that need to be filled. The success of Pennsylvania's transition will depend on how well older adults are diverted from or delayed from nursing home placement and Options services is a critical element to this success. Older adults should not be unnecessarily diverted to nursing facilities because of concerns about the risks they may incur from inadequate care plans. In addition, 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. Adequately funding lottery supported programs and services would be a "win-win" situation for both consumers and the state budget.

Another growing concern is the quality of the care plan and services consumers receive. Particularly as resources diminish and the focus shifts to shorter assessments with faster delivery of services, we are concerned that care plans may be limited. The myriad of services that help older adults maximize their independence and have quality in their life are often forgotten and underutilized. For example, essential programming such as adult day and mental health services are frequently underutilized. Care managers or other staff should be helpful in educating older adults about all of their options and linking them to services. Care managers should be encouraged to utilize various programs and experienced supervisors should carefully review care plans to ensure they are comprehensive in nature and meet the clients' needs.

When discussing the issue of quality, it is essential that the Department establish effective quality assurance policies and procedures that work to identify and resolve complaints and problems with care provided through the Aging Waiver and Options programs. Pennsylvania has long mandated the provision of an ombudsman for older consumers receiving home and community based care; however, the program has never been funded. 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.

Through our CARIE LINE, advocates routinely hear from older adults who have problems accessing services and those who simply have trouble navigating the complex health care system. CARIE's ability to help educate consumers about their health care rights as well as to directly assist older adults who are experiencing problems has made a significant difference for these individuals. 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 the positive trend continues in Pennsylvania of balancing the system of facility based and home and community based services, the need for a community ombudsman to advocate for and with consumers becomes even more critical. We therefore

recommend that Aging Waiver and Options consumers have access to a long term care ombudsman similar to what is available for residents of long term care facilities.

The appeal process for reduction or elimination of Aging Waiver services should also be reviewed and changes be made to improve the process. Clients should be afforded the necessary time needed to gather information and support to appeal decisions or to ensure a smooth transition to an alternate care plan. Clients should not have to wait months for a final decision in regard to their appeals.

As a member of the Pennsylvania Intra-Governmental Council on Long Term Care (IGCLTC), I want to direct your attention to the Home and Community Based Care Barriers Elimination Work Group Report. This report was originally drafted six years ago and was recently reviewed and reaffirmed by the Council. CARIE strongly recommends that the Department work with the Department of Public Welfare and the Office of Long Term Living to review the report and develop an action plan with a timeline to begin to remove the barriers that are identified.

The Department needs to make housing a priority area in the plan. Planning should include the identification of clear goals and partnerships to help address the housing shortage, as well as home repair and home modification needs. 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 also directly linked to improving housing. The needs of older adults in nursing and personal care homes should be included with a particular focus on the quality of care and life in institutional settings. CARIE's ombudsman have witnessed the plight of the personal care home residents with low income being moved – sometimes repeatedly, as personal care homes close. These residents should not be forgotten as Pennsylvania tries to “right-size” its long term care system. Again, I'd recommend that you look to the 2007 IGCLTC Housing Alternatives Workgroup report for proposed solutions.

As the population ages, having a reliable, accessible, and affordable transportation system is imperative for the physical and psychological well-being of older adults. Many older Pennsylvanians have either experienced a problem with the shared ride program or are aware of someone who has had a complaint about the system. Shared ride services could be improved in the following ways. First, the shared ride program service area should be expanded so that older adults can travel beyond the currently established county limits to assure that they are able to travel to necessary destinations. One example of this problem is older consumers who want to visit spouses who live in nursing homes in other counties but who are unable to make such visits due to the geographic limitations of the shared ride program. Second, providing subsidized rides for non-sponsored shared rides would assist low income older adults in accessing the shared ride program. Currently, it costs \$4.00 one-way to use shared ride in Philadelphia. Many older adults simply cannot afford the \$8.00 round-trip fare. Third, funding should be increased to senior centers for their sponsored rides to assure that senior center consumers can continue to participate in center activities. The 2007 shared ride fare increase in Philadelphia from \$3.50 to \$4.00 has put a strain on the allocation of sponsored rides at senior centers, causing some trips to be eliminated. Finally, the issue of driver insensitivity has been an issue of concern for quite

some time. The Department would be in an excellent position to work with the Department of Transportation to provide an interactive curriculum to use for driver training. In addition, increased funding for Attendant Transportation Service (ATS) and expansion of ATS to all Area Agencies on Aging would benefit homebound older adults. The Department should work more closely with the Department of Transportation to develop improved standards and outcomes as well as provide better oversight to hold service providers accountable especially when consumers are stranded for hours. Public transit also needs to be improved for older riders. Riding and waiting for public transit can be a frightening experience. Bus stops often do not have seating so older adults are subject to long periods of standing. Bus drivers often accelerate before passengers are seated, leaving older riders vulnerable to falls.

Since public transportation and shared ride have not adequately met the transportation needs of older Pennsylvanians, the Department should explore successful models for volunteer programs that drive and escort older adults. Guidelines could be provided to the AAA network as well as churches and community based agencies to ensure a successful outcome.

The Department's plan should address workforce issues. CARIE's experience with Better Jobs Better Care - Pennsylvania (BJBC-PA) demonstrated that the quality of service provided to older adults depends upon direct care workers being adequately trained and supported. These are often difficult jobs that experience high turnover. Training direct care workers helps improve the quality of care and can help prevent turnover. Pre-employment training and certification of core competencies for direct care workers common across all long term care settings as well as advance training for certification as a nurse aide or home health aide would prove beneficial.

### Goal #3

*Empower older Pennsylvanians, including those from diverse communities, to stay active and healthy.*

When developing goal #3, CARIE would encourage the Department to include those who are homebound whenever possible. For example, individuals who are homebound could benefit from health promotion and disease prevention as well as socialization activities. The Department needs to think about ways to integrate homebound isolated consumers into their communities. It is important that consumers have contact with someone other than their home care aide. This could be accomplished through the increased use of adult day services or innovative programming at senior centers. The Department should conduct an assessment of all types of programming and develop a plan as to how to provide services such as recreational activities, telephone reassurance, adult education, and homebound library services.

### Goal #4

*Ensure older Pennsylvanians, including those from diverse communities, are free from abuse, neglect, exploitation and abandonment.*

While all four goals need to be edited to more clearly reflect all of the "key items for discussion," goal #4 does not begin to address all of the key elements such as behavioral health. By excluding references to behavioral health, it is too easy to overlook or minimize the

significance of this vital issue. Even the facilitator at the Philadelphia town meeting ignored this issue even though behavioral health was on the list to be discussed at the breakout session. Unfortunately, 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. We hope that the Department will address the accessibility and quality of mental health services for older Pennsylvanians. The Department should work to help increase the availability of mental health services so that consumers can have access regardless of where they reside. The cost sharing policy should immediately be changed to exempt mental health services from costs that the consumer must share. Care plans should be reviewed to ensure mental health needs are being met.

CARIE is pleased that the Department has included supports for family caregivers as a key item, especially since the overwhelming majority of older adults who need long term care assistance live outside of facilities. When planning for the needs of caregivers, it is important to recognize that caregivers fit varied profiles. Some are raising children and are classified as the “sandwich generation” juggling caregiving and parenting responsibilities. Many caregivers are employed and struggle to meet the demands of their jobs while providing their loved ones’ needed care. Older spousal caregivers may also experience chronic conditions themselves and in fact are found to have a 63% higher mortality rate than other older adults who do not have caregiving responsibilities. Data even confirms that there are children under 18 who are assuming some caregiving responsibilities. In addition to recognizing some of the challenges that caregivers face, the Department should take a more aggressive role in advocating for an increase in the monthly financial allowance and maximum lifetime home modification allowance currently provided through the Family Caregiver Support Program. It is also important to advocate for an increase in the program’s capacity so that more caregivers may be served. Pennsylvania’s long term care system should ensure that family and informal caregivers are supported in their vital role.

The Long Term Care Ombudsman Program should be evaluated so that the resources provided meet the Department’s expectations for the program. While the increased use of volunteers is a positive trend, resources are needed for effective volunteer programs. Having incentives such as stipends would also ensure the success of a volunteer program.

When developing goals regarding elder abuse and exploitation, the Department should plan partnerships and educational opportunities with the criminal justice system. Often judges and officers of the court are not sensitized to the unique needs of older victims and some even display ageist attitudes. There is also a tremendous opportunity to have court staff, law enforcement, and every District Attorney’s Office throughout the Commonwealth learn about resources that could be beneficial to older adults.

### General Comments

As the Department develops its state plan, we hope that there will be a focus on information garnered through statistical analysis as statistical analysis is the basis for successful planning and ultimately successful action steps. For example, statistical analysis can help inform whether the current funding formula is indeed equitable. We have been working with the lead agency Pathways PA to see that the PA Elder Economic Security Standard is released shortly.

This should prove to be an excellent planning tool to help identify gaps as well as where PA programs are having the most positive impact on older Pennsylvanians.

Since there are many government agencies that provide assistance and resources to older Pennsylvanians, The Department's plan should identify how it will complement and work in tandem with these agencies to achieve common goals with the least amount of administrative resources. More specifically, the Department should clarify its role and relationship with the Office of Long Term Living, the Department of Public Welfare, and the Department of Health.

We urge the Department to carefully consider its role as the ADVOCATE for Older Pennsylvanians. The times demand a strong voice to help avert ageist attitudes and promote policies that best meet the needs of older adults particularly as the Commonwealth expands its bureaucracy in the delivery of services to older adults. It would be beneficial that as staff is employed, they receive advocacy training and encouragement to utilize these skills. Staff should also be trained to promote programs that the Department offers. At the Philadelphia town meeting, a staff member from the Department of Aging suggested that a participant contact the Department of Health when she expressed concerns about the quality of care at a nursing facility. While this was an appropriate referral, it would have been an excellent opportunity for the representative from the Department to mention the Department's own Long Term Care Ombudsman program. At the state level, the Department should be educating the Governor's staff and legislature of the problems associated with using lottery funds to pay for budget items such as the loss of Intergovernmental Transfer Funds. The Department should advocate more aggressively at the federal level for better funding and needed reforms to the long term care system. For example, until there is a fundamental way in which long term care is funded, it will be difficult to achieve many needed reforms. While the "Baby Boom" generation will clearly have a tremendous impact on the service system, it is politics, especially federal policy, not demography that will prove to have the greater impact.

The Department should recognize the growing use and benefits of technology as well as the limitations when developing the state plan.

### Conclusion

Founded in 1977, CARIE is a nonprofit organization dedicated to improving the quality of life for frail older adults. CARIE's focus of concern includes all consumers of long term care services from those who need home or community-based services to those who are institutionalized. Older adults who experience physical or psychological impairments have difficulty advocating for themselves and are often a silent group—CARIE works to protect their rights and promote awareness of their special needs and concerns.

CARIE wishes the Department every success as it develops and implements its four year plan. Please do not hesitate to contact us should you need any assistance with the plan or in your work to improve the lives of older adults.