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September 30, 2011

Gary D. Alexander, Secretary
Department of Public Welfare
P.O. Box 2675
Harrisburg, PA 17105

Re: "Shared Living" Request for Information
Submitted to: Pam Kuhno at sharedliving@state.pa.us

Dear Secretary Alexander:

On behalf of the Center for Advocacy for the Rights and Interests of the Elderly (CARIE), I am pleased to submit the following comments in response to the Department of Public Welfare's "Shared Living" Request for Information.

CARIE is a non-profit organization dedicated to improving the quality of life for frail older adults by working to protect their rights and promote awareness of their needs and concerns. Since 1977, we have been providing advocacy services and options counseling for older adults and their caregivers. CARIE also provides long term care ombudsman services to residents in about 120 nursing facilities, personal care homes, and domiciliary care homes in north, west, south and central Philadelphia. We are in a unique position to understand the needs of current domiciliary care residents as well as the needs of older adults and their caregivers who are seeking options for long term services and support.

CARIE is supportive of the overarching goal as defined in the RFI provided that a new model does not marginalize the current population being served or make those in the "Preventive Need Group" a low priority. In addition, the planning process must be transparent and engage all stakeholders.

Should you require any additional information, please do not hesitate to contact me at 267-546-3434 or menio@carie.org.

Sincerely,



Diane A. Menio
Executive Director



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Pennsylvania Department of Public Welfare
“Shared Living” Request for Information

The Center for Advocacy for the Rights and Interests of the Elderly (CARIE) respectfully submits the following comments for consideration as the Department explores whether to enhance the scope of existing Shared Living Programs (SLPs) in Pennsylvania. CARIE is supportive of the overarching goal as defined in the RFI provided that a new model does not marginalize the current population being served or make those in the “Preventive Need Group” a low priority. In addition, the planning process must be transparent and engage all stakeholders.

Conceptual Solutions and Strategies

CARIE considers ensuring quality of care to consumers as the most important component for a SLP. It is important to design a program to provide an appropriate environment that ensures the safety and well-being of residents. The Department should meet with ombudsman and other stakeholders to address quality of care and oversight issues. Care plans must describe resident needs, preferences, and abilities. State and local Fire Marshalls should be consulted to identify fire safety requirements. Provider qualifications and training should be defined for each tier and training should include orientation, basic training, and continuing education. Training must be measured by demonstrated competency in core areas. Since a higher level of care is being proposed, it is also important to support and improve the competency of existing providers. Providers who serve residents with special needs such as dementia or mental illness should be required to obtain specialty training on the knowledge and skills needed to effectively and safely care for residents with special needs. The Department should consider the difficulty small providers, especially those in rural areas, have in dedicating time to attend trainings. Developing and offering online training would be helpful. If family members are included in the SLP, they too should receive training and demonstrate competency to provide needed care.

Recruiting a sufficient number of providers to offer all three tiers of care or serve specialized populations may be a potential challenge especially for “mom and pop” type of providers. The Department should consider licensing different levels of providers to maximize recruitment. It will be beneficial to provide respite care for providers particularly for those caring for individuals requiring high levels of care. If family caregivers are included in the SLP, their needs should be assessed and addressed in the care plan. The hospice model, excluding end of life criteria, may be particularly useful in developing a SLP model that addresses both consumer and caregiver needs in a holistic way.

The administration of medication is another important area for consideration particularly with proposed tiered eligibility groups. Any staff member who administers medications must be trained. Stringent regulations need to be developed to avoid adverse outcomes. Having effective medication management protocols will help with successful transitions out of nursing homes, institutions and hospitals.

It is vital to protect participants’ rights and ensure freedom from abuse and neglect. Residents must be informed about their rights and how to exercise them. Information about the ombudsman program, protective services, and the licensing agency should be easily accessible. Unaddressed complaints and incidents may cause irreparable harm to residents. A strong regulatory system needs to be in place to ensure timely responses to complaints and to create an

environment that promotes the safety and well-being of residents. Poor performing providers who are not able to correct problems and deficiencies should be prohibited from providing care to vulnerable adults. There should be strong regulations related to the right to appeal discharges similar to the discharge rights provided to nursing home residents.

Participants must also be free from fraud and regulations should be in place to ensure ethical management of their personal funds. The principle of person-centered care must also apply to money management. Providers do not recognize residents' rights to manage their own money as readily as the right to direct their own care. Often there is a stigma attached to residents having control over their money with the thought being that they would simply be wasteful without someone controlling their finances. The role and limitations of a representative payee must be clarified. Typical complaints from current residents include that they do not recall giving someone permission to be their representative payee and the provider is not willing to assist them in removing the representative payee to help regain control of their finances. Regulations should reflect the importance of resident directed decision making so if a resident wants to change their representative payee or power of attorney, the provider must assist them if they need help. At the very least, providers should refer residents to an entity who can help them.

Addressing Potential Challenges and Barriers

Housing issues will be a barrier with an expansion of the SLP particularly if family members or "mom and pop" owners are recruited as providers. Steps make homes inaccessible and many bathrooms are not equipped to accommodate those with functional impairments. Since reimbursement rates do not make being a SLP provider profitable, the SLP should help pay for home modifications to make private homes accessible.

CARIE also recommends that if the Department implements a SLP, it should start as a demonstration project in one or two regions of the Commonwealth that include urban, suburban and rural areas. The department should use university-based researchers to collect and analyze various performance measures so any needed changes are made before the program expands statewide. An advisory committee comprised of various stakeholders should also be part of the process of evaluating the SLP as well as helping to identify and resolve any systemic problems.

Pricing Methodologies and Potential Cost Savings

Since the Department is proposing three tiered eligibility groups, rates should be based on acuity levels to create incentives to serve those with higher needs and residents who want to age in place. CARIE opposes the use of existing Medicaid waivers to fund the SLP unless there is an expansion of waiver slots to meet the new need. Since the ability to access waiver services in a timely way is a problem in Pennsylvania, having another demand placed on the current supply will put individuals at a higher risk of institutionalization. In addition, using current waiver slots could create a perverse incentive for individuals in need of long term services and supports to move from their homes to access waiver funded care.

Finally, if SLP providers are properly trained and supported, this option could serve as a viable alternative for more costly care.

Other Relevant Considerations and Information

CARIE has concerns about using an RFI as the first step in engaging stakeholders in a planning process. In addition, not all stakeholders have the ability to respond to a RFI. The Department has numerous advisory groups at its disposal that should have been consulted and engaged in a dialogue about a SLP. Consumers should also have been consulted about their values and needs before releasing a RFI. The Department should keep these groups and all interested stakeholders informed as plans progress and consult them along the way for feedback. Stakeholder planning meetings should offer the opportunity to participate by phone or via the internet for those not able to travel to Harrisburg. Stakeholder input at every stage of the planning process is essential to the success of any new program.

It is vital that the Department proceed with this planning process in a transparent way. CARIE recommends dedicating a webpage that includes all information submitted in response to the RFI as well as any draft documents and meeting information. Stakeholders should not have to go through a Freedom of Information Act process to obtain information. If the Department works with stakeholders in a meaningful and transparent way, it will help ensure a successful outcome.

Thank you for the opportunity to submit comments. Should you have any questions, please contact Diane Menio at 267-546-3434 or menio@carie.org.