

The Office of Long Term Living
Aging Waiver Listening Sessions – Norristown
February 6, 2008

Submitted By:

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Introduction

Good morning. My name is Diane Menio and I am the Executive Director of the Center for Advocacy for the Rights and Interests of the Elderly also known as CARIE. Thank you for sponsoring the Aging Waiver listening sessions and for the opportunity to testify. I am here to speak on behalf of older consumers with a focus on access to services and quality care.

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.

Program Transparency

There appears to be a significant problem with 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 has

tremendous negative implications for many consumers. The change in the new Level of Care (LOC) assessments and reassessment practices are also presenting similar problems. When older clients and the professionals who serve them are not aware of new rules or 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 had 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 Office of Long Term Living make the rules, policies and procedures of the Aging Waiver program transparent and readily available to consumers, their families and the professionals that serve them. Consumer friendly materials as well as a website that includes this information should be developed. In addition, the website should also include information about consumers’ rights and responsibilities, outcomes and performance measures, as well as any correspondence to and from CMS in regard to the Aging Waiver.

Consumer Education

There is a lack of useful consumer information that describes the Options and Aging Waiver programs. There are 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. Many clients still refuse Aging Waiver services out of fear of losing their homes. For example, some fear that if they leave their homes for any reason such as a hospital stay, their homes 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.

Quality Care

CARIE is pleased to see that the Office of Long Term Living plans to develop an integrated quality management strategy across all waivers. In this pursuit, it is essential that the Office of Long Term Living establish effective quality assurance policies and procedures that work to identify and resolve complaints and problems with care provided through the Aging Waiver. 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. We therefore recommend that Aging Waiver 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 should 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 shouldn't have to wait months for a final decision in regard to their appeals.

Barriers Elimination

As a member of the Pennsylvania Intra-Governmental Council on Long Term Care, 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 you review the report and develop an action plan with a timeline to begin to remove the barriers that are identified.

Expand Home and Community Based Services

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. According to the Pennsylvania Medicaid Policy Center, there are about 78,000 nursing facility residents and about 20,000 Aging Waiver participants. Pennsylvania still has a long way to go to balance its system and more Waiver slots are needed. 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 success of Pennsylvania's transition will depend on how well older adults are diverted from or delayed from nursing home placement.

Conclusion

Thank you once again for the opportunity to provide comments. Please do not hesitate to contact me should you need any additional information or assistance.