

NAPA National Plan Recommendations

The Center for Advocacy for the Rights and Interests of the Elderly (CARIE) is pleased to submit the following recommendations for inclusion in the NAPA National Plan. 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, CARIE has been providing advocacy services and options counseling for older adults and their caregivers. CARIE coordinates the Dorothy S. Washburn Legislative Committee comprised of legal, health and human services professionals as well as older adults who advocate to improve public policy impacting older adults and their caregivers.

CARIE is concerned about the issue of unbefriended elderly, more specifically, those with Alzheimer's disease and other dementia who do not have a caregiver or responsible party to help them. There have been problems with these older adults being prematurely admitted to nursing facilities or being denied in-home services because of concern about liability. CARIE requests that the NAPA National Plan begin to address the needs of this population. There should be a dialogue about how to best strike a balance between preserving autonomy and allowing consumers to take some risks versus ensuring safety through more protective measures. While there is an abundance of information about Alzheimer's disease and related dementia and support for caregivers, there is little, if any, information for those who do not have a caregiver or responsible party. There is enough anecdotal evidence to assume that not all older adults have family or close friends available to help.

CARIE's Dorothy S. Washburn Legislative Committee makes the following recommendations for the NAPA National Plan:

Recommendations

1. Include the issue and needs of unbefriended elderly in the NAPA National Plan and encourage the inclusion of the needs of this population in state plans.
2. Implement an epidemiological study to identify the scope of the problem.
3. Implement research to help identify best practices for ways to ensure early diagnosis for unbefriended elderly. Issues related to stigma and cultural differences should be addressed. Quality assessments should be readily available in all communities for consumers who are becoming concerned about symptoms.
4. Design and fund demonstration projects to identify best practices and practical, cost-effective models for service delivery. There should be a balance between consumers' safety and their need for autonomy. Different needs, preferences and values should be considered. Models should be tested among various cultural groups to identify potential variance with approaches. Identify benchmarks and performance measures that foster good outcomes.

5. Research, design and implement clinical tools to help assess the decision-making capacity of individuals and work to maximize autonomy and ensure individuals are engaged and involved in making decisions to the greatest extent possible.
6. Identify and utilize an ethical framework for assessment, planning and service delivery to ensure autonomy to the best extent possible as well as cultural considerations.
7. Identify best practices for health care professionals, social workers, and paraprofessionals needed to work with this population including competencies and knowledge needed.
8. Create training programs and help implement best practices for public safety officials such as police and fire fighters, emergency management personnel, and postal workers to help them identify those in need as well as where to turn for further assistance. Information should include but not be limited to what to do for someone who is found wandering.
9. Develop strategies to prevent financial exploitation and premature guardianships for those in the early stages of Alzheimer's disease or other dementia. Ensure access to legal services.
10. Create, test, and implement model community educational programs to increase public awareness and decrease stigma.

Please contact Kathy Cubit at CARIE at cubit@carie.org or 267-546-3438 for more information.