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Helen Lamont, Ph.D
HHS Office of the Assistant Secretary for Planning and Evaluation
Room 424E, Humphrey Building
200 Independence Avenue, SW
Washington DC, 20201

Dear Dr. Lamont:

On behalf of the Pennsylvania Department of Aging, I am respectfully submitting comments on the Draft National Plan (Plan) to Address Alzheimer's Disease. In general, I believe the Plan is well timed, comprehensive, and ambitious and our Department supports the Plan. Accomplishing the Plan goals will require collaboration with many different service systems, and the Department of Health & Human Services will likely face challenges in coordinating efforts across these systems.

While achieving the vision of eliminating Alzheimer's Disease (AD) by 2025 is the ultimate goal, the immediate need is appropriate care for those with AD and relief for caregivers. Further, research needs to be expanded into areas that are supportive to caregiving. The Plan should also address the issues and propose solutions of excess deficits that cause unneeded anguish to both the person with dementia and their formal and informal caregivers.

Because of the scope and complexity of needs of those with dementia, I believe it is helpful to prioritize those areas of need. First and foremost, there is a wealth of knowledge that enables clinicians to diagnose and treat persons with memory disorders. However, the greatest need is having adequately trained physicians to diagnose and provide care for dementia residents. This issue isn't new; it has been known for the past 10 years. With only 7,162 trained geriatricians in the country or one geriatrician for every 2,620 residents over 75 years of age, there isn't an adequate supply of geriatricians to provide geriatric educational needs among the US medical schools.

There is discussion in the draft plan about the need to expand and prioritize research aimed at developing new pharmacological interventions for preventing and treating Alzheimer's Disease. There is also some mention about reducing the use of antipsychotic medications for treating the symptoms of AD in institutional settings. Both of these action items are laudable. What is missing is a recommendation to reduce the current widespread, wasteful and in some cases harmful, overuse and misuse of the cholinesterase inhibitors and related combination therapies in treating AD. Practice guidelines for cost effective and efficacious pharmacological interventions in the treatment of AD are available but not widely adhered to.

In Pennsylvania, there discussions are currently being held about the Behavioral Risk Factors Surveillance System. Numbers of people are not now being identified; therefore a module asking respondents if someone in their home has dementia and the follow-ups would greatly help us identify the numbers outside of proper care, care-home settings, etc., that currently suffer dementias.

For your consideration, together with the above general recommendations, I respectively offer more specific comments. For example, although the Plan makes mention of emergency rooms, there needs to be “best practice” models that are shared with the thousands of hospital emergency rooms in the US. In addition, I propose these suggestions on specific goals, strategies, and actions:

Strategy 1.E: This priority deals with translating findings into medical practice and public health programs. There should be a separate action item that addresses the shortcomings in the current pharmacological treatment of AD and guidance to prescribers on how to remedy this problem.

Action 1.A.1: This priority is not just important, it is essential if we expect to slow progress, delay onset and prevent AD. It needs to be a collaborative effort that is international in scope (Strategy 1.D) with high level commitment and energy that includes public and private resources and their networks interconnected. Money for research alone will not achieve what is needed. We need to look at past models of disease threats like tuberculosis, polio and HIV that had a grass roots demand for a cure.

Action 1.B.3: This is also essential; we need some fast “wins” through medical research that energize the world-wide community committed to eliminating dementia illnesses. And, in addition to expanding the enrollment of all racial and ethnic populations, we need to have several drug investigations on an urgent fast-track that not only give people hope but the belief that we are doing everything possible to get these issues under control.

Action 1.E.3: ADEAR (Alzheimer’s Disease Education and Referral) needs to be a more widespread publically funded resource; there needs to be, for example, posters advertising it in post offices, libraries, and other public spaces.

Goal 2: The lack of adequately trained providers is addressed by dedicating “6 million dollars over two years for provider education and outreach.” This is a limited amount of money to fix the national issue of solving the access to care issue with competent geriatricians. Further, there needs to be expanded roles for Advance Practice Registered Nurses in geriatric care.

Strategy 2.A: This strategy has a direct connection to PDA programs. PDA has done some work through the Long-Term Living Training Institute and Direct-Care Worker initiatives around educating and strengthening the direct care workforce to ensure workers are dementia-capable. PDA would welcome additional support in this area.

Action 2.A.4: PDA supports this action and sees the need for additional resources to train more direct workers in nursing homes and professionals that provide services in home and community based settings. PDA has provided funding to the Delaware Valley Alzheimer’s Association to provide dementia specific training to those professionals that provide in-home care. The training is designed to improve care techniques that can be directly applied to day-to-day care in the home which can reduce the stress and burden on both professionals and family caregivers.

Strategies 2.C and 3.B: Contained in Pennsylvania's assessment for services for older adults is a 24-question assessment of caregiver status and needs. PDA would be interested to learn what other states are using and their best practices in terms of caregiver assessment instruments.

Action 2.H: PDA supports this action and sees the need for additional resources to improve care for certain populations, specifically those with intellectual disabilities. PDA currently co-chairs the Joint Committee on Aging & Intellectual Disabilities (ID) with the Office of Developmental Programs. The committee was formed to improve services and supports available to older persons with ID by working together through interagency coordination and collaboration. As the number of people aging with ID continues to grow, education for both professionals and caregivers along with proper supports should be a focus and be given special consideration to ensure the proper care for this population.

Strategy 3.E: PDA supports this action and sees a great need for increased housing options for individuals with AD. Affordable, safe housing is a special problem during the early to middle stages of the disease for individuals who live alone and do not have informal caregivers to provide support.

Strategies 4.A and 4.B: Public awareness campaigns and pooling/compiling resources should be organized around a single, nationally recognized association/entity related to Alzheimer's disease.

In conclusion, some components of the Plan have a direct connection to PDA programs, such as support of caregivers and enhancing the knowledge of direct care workers. Other components of the Plan such as methods for diagnosis, direct treatment, and research, do not have a direct connection to our programs. However, as I stated above, our Department supports the Plan and, while recognizing that there is no one quick, easy solution to dealing with such wide, complex needs, I feel my comments and suggestions are important for improving the Plan and thereby improving the lives of those with Alzheimer's Disease and their families and caregivers.

I thank you for the opportunity to provide input and look forward to hearing from you regarding my comments.

Sincerely,



Brian M. Duke
Secretary