January 18, 2012

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

Dear Dr Lamont and The Advisory Council on Alzheimer's Research, Care, and Services:

The following is a summary of the comments I provided on January 17, 2012 during the Public Input session of the Advisory Council on Alzheimer's Research, Care, and Services meeting. In addition, I have also included other comments based on discussions heard over the 17-18 Jan meeting.

As a sibling, caregiver, registered nurse, health care executive, and advocate to improve the care and support for individuals with intellectual developmental disabilities and Alzheimer's disease (AD) and their families and caregivers, I sincerely appreciate the opportunity to provide the following comments for the Council's consideration and action. The work and commitment of the Health and Human Services staff and the Advisory Council in developing a national plan to address Alzheimer's disease is to be commended.

My youngest brother, Carl Srsic, who was born with Down's syndrome, died from the advanced stages and complications of Alzheimer's disease at the age of 50 years old on October 13, 2010. My experiences in caring and coordinating my brother's care first with my parents and then his group home staff, parallel the issues identified by the thousands of family members and caregivers who provided input for the National Alzheimer's Plan. The issues however, are compounded for individuals with intellectual developmental disabilities. Therefore, the National Plan must address the needs of these individuals. I will address my comments in general and within the framework of the national Alzheimer's plan framework presented on 17 Jan 2012.

- In general:
    - Funding must be prioritized to address the devastating and growing impact of Alzheimer's disease particular in the baby boomer's general and for caregivers, particularly family caregivers. In the past, this nation prioritized funding to combat heart disease, diabetes, cancer, and HIV/AIDs. The time is now to prioritize funding to combat Alzheimer's disease. We cannot afford to delay.
    - I also encourage a balance between research and building evidence-based prevention, slowed progression, and ultimately effective treatment and cure for Alzheimer's disease with meeting the current day to day needs and support of individuals, families, and caregivers.
    - Fragmentation and 'silos' must be eliminated so that collaboration and coordination can provide the synergy needed to address effective action and outcomes.

  - One size does not fit all in terms of prevention, screening, treatment, and ultimately a cure. For instance, individuals with intellectual disabilities and Alzheimer's have confounding cognitive and other medical conditions that can make screening and assessment challenging and they react differently to medications and other treatment modalities. Therefore, individuals with intellectual developmental disabilities must be considered as a special population affected by Alzheimer's disease.
  - I applaud and encourage applications to the Center for Medicare and Medicaid Innovation (CMMI) to develop new guidelines and creative care management and service support programs.
  - At some point, Alzheimer's disease must be incorporated into the National Quality Strategy. Much discussion occurred about the need for data and metrics - process and outcome success measures must be developed to measure success. In addition, as CMS developed evidence-based core measures for heart failure, community acquired pneumonia, etc. , so too, there should be core measures developed for care management and service support for Alzheimer's disease.
  - The Center to Advance Palliative Care should be consulted to collaborate on palliative care guidelines for individuals with AD.

- Goal 1 - Prevent and Effectively Treat AD by 2025: Individuals with intellectual developmental disabilities (IDD) must be included as a population within and specific to all the goals of the National Alzheimer's Plan. Research priorities must include studies specifically focused on individuals with IDD as the prevention, screening, and treatment methods may not be applicable as in the general population. To even gather an adequate sample of individuals for potential research study samples, more effective means of identifying individuals with IDD must be developed and databases established locally, regionally, and nationally. Individuals with IDD are not a socioeconomic or race or ethnic population that is commonly associated with health care disparity groups; they are a special population in and of themselves that must be recognized and identified as such in the national plan.

- Goal 2 – Enhance Care Quality and Efficiency: While there are health care providers who are limited in their knowledge and plan of care about AD in the general population, there are even less providers who have the knowledge and skill to manage individuals with both IDD and AD. Finding a qualified, competent, and compassionate provider to guide and coordinate care management is difficult, for individuals who even know and work in the health care system. Current centers for the aging may not have the knowledge and skill for managing individuals with IDD and AD and centers for those with developmental disabilities many times do not have the knowledge and skill for managing individuals in various stages of aging and AD. Support to family members and caregivers is crucial – as these individuals have had to deal with multiple challenges in caring for a son, daughter, or sibling from birth and then that caregiving becomes even more overwhelming when AD develops. Evidence-based clinical practice guidelines must address the multiple needs of individuals with IDD and AD. Aging in place, such as in group home settings with augmented services and supports must be explored as a cost –effective alternative to nursing homes. Consistency, familiarity, and minimizing transition are key to the overall well-being for individuals with IDD and those elements of care are even more relevant for an individual with IDD and AD. With the advent of ACOs and medical homes, models of care coordination management and transition within types of care should be developed to include individuals with IDD and AD. These new approaches to care center on the patient in a truly more holistic approach to care. As in many approaches used for management of other diseases, such as multidisciplinary care coordination or the use of patient navigators or specific case managers, so too should such strategies be considered for individuals with AD.

- <u>Goal 3 – Expand Patient and Family Support:</u> Many individuals with disabilities still live at home with aging parents who also may be developing or have Alzheimer's disease. Families may not be within any support system to specifically help them manage and cope with AD in addition to IDD. They need information about AD, resources, safety, coordination of care, respite care, end of life care, etc. Community supports and easy to find information about resources must be developed and/or incorporated into services for families. It is not just a matter of disseminating information – reaching individuals, helping them know how to access resources from a central location rather than fragmented searching is critical.

- <u>Goal 4 – Enhance Public Awareness and Engagement:</u> Parents of individuals with IDD need to be alerted to potential early onset Alzheimer's. Caregivers, particularly those in group homes, day programs, etc must have required training in not only IDD but also aging and AD care management. The state Developmental Disability Services must also incorporate timely resources to support individuals, families, and caregivers specifically addressing the needs of those with IDD and AD. The need for services (e.g., increased staffing, environmental safety measures, etc) must be available when there are acute needs and not delay care and services due to bureaucratic processes. Collaboration among agencies and services must develop synergy and cost-effective strategies rather than having 'silo' services that are limited, fragment, or overlap.

- <u>Goal 5 – Improve Data to Track Progress:</u> Data about individuals with IDD is often lacking and not uniformly centralized which compounds accurate data collection for those with IDD and AD. Tracking for high 'at-risk' populations with IDD and progress in care management is crucial for effective and efficient resourcing.

While I realize there are many competing priorities and limited funding, the Plan must address the needs of all people with Alzheimer's disease/ related dementias. Our nation made it a health priority to address other major diseases in the past such as cardiac/stroke, diabetes, cancer, and HIV/AIDS with remarkable advances. Action to prevent and treat Alzheimer's disease must be now. Thank you for the opportunity to provide comments for your consideration into the National Alzheimer's Plan.

Sincerely,

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