

March 27, 2012

Advisory Council on Alzheimer's Research, Care, and Services  
c/o 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:

The National Association of State Directors of Developmental Disabilities Services (NASDDDS) is a professional organization comprising the directors of state agencies serving individuals with intellectual and developmental disabilities (IDD) in all 50 states plus the District of Columbia. The Association assists state IDD agency officials respond to emerging state and federal policy issues that affect their efforts to ensure the delivery of services and supports to individuals with IDD in their respective states and jurisdictions. Association staff provide member state agencies with extensive technical assistance on a wide range of system and program related issues, in-depth analyses of Medicaid and other federal statutory and regulatory policies affecting people with IDD, and cutting edge information on state-of-the-art programs and service delivery practices. NASDDDS collaborates closely with the American Academy of Developmental Medicine and Dentistry (AADMD) and the National Task Group on Intellectual Disabilities and Dementia Practices (NTG) to improve health and healthcare of people with IDD nationwide.

State IDD service delivery systems are large with total annual state and federal expenditures in excess of \$53 billion. Data reported by the University of Minnesota Research and Training Center on Community Living reveal that over 1,000,000 individuals with intellectual and developmental disabilities, including autism, cerebral palsy and related conditions received publicly financed residential supports through Medicaid and other state/federally funded programs. The majority of these individuals, approximately 57% live with their families, receiving the supports that they need at home, at work and in a variety of in day programs in the community. Of the

approximately 440,000 remaining individuals, about 72% live in local group homes or other neighborhood settings of less than 6 persons. Fewer than 28% reside in large state and privately operated institutions.

The purpose of this correspondence is to provide feedback to the Advisory Council on Alzheimer's Research, Care, and Services regarding the *Draft National Plan To Address Alzheimer's Disease*. We are pleased that the Draft Plan specifically identifies people with intellectual disabilities in Strategy 2.H as a group of Americans who are at exceptionally high risk for contracting Alzheimer's disease. Including people with IDD in the report recognizes their particular vulnerability to these conditions and suggests the challenges that publicly financed systems of support will need to meet in the very near future. We believe, however, that the report does not go far enough in addressing the specific issues identified by NASDDDS member state agencies and articulated by a national report prepared by NTG entitled, *My Thinker's Not Working: A National Strategy for Enabling Adults with Intellectual Disabilities Affected by Dementia to Remain in Their Community and Receive Quality Supports*, and the related *National Dementia and Intellectual Disabilities Action Plan*. Our specific concerns and suggestions include the following:

***Issue 1. The relationship between the presence of Down Syndrome and the risk of Alzheimer's disease is not given proper focus in research and practice recommendations.***

Goal 1 of the Draft Plan highlights research but does not reference the need for targeted examination and analysis of the etiology and course of dementia for people with Down syndrome, a group of individuals expressing a particular high risk for Alzheimer's disease. Sustained research in this area is clearly warranted to better understand the course and treatment of the disease and to inform and hopefully improve public policy in this area. We believe that continued support of research concerning and involving people with Down syndrome will not only potentially benefit the general population, but will also benefit the thousands of adults aging with Down syndrome and who are at high risk for and are affected by early onset dementia. Like individuals with genetic mutations resulting in early onset Alzheimer's disease, people with Down syndrome demonstrate early onset of symptoms and more research into this phenomenon is necessary. It should be emphasized that focused research into a relatively homogeneous population such as individuals with Down syndrome and Alzheimer's dementia can provide important clues when generalizing to the larger population of people with Alzheimer's but absent Down syndrome.

**Recommendation.** NASDDDS strongly recommends that Goal 1 of the Draft Plan emphasize the need for focused basic and treatment research addressing the conditions and support needs of people with Down syndrome at high risk of Alzheimer's disease.

**Issue 2. Addressing the specialized programmatic and care challenges faced by people with intellectual disabilities in Goal 2.**

NASDDDS agrees with the observations and recommendations of the NTG that the Council revise the Draft Plan to recognize the importance of the special programmatic and care challenges faced by people with intellectual disabilities in Goal 2, under Strategy 2.H (Action 2.H.1). And that the discussion of the special circumstances of adults with Down syndrome and other intellectual disabilities be mentioned earlier on in this section to make it clear that the strategies included under Goal 2 apply equally to this population. It is important that the Draft Plan recognize that Alzheimer's disease impacts adults with lifelong intellectual disabilities in the same manner as it does other people, but sometimes has a more profound effect due to particular risk factors - including genetics, neurological injury, and deprivation. Furthermore, we believe that it is important that any NAPA-related task forces created (as cited in the Draft Plan) not only address improvements of care for this specific population, but also, are designed to increase awareness, improve screening and early recognition, and conduct population specific clinical trials involving adults with intellectual disabilities.

**Recommendations.** NASDDDS recommends that:

- The Draft Plan and any resulting guidelines produced include reference to the special circumstances and challenges involved in assessing and determining the presence of dementia in adults with Down syndrome and other intellectual disabilities, and that this acknowledgement be placed earlier in the second section so that it is clear that the Strategies included under Goal 2 apply equally to this population.
- The Draft Plan reference under Strategy 2.B the need for specialized screening instruments that are designed and normed for use with adults with intellectual disabilities. The administrative screening tool currently under development by the NTG will have specific application to people with intellectual disabilities who otherwise may not be adequately or successfully screened by tools in existence and applicable to the general population that are not normed for use by people with cognitive disabilities.

- The Draft Plan reference under Strategy 2.E the need for long-term ‘dementia capable’ services and supports to be offered in small community settings rather than institutional facilities, consistent with the 2002 Madrid International Plan of Action on Ageing. Research in the intellectual disabilities services area has shown this small group home model to be particularly effective in providing quality care for those adults with intellectual disabilities affected by dementia.

***Issue 3. Need to address the special support needs of aging caregivers providing long-term in-home care of adults with intellectual disabilities.***

As noted above, the majority, over 57%, of all people with IDD receiving publicly financed support reside in the home of a family member. The age of family caregivers, like the average age of the U.S. population in general is growing older however, and these caregivers are now themselves needing support. Tragically, the availability of services has not kept pace with the demand for support. Plummeting state budgets and reductions in Medicaid and state-funded supports have expanded waiting lists and placed a greater burden on families with relatives in need of personal care and assistance. The ability to provide quality care to people with IDD who are aging both now and in the future depends on the ability of state and federal service delivery systems to support the capacity of families to furnish needed long term assistance.

The majority of adults with Down Syndrome and other intellectual disabilities need assistance in decision making and consent. Adults with intellectual disabilities are not the ones planning for their own long-term care needs and consideration must be given to enabling parents or other family members, providing primary care, to undertake productive long-term care planning.

***Recommendations.*** NASDDDS strongly recommends that the Draft Plan address the special challenges faced by life-long caregivers of some persons with intellectual disabilities, (see Strategy 3.C.1)

***Issue 4. Need to expand public education activities to include individuals with IDD and their families.***

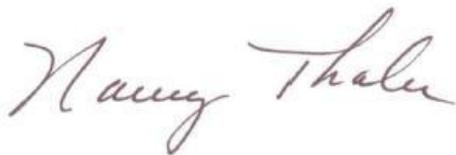
NASDDDS believes that Goal 4 be expanded to ensure that the needs of family caregivers and people with intellectual disabilities are specifically addressed by public education campaigns and to improve coordination efforts by government and the voluntary sector. State IDD agencies are instrumental in organizing, managing and delivering services and supports to people with intellectual and developmental disabilities and their families. It is essential that these state agencies be included in

public education efforts and that education and training for health professions with respect to aging individuals with dementia – especially of the Alzheimer’s type – should be included as part of primary health care education. Aggressive education campaigns addressing the nature of intellectual disabilities and the needs of individuals with IDD should be targeted to universities, hospitals, emergency rooms and general medical specialists.

**Recommendation.** NASDDDS recommends that the Draft Plan include consideration of additional and targeted efforts related to public and medical education so that these efforts have a functional effect on helping people with intellectual disabilities affected by dementia.

NASDDDS member state agencies furnish a wide array of publicly financed services and supports to people with intellectual and developmental disabilities. As the age of the population increases, state service delivery systems are working to develop effective strategies for meeting the needs of people with IDD in a way that allows them to age in place and remain a part of their families and communities. The National Plan to Address Alzheimer’s is an important step forward. We appreciate the work and recommendations of the Advisory Council, not only for the population in general, but particularly for persons with intellectual and developmental disabilities who are especially vulnerable to this condition. NASDDDS gratefully acknowledges the work on this issue by the National Task Group on Intellectual Disabilities and Dementia Practices and their assistance in forming the recommendations of this Association.

Sincerely,

A handwritten signature in cursive script that reads "Nancy Thaler". The ink is dark and the signature is fluid and legible.

Nancy Thaler, Executive Director