



National Task Group on Intellectual  
Disabilities and Dementia Practices

March 22, 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:

We, Drs. Matthew P. Janicki and Seth M. Keller, are the co-chairs of the National Task Group on Intellectual Disabilities and Dementia Practices. On behalf of the National Task Group, we wish to make our thoughts and recommendations available to the Advisory Council with respect to the Draft National Plan to Address Alzheimer's Disease. To complement the National Alzheimer's Plan Act process, the National Task Group was convened and produced a report titled, "**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**", which was designed, in part, to develop and enhance community care options for aging adults with intellectual and developmental disabilities. The National Task Group also issued the "**National Dementia and Intellectual Disabilities Action Plan**" as part of this report. The National Task Group issued this Action Plan in January 2012 in the hopes that it would promote better understanding of how adults with intellectual and developmental disabilities age and how dementia, in particular, affects them.

We note that the issues we identified in the National Task Group's report, which was submitted to the Advisory Council at its January 17th meeting, has many parallels with those raised in the Draft Plan. Our report summarized and addressed some of the challenges facing the nation due to the increasing rate of dementia found in older people with Down syndrome and other intellectual disabilities. Our report also noted that older adults with intellectual and developmental disabilities have special needs that at times require different actions than those provided for people in the general population. Alzheimer's disease affects everyone; but not everyone can be treated the same way when they are affected by this disease.

We have submitted these comments in order to clarify and provide feedback to the Advisory Council regarding its Draft Plan. First, we would like to note that the National Task Group is pleased that the Draft Plan contains mention of intellectual disabilities (in Strategy 2.H) as this group of Americans is composed of a significant number of individuals who are at exceptionally high risk for Alzheimer's disease. We also would like the Draft Plan to contain at least mention of some general issues that we

have raised in our Report and also have more elaboration on some key specific issues affecting people with intellectual disabilities.

Given this, we'd like to offer the following comments:

**1. Missing mention of the significance of Down syndrome in Alzheimer's research**

We are concerned that the text under Goal 1, neglects mention of the research with respect to the needs of people with Down syndrome, a group of individuals expressing a particular high risk for Alzheimer's disease. Certainly sustained research is warranted to better understand the etiology and course of dementia in this group of individuals. Additionally, notwithstanding the competing beliefs of whether research involving people with Down syndrome will benefit general research into the nature and cause of Alzheimer's disease, we feel that continued support of research concerning and involving people with Down syndrome will not only potentially benefit the general population, but will certainly 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, individuals with Down syndrome also demonstrate early onset of symptoms and more research into this phenomenon is necessary. We would like to emphasize 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.

***Thus, we strongly recommend that the Draft Plan include mention that given the high risk of Alzheimer's disease among adults with Down syndrome, there is the continued need for focused basic and treatment research involving people with Down syndrome – and this should be included under Goal 1.***

**2. Mention of the special programmatic and care challenges faced by people with intellectual disabilities**

We note with satisfaction that the Advisory Council's Draft Plan recognized the importance of the special programmatic and care challenges faced by people with intellectual disabilities and included mention of this in Goal 2, under Strategy 2.H (Action 2.H.1). However, we would like to recommend that mention of the special circumstances of adults with Down syndrome and other intellectual disabilities receive mention earlier in this section, so that it is clear that the Strategies included under Goal 2 apply equally to this population. We would like to see the Draft Plan recognize that Alzheimer's disease mostly impacts adults with lifelong intellectual disabilities in the same ways as it does other people, but sometimes has a more profound effect due to particular risk factors - including genetics, neurological injury, and deprivation. Further, under the Strategies noted under Goal 2, it is important to propose that any NAPA-related task forces created (as cited in the Draft Plan) not only look into improvements of care for this

specific population, but also, and perhaps more importantly, increase awareness, improve screening and early recognition, and conduct population specific clinical trials involving adults with intellectual disabilities.

***Thus, we strongly recommend that the Draft Plan include mention of the special circumstances of adults with Down syndrome and other intellectual disabilities earlier in the second section, so that it is clear that the Strategies included under Goal 2 apply equally to this population.***

Under Strategy 2.B, we would also like to recommend that mention be made of the challenges of carrying out effective screening and diagnoses for dementia among most individuals with intellectual disabilities due to their inherently varying abilities and cognitive functions. When nationally applicable instrumentation is developed or recommended it would be highly beneficial to make mention in the Draft Plan of the need for specialized screening instruments for use with adults with intellectual disabilities. The National Task Group is currently undertaking the development of such an administrative screen, which would 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. Recognition of this special need and work by the National Task Group would go far to gain acceptance of a regularized screen applicable to adults with intellectual disabilities.

We also would recommend – adding text under Strategy 2.E – that the notion that community care, as noted in the 2002 Madrid International Plan of Action on Ageing, be the paramount means of long-term ‘dementia capable’ care delivery. We note specifically the growing evidence-based research that is supporting the inclusion of small group homes – as a viable assisted living model – and their role as a potentially powerful alternative care setting for people with dementia, and in particular those with lifelong disabilities. Research in the intellectual disabilities services area has shown this model to be particularly effective in providing quality care for those adults with intellectual disabilities affected by dementia.

***Thus, we strongly recommend that the Draft Plan include consideration of the special challenges in assessing and determining the presence of dementia in adults with certain intellectual disabilities and that any national guidelines produced contain this consideration.***

***We also strongly recommend the consideration of the use of small group homes for the community ‘dementia capable’ care of adults with intellectual disabilities affected by dementia as backed by evidence-based research in the intellectual disabilities field.***

### **3. Mention of the special support needs of aging caregivers providing long-term in-home care of adults with intellectual disabilities**

As many adults with intellectual disabilities and in particular those with Down syndrome remain in their family homes living with their parents or other family caregivers as they grow older, it is

crucial that under Goal 3 inclusion of the challenges faced by these caregivers – when providing care-at-home to their relatives with intellectual disabilities and dementia – be given due mention. These ‘life-long caregivers’ warrant special attention in the Draft Plan as they are providing an important and crucial bulwark against costly institutionalization and oft-times inappropriate admissions to long-term care facilities. They are also often vexed by emerging symptoms of dementia in their adult children who have successfully mastered many general activities of daily living and now are manifesting decline. Special mention to the situations of these lifelong caregivers should be made in the Draft Plan. In this context, the National Task Group also recommends that Strategy 3.C.1. be amended to recognize that in many settings concerned with adults with intellectual disabilities, decisions are often made by proxy (and not by ‘middle-aged adults’) and that adults with intellectual disabilities are not the ones planning for their own long-term care needs. Thus, consideration should be given to enabling parents or other family members, providing primary care, to undertake productive long-term care planning.

***Thus, we strongly recommend that the Draft Plan include consideration of the special challenges faced by life-long caregivers of some persons with intellectual disabilities.***

#### **4. Mention of the enhanced public education resources related to intellectual disabilities**

Under Goal 4, we strongly recommend including the needs of family caregivers and people with intellectual disabilities under public education campaigns and that the greater coordination efforts by government and the voluntary sector should get mention. As the state developmental disabilities authorities (agencies) are instrumental in helping organize state functions and programs with respect to intellectual and developmental disabilities it would be extremely beneficial to include these entities (and state developmental disabilities planning councils) in any public education efforts at the state level. Also, 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. As there are health care disparities, an aggressive education campaign should involve universities, hospitals, emergency rooms and general medical specialists as it relates to cognitive and functional disability and its detrimental effect on caregivers and quality of life of the individuals with intellectual and developmental disabilities.

***Thus, we strongly recommend 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.***

The National Task Group recognizes that dementia has a devastating impact on all people – including people with an intellectual disability and their friends, families and the staff who may be

involved with them as advocates and caregivers. Given this, we are very pleased that the Advisory Council recognized the import of the special challenges faced by people with intellectual disabilities and included mention of this group in Strategy 2.H. We would hope for those adults with intellectual disabilities currently affected by dementia and those in the next generation who may be affected (as the timeline for the NAPA process encompasses the next 13 years) that the Advisory Council will recognize other areas of inclusion of the specific issues affecting individuals with intellectual disabilities within the Draft Plan and accept our recommendations for additional areas of mention and focus.

We trust the our comments and recommendations will be accepted in the spirit in which they are provided – as the collective concerns and thoughts of a significant body of professionals, scientists, administrators, family caregivers and advocates, and persons personally affected by dementia – who are represented by the National Task Group on Intellectual Disabilities and Dementia Practices.

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