

Public Testimony
NAPA Advisory Council Teleconference Meeting
March 14, 2012

On January 17, 2012 I addressed the Advisory Council about the need to include people with Down syndrome in all aspects of dementia related research, including clinical trials. I come before you today with great concern that any reference to Down syndrome, a genetic condition known to pose a considerable risk with respect to dementia, has been obviously omitted from the current Draft National Plan, particularly in Goal 1. This group of individuals deserves to be specifically identified in the National Plan. A vague reference to their existence embedded in the 21st page of the current Draft is grossly understated and should be remedied in future Draft National Plans.

Support for research is essential to better understand the disease process, the potential for early identification and the possibility for improved treatment practices. This research may not only benefit individuals with Down syndrome but the general population as well. The Research Summit in May 2012 referred to in the Draft National Plan should be inclusive of those involved in the study of Down syndrome. I strongly urge you to give serious consideration to the letter submitted by the nationally recognized group of researchers and clinicians read today by Dr. Peterson. Inclusion will help to reduce the potential for greater medical disparities so often faced by this group of individuals. I urge you to act responsibly in their regard. Though some members of the Advisory Council may consider Alzheimer's disease within the Down syndrome community as a different disease process, I can assure you, as a family

member, that it looks the same, acts the same and has the same tragic ending, more often at a much younger age.

Families of those with Down syndrome and other intellectual disabilities deserve more than inattention by the Advisory Council and the Draft National Plan. Care commitments for adults with late life disability attributed to the onset of dementia can differ from the care commitments required for those with lifelong disabilities who then develop dementia. Certainly, these distinctions warrant mention in the Plan. The plan should include specific reference to the need for special supports for family caregivers now dually challenged by lifetime care sacrifices and the emerging additional needs of an adult child with an intellectual disability affected by dementia. As individuals with intellectual disabilities live longer and may be predisposed to the development of Alzheimer's disease, the role of caregiving is now, more than ever, assumed by siblings of the individual. These family members potentially face the challenges of not only the care needs of their adult sibling with an intellectual disability and dementia but also their parents who may be facing the same issues related to decline. This overwhelming dual role is under recognized and most worthy of notation in the National Plan.

The current draft plan makes no mention of individuals with intellectual disabilities other than the reference in section 2H. Section 2.H.1 recommends the establishment of a future task group to address the issues related to "racial and ethnic minorities and people with intellectual disabilities". It is important to clarify that people with intellectual disabilities tend to develop Alzheimer's disease at the same rate as the general public. People with Down syndrome have a known genetic mutation that results in early onset and a much higher incidence. Reference to the needs of those with Down

syndrome should be specifically embedded in all sections of any finalized document, not deferred to some future taskforce.

My great concern is that little or no attention will be paid to the populations disproportionately affected by Alzheimer's disease after the National Plan is finalized and disseminated. The potential for this to occur can easily become reality as the Affordable Care Act is brought into question and the possibility for a change in HSS leadership exists in an election year. I urge both federal and non-federal members of the Advisory Council to do the hard work required to address the needs of **all** individuals that face the debilitating ravages of Alzheimer's disease. Be thorough and inclusive in your plan and do not yield to the pressure to produce a document that cannot be defined as such.

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