

My name is Mary Hogan. I am one of 8 older siblings of the late Bill Hogan. I submit this request to you today, December 30, 2011, in honor of my brother and hopefully for other families who are facing the challenges related to Down syndrome and Alzheimer's disease.

In January 2006, at the age of 45, Bill was diagnosed with dementia, Alzheimer's type. Over the course of the next 4 years his journey became far more complex. He experienced a very rapid deterioration during the last 13 months of his life and died of chronic aspiration pneumonia on February 25, 2010, two months shy of his 50th birthday. My brother was a member of a subgroup of individuals with Down syndrome that develop AD early, decline rapidly and face a premature death. This has been a great loss for our family and Bill's community at large.

Extraordinary efforts to advocate for Bill were required during the final years of his life. Active advocacy was sometimes lonely and often a frustrating process. Obstacles for advocacy increased significantly after Bill's diagnosis of Alzheimer's disease. Our experience is most likely replicated in other families as well.

I write to you today to request the following considerations for the National Alzheimer Project Act Advisory Council on Alzheimer's Research, Care and Services:

1. People with Intellectual Disabilities, and their caregivers, should be included in future planning with the **same access** to appropriate care and support as individuals in the general population. The growing incidence of Alzheimer's disease will be mirrored in the ID population, most especially with individuals with DS who have a far greater likelihood of developing this insidious disease by age 60. Inclusion in any future planning will ensure that this often marginalized group will have access to appropriate care across their lifetime.
2. Most often individuals with ID, including those with DS, are cared for by their families well into their adult lives, often by aging family members. Recognition of the need to enhance support for this group of caregivers will be critical in the future. I ask that NAPA Advisory Council recognize the need for improved dementia care for individuals with intellectual disabilities in conjunction with increased support for family members as caregivers and advocates.
3. Since individuals with Down syndrome are at increased risk for developing Alzheimer's disease, families, caregivers, agencies, medical providers and researchers will need to work together to maintain their "quality of life". Families facing DS/AD need access to information about both disease process and advocacy. I suggest a review of what has been produced by Alzheimer's Australia and the Australian government as a sample of what might be provided.
4. A consortium of providers (i.e. Alzheimer's Association, Health and Human Services, the Administration on Developmental Disabilities or Administration on Aging, UCEDD, families, and advocacy organizations, etc.) should disseminate best practice guidelines related to adults with intellectual disabilities and dementia. This will include training and

education for care providers across a multitude of settings. I suggest careful consideration of the forthcoming document produced by the National Task Group on Intellectual Disabilities and Dementia Practices.

I am hopeful that in this day of limited funding the needs of **all** people with Alzheimer's disease will be addressed creatively and with the greatest of compassion and that the National Alzheimer Project Act Advisory Council will provide leadership and direction for the future.

I thank you for the considering this request.

Mary Hogan
Maine