



Advisory Council on Alzheimer's Research, Care and Services  
c/o Helen Lamont, PhD  
HHS Office of the Assistant Secretary for Planning and Evaluation  
Room 424E, Humphrey Building  
200 Independence Avenue, SW  
Washington, DC 20201  
[napa@hhs.gov](mailto:napa@hhs.gov)

Dear Dr. Lamont:

On behalf of the National Down Syndrome Society (NDSS), I am writing to urge the Advisory Council on Alzheimer's Research, Care, and Services to ensure that the population of people with Down syndrome (Ds) is specifically identified in the "National Plan" to address Alzheimer's disease and related dementias (ADRD). The NDSS is a nonprofit organization representing the more than 400,000 Americans with Down syndrome and over 350 affiliates worldwide. The mission of NDSS is to be the national advocate for the value, acceptance and inclusion of people with Down syndrome.

NDSS would like to stress the important scientific relationship between Ds and ADRD. Research indicates that virtually all individuals with Down syndrome exhibit the characteristic neuropathology of Alzheimer's disease by age 40, and 25-75% or more of individuals with Down syndrome over age 40 show the signs and symptoms of ADRD and the percentage increases with age. The incidence of ADRD in people with Down syndrome is estimated to be three to five times greater than that of the general population, which according to the Alzheimer's Association is now estimated to be 5.4 million people, 1 in 8 individuals, living with Alzheimer's. In the past several years, important progress has been made by scientists focused on understanding the connection between Ds and ADRD, yet much more research is needed. For many years, the National Institutes of Health (NIH) has invested in programs and studies. Some examples include: a 30-year study on aging and dementia in adults with Ds, a current grant focused on aging of the frontal structures of the brain (including dementia), developing imaging techniques to predict cognitive decline in adults with Ds, and a natural history study on the amyloid deposits in adults with Ds.

A more integral and specific inclusion of Ds in the overall ADRD research efforts, both fundamental and translational, would significantly contribute to progress more broadly and rapidly. **To that end, we would respectfully request that a representative from the Ds research community be added to the Advisory Council on Alzheimer's Research, Care, and Services and that the National Plan be amended to incorporate Ds in the research section of the National Plan but also in sections related to public awareness, education and care giver support.**

Individuals with Ds and their families deserve to have the need for research and population specific clinical trials identified specifically and clearly as necessary actions in the final ADRD National Plan as well as the care challenges they face that require increased awareness, early recognition and supports.

Thank you for the opportunity to provide input on this important National Plan. Please do not hesitate to contact me with any further questions.

Sincerely,

Madeleine Will  
Vice President, Public Policy  
National Down Syndrome Society  
[mwill@ndss.org](mailto:mwill@ndss.org)  
202.364.2296