



## Inclusion of the Down Syndrome Community in Alzheimer's Initiatives

### Legislative Request

Please support the inclusion of the Down syndrome community in Alzheimer's disease initiatives by:

- Cosponsoring the **NAPA Reauthorization Act (S.133/H.R. 619)**, as amended by the Senate HELP committee, to build upon efforts to address Alzheimer's disease and related dementia through the coordination of federal planning and programs
- Supporting efforts to increase access to diagnostic care and treatment
- Supporting efforts to better support caregivers of individuals with Down syndrome and Alzheimer's disease by providing training and respite care

### Background

People with Down syndrome are uniquely situated in the Alzheimer's landscape because they have an extra copy of chromosome 21. The 21st chromosome carries the amyloid precursor protein (APP) gene, which is strongly associated with the formation of amyloid peptides and plaques, a hallmark of Alzheimer's disease. As a result, individuals with Down syndrome have an elevated lifetime risk for developing Alzheimer's disease, with the onset of symptoms coming earlier and progressing faster than in the general population. In fact, Alzheimer's disease is the number one cause of death for individuals with Down syndrome.

Unfortunately, Alzheimer's disease is commonly misdiagnosed in patients with Down syndrome due to some observable traits that are common to both conditions – an issue called diagnostic overshadowing. This issue, combined with a general lack of education about Down syndrome provided to our nation's medical professionals, makes it likely that individuals with Down syndrome will be left out of clinical trials for drugs to treat or prevent Alzheimer's disease.

Older Americans who develop Alzheimer's disease frequently receive care from their children, whereas people with Down syndrome are typically provided care by their parents. For parent caregivers, this reality can cause uncertainty of who will care for their children as they themselves also age. Many memory or long-term care centers will not accept individuals with Down syndrome due to the age of the person with Down syndrome and their Alzheimer's diagnosis. Siblings will frequently step in to provide care when their parents are no longer able, but this transition often necessitates a move to a new state and can result in the loss of vital government benefits such as those for home and community-based services.

**For more information, please contact Anna Fedewa, National Down Syndrome Society Manager of Federal Government Relations, at [afedewa@ndss.org](mailto:afedewa@ndss.org)**



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### **Policy Considerations**

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#### **NAPA Reauthorization Act (S.133/H.R. 619)**

Introduced by Representatives Paul Tonko (D – NY), Christopher Smith (R – NJ), and Maxine Waters (D – CA) in the House and Senators Susan Collins (R – ME), Mark Warner (D – VA), Shelley Moore Capito (R – WV), Edward Markey (D – MA), Jerry Moran (R – KS), Robert Menendez (D – NJ), Lisa Murkowski (R – AK), and Debbie Stabenow (D – MI) in the Senate, the NAPA Reauthorization Act would build upon efforts to address Alzheimer's disease and related dementia through the coordination of federal planning and programs. On June 15th, 2023, the Senate Health, Education, Labor, and Pensions (HELP) Committee passed the bill out of committee with two amendments that benefit the Down syndrome community. NDSS strongly supports these amendments and urges the full Senate and the House to move this legislation forward as amended by the Senate HELP Committee.

#### **Increasing Access to Diagnostic Care and Treatment**

Congress must ensure that insurance coverage, especially at the Centers for Medicare & Medicaid Services, provides meaningful access to diagnostic care and treatment for individuals with Down syndrome, on par with care received by members of the general public. Since people with Down syndrome often show symptoms of Alzheimer's-related dementia earlier than others, threshold ages must be lowered as necessary, and key government healthcare benefits must be portable across state lines.

#### **Supporting Caregivers**

Congress must ensure that families have evidence-based training to provide high-quality care to their loved ones, community-based supports to allow them to care for themselves, and information necessary to prepare adequately for the financial impact of providing care. Congress should also consider ways in which memory care and long-term care centers can be more adequately supported in providing care to populations who experience Alzheimer's disease and related dementia at an earlier age and those with both Down syndrome and Alzheimer's disease.

**For more information, please contact Anna Fedewa, National Down Syndrome Society Manager of Federal Government Relations, at [afedewa@ndss.org](mailto:afedewa@ndss.org)**