



October 31, 2023

I have the fortunate honor of representing the National Down Syndrome Society, as their Director of Advocacy and Policy. I would like to respectfully express my sincere disappointment for the ongoing absence of representation from the Down syndrome community on the NAPA Advisory Council. This is further reflected in the 2023 recommendations, where Down syndrome is seemingly listed tangentially given the alarming statistic that over 90% of individuals with Down Syndrome develop Alzheimer's disease. It is vital that this community be given a voice at the table to address the unique challenges they face, which in turn can add to the ongoing and needed growing body of Alzheimer's research. In the following comments, I will outline the pressing need for such representation and offer recommendations on how to bridge this gap.

The Down syndrome community's relationship with Alzheimer's disease is an urgent concern that cannot be overlooked. Not only do individuals with Down syndrome have a significantly higher chance of developing Alzheimer's disease than the general population, but Alzheimer's has also become the leading cause of death for adults within this community. These disturbing statistics underscore the dire need for the Advisory Council to not only keep Down syndrome top of mind in its annual plan recommendations as mandated by the National Alzheimer's Project Act, but also to include someone from the community on the Council.

To address this issue comprehensively, I strongly reiterate past comments of my colleagues and urge the Advisory Council to establish a dedicated subcommittee. This subcommittee would focus on improving diagnostic and clinical support for adults with Down syndrome and intellectual and developmental disabilities, aiming to provide targeted solutions that are intentionally inclusive for individuals who cannot access these programs without modifications. Until the Advisory committee has representation from the Down syndrome community, the subcommittee would establish a process to integrate thinking and consideration of the impact of Alzheimer's disease on the Down syndrome community for the Advisory Council.

The subcommittee's mission should encompass several key areas we highlighted in our letter to the Advisory Committee back in 2021:

**Access to Adequate Clinical Care:** We must prioritize the education of clinicians, both students and practitioners, to ensure they have the necessary knowledge to provide quality care to individuals with Down Syndrome and other intellectual and developmental disabilities. This includes crafting training curricula and developing resources for technical assistance.

**Increased Support for Research:** Research specifically aimed at understanding the intersection between Down Syndrome and Alzheimer's disease is essential. A dedicated focus on this area will help in advancing knowledge and developing effective treatments.



Access to New Alzheimer's Treatments: Collaboration with the Centers for Medicare & Medicaid Services (CMS) is crucial to ensure that new Alzheimer's therapies are affordable and accessible to individuals with Down Syndrome.

Inclusion in Clinical Trials: Promoting the inclusion of individuals with Down Syndrome in clinical trials is vital for research that seeks to develop Alzheimer's treatments and therapies. This can be achieved through regulatory or subregulatory guidance.

Access to Long-Term Services and Supports: It is imperative that healthcare providers in congregate care settings are trained in memory care for individuals with Down Syndrome. Conversely, providers in dedicated LTSS care settings must also be equipped to care for individuals with Down Syndrome and other intellectual and developmental disabilities.

Dr. Rafii highlighted the significant risk individuals with Down syndrome face regarding Alzheimer's disease and the biological reasons for it. Because of these factors, inclusion in clinical trials and equitable access to treatments are equally essential.

We believe that addressing these concerns necessitates the creation of a special subcommittee within the NAPA Advisory Council, focusing on intellectual and developmental disabilities, including Down Syndrome. Such a subcommittee would not only serve as a beacon of hope for the Down Syndrome community, providing them with the advocacy and support they deserve, but also play a critical role in research progress on Alzheimer's.

In conclusion, I urge the NAPA Advisory Council to act swiftly and decisively to address the urgent needs of the Down syndrome community regarding Alzheimer's disease. The time for research, equity, and improved access to care is now. Let us work together to ensure that no individual is left behind, that everyone has a fair chance at a healthy and fulfilling life, and that Alzheimer's disease in the Down syndrome community is a challenge we are determined to conquer together. As a starting point, I would encourage you to consider the work of the INCLUDE (INvestigation of Co-occurring conditions across the Lifespan to Understand Down syndromeE) Project. Their directive called for a new trans-NIH research initiative on critical health and quality-of-life needs for individuals with Down syndrome, and ask the project leads to provide assistance in coordinating the subcommittee.

Thank you for your time and consideration.

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