



October 25, 2022

Good afternoon,

I serve as the Manager of Health Programs, Aging & Caregiving at the National Down Syndrome Society. NDSS is the leading human rights organization for all individuals with Down syndrome.

My work at NDSS centers on connecting members of our community directly with experts in the field. Specifically, I manage the NDSS Adult Summit, which is an interactive conference that spotlights issues related to aging and Down syndrome through a comprehensive, whole-person approach. The summit cuts across ages and content areas and seeks to provide our families, caregivers, and professionals with resources and materials to help them navigate the challenges that are endemic to aging and disability.

In the past, much of the work of disability advocates focused on children, but due to countless advancements in civil rights protections, healthcare, education, employment, and an overall improved cultural awareness of disability, people with Down syndrome are living longer than ever before. At NDSS we understand that the next set of critical policy challenges lies in the adult and aging space. As you've heard from my colleagues over the past year, we know that the ecosystem of services and supports for this part of our community is not yet ready to meet its needs, and, as the adult population continues to grow, we expect to find innumerable opportunities to improve the policies that address aging.

We are here to help this council work proactively to support the Down syndrome community. I urge you, once again, to establish a special subcommittee to focus on how HHS can improve the diagnostic and clinical supports available to individuals with Intellectual and Developmental Disabilities, including Down syndrome. We believe that doing so is in line with last December's updates to the National Plan to Address Alzheimer's Disease -- especially the new Goal 6, meant to promote healthy aging.

I said earlier that my work at NDSS revolves around connecting members of our community directly with experts in the field -- and that is exactly why I am here today. The members of this council, both federal and non-federal, are experts in the field of Alzheimer's disease and related dementias. I am here to offer you a direct connection to our community, which has a clear need for your knowledge and support.

Thank you very much for the opportunity to address the council today. NDSS is ready -- and eager -- to work with you in partnership to improve the services and supports people with Down syndrome are able to receive as key members of the Alzheimer's community.

Rachel Grimm
National Down Syndrome Society
Manager of Health Programs, Aging & Caregiving