national down syndrome society®

Down Syndrome
Advocacy
Conference

2025 Down Syndrome Advocacy Conference

The National Down Syndrome Society (NDSS) Down Syndrome Advocacy Conference brings advocates from across the country together to advocate for priorities that impact the Down syndrome and broader disability community. We are seeing countless proposed changes in this Congress that have a significant impact on the Down syndrome community. Your elected officials need to hear directly from YOU on how these changes will impact you, your family, and the disability community. The Down Syndrome Advocacy Conference is an opportunity to make your voice heard and influence public policy that impacts individuals with Down syndrome and their families. Now, more than ever, YOUR advocacy is needed!

The 2025 conference will be held on April 28 – 30, in Washington D.C. For more information and to register, visit https://ndss.org/down-syndrome-advocacy-conference.

***Please note that the priorities below are tentative and subject to change.**

Legislative Priorities

The Charlotte Woodward Organ Transplant Discrimination Prevention Act (H.R. 1520)

The Charlotte Woodward Organ Transplant Discrimination Act, named after NDSS staff member, self-advocate, and transplant recipient, Charlotte Woodward, would prevent discrimination based on disability in the organ transplant system. Additionally, it would establish an expedited review of claims of discrimination at the Office of Civil Rights at the United States Department of Health and Human services that would give timely relief to those who have been discriminated against.

The Ensuring Nationwide Access to a Better Life Experience Act (S. 627 / H.R. 1436)

The Ensuring Nationwide Access to a Better Life Experience Act (ENABLE Act) would make permanent three important provisions of ABLE accounts that would otherwise expire in 2025. Without the permanent extension of these provisions, individuals with disabilities would face more limited opportunities to save for their independence and futures.

Educational Priorities

Educational priorities are issues of critical importance to the Down syndrome and broader disability community, but may not currently, or at the time of the conference, have a bill introduced in Congress. The goal of including these priorities is for advocates to have the opportunity to educate their elected officials on these important issues even if there is not a specific bill that they are asking the Members to support.

Protecting Medicaid

Medicaid is a government program that provides free or low-cost health insurance to eligible individuals, including individuals with Down syndrome. It covers essential medical services like doctor visits, hospital stays, and prescriptions. It is also the only payer of Home and Community-Based Services (HCBS) and can be used to cover necessary therapies and interventions provided in a school setting for students with disabilities, such as speech therapy, occupational therapy, and more.

Protecting Access to High Quality Special Education

The Individuals with Disabilities Education Act (IDEA) ensures that students with certain disabilities, including Down syndrome, have access to a free appropriate public education (FAPE). The Department of Education plays a key role in implementing this by allocating grants to states, overseeing compliance, and offering technical assistance to state and local education agencies. To safeguard the continued provision of special education services for students with Down syndrome, NDSS is focused on keeping special education programs within the Department of Education while continuing to advocate for the full funding of IDEA.

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

Given the genetic connection between Down syndrome and Alzheimer's disease, it is imperative that the Down syndrome community is included in all federal initiatives related to Alzheimer's disease. The NDSS team is dedicated to ensuring individuals with Down syndrome have their say in Alzheimer's related clinical studies, initiatives, and legislation.

Benefits Reform

Many individuals with Down syndrome rely on public benefits programs such as Medicaid and Supplemental Security Income (SSI). However, these individuals also face several barriers in maintaining eligibility for and access to these critical benefits, potentially jeopardizing their financial security or access to quality care. NDSS has identified several priorities that would ensure public benefits are more accessible to the disability community. These include ensuring the Home and Community-Based Services (HCBS) Waiver program is portable across states, expanding the HCBS workforce, reforming Supplemental Security Income (SSI) asset limitations, and eliminating the SSI marriage penalty.

Legislative Priorities FAQ

How are the annual priorities chosen?

The NDSS Advocacy and Public Policy team carefully chooses the legislative priorities based on several factors, including constituent and community input, the current political climate and balance of power in Congress, and the likelihood of movement/progress on the chosen priorities. Our team's goal is to maximize your efficacy and impact by choosing priorities that are meaningful to our community. We also determine priorities that have a clear path toward passage in the United States Congress.

A priority I really care about or have previously advocated for is not on this year's list! What happened?

In order to maximize impact, the number of priorities that can be discussed in a single meeting is limited. Therefore, there may be priorities that are important to you or that you have advocated for previously that were not chosen to be part of this year's conference priorities. This does not mean that NDSS and our grassroots advocates are not actively engaged with these issues! In fact, there are several events, advocacy campaigns, and grassroots activations that NDSS leads throughout the year in support of other priorities. If you are interested in staying connected with this work, please consider joining the NDSS Down Syndrome Ambassador® grassroots advocacy program. More information can be found at https://ndss.org/be-an-advocate.

I am not familiar with one or more of the chosen priorities. What should I do?

The Down Syndrome Advocacy Conference is open to advocates of all ages and all experiences! You do not need to be an experienced advocate to attend. The first two days of the conference (April 28-29) will be devoted to educating attendees on our priorities as well as how to effectively advocate on Capitol Hill. NDSS also provides numerous pre-conference trainings and resources to help advocates familiarize themselves with the issues.

Will I be able to advocate on priorities other than the NDSS identified priorities while I am on Capitol Hill?

Attendees are asked to only address the legislative priorities identified by NDSS during their time on Capitol Hill for the conference. This helps contribute to a unified, and ultimately the most impactful, voice on Capitol Hill. Additionally, members of Congress and their staff are sent notice of the priorities and supplemental materials ahead of their meetings with constituents to ensure that the most productive meeting possible can occur. If advocates discuss priorities outside of those identified by the conference, members of Congress and their staff may be unprepared or unable to meaningfully discuss these additional priorities. Attending the conference is a great way to build a relationship with your members of Congress and their staff so that you may approach them with additional requests or priorities in the future!

Who should I contact if I have questions about any of the legislative priorities or the conference?

Please contact policy@ndss.org with any questions.