

Program Summary

The NDSS Advocacy & Public Policy Program champions federal, state, and local policies that positively impact all people with Down syndrome across the country. Through our grassroots advocacy programs, NDSS works with Congress and federal agencies, as well as state and local officials, to develop and improve laws, regulations, and policies for the benefit of the Down syndrome community. NDSS also empowers self-advocates, parents, and others to influence policy themselves. The NDSS legislative agenda spans the life experience of individuals with Down syndrome from birth to adulthood, centered on five important areas: healthcare and research, education, economic self-sufficiency, community integration, and employment.

Legislation, Regulation, and Technical Assistance:

The government has many touch points with society. The United States Congress and state legislatures debate and pass laws that impact everyone's daily lives. The federal agencies and their state counterparts carry out those laws. They also develop and offer best practices and other guidance. The NDSS Advocacy & Public Policy team works directly with legislators and administrators to make sure their work is increasingly inclusive of the Down syndrome community and progressively beneficial.



Community Empowerment:

Advocacy work is meaningless if carried out without the support and direct engagement of the community. The NDSS grassroots advocacy program works hand-in-hand with our national network of local affiliates and the support of our community-based advisory committees. Its goal is to provide a two-way street between the community and the government: our state and federal advocacy is guided by the needs of our community, and our community can support those efforts on the ground. Responsiveness to and empowerment of the community will always be a core principle of NDSS' advocacy.

Collaboration and Intersectionality:

No one has only one identity. Any person with Down syndrome is also a family member, a student at a school or an employee at a company, a person with a specific ethnicity and gender identity, or a person with other disabilities. Every person belongs to many communities, and at NDSS we know that our advocacy must reflect our diversity. We also know that many of the laws that support the Down syndrome community also apply to much broader populations. For this reason, NDSS takes collaboration and cooperation very seriously and proactively partners not only with other Down syndrome groups, but also organizations and individuals whose reach extends beyond Down syndrome-specific advocacy. We know that to improve systems of support for our community, we have to recognize we are part of a larger one.



“As an advocate with NDSS, I raise awareness, educate, and advocate for the Down syndrome community and all people with disabilities. It makes me so proud to use my voice to advocate for myself and others with disabilities.” - Sara Nye

Advocate with us!

Action Alerts

The most powerful advocacy tools we have are the voices of individuals with Down syndrome and those who care about them. Advocacy Action Alerts are one way we work to help you raise your voice and share your experiences with lawmakers. By signing up for alerts, you'll be notified about important advocacy opportunities. We'll make it easy for you to contact your representatives and explain why the issue matters to you. You can find our current Action Alerts at www.ndss.org/action-alerts

Down Syndrome Advocacy Conference – April 28-30, 2025

NDSS will be hosting our Down Syndrome Advocacy Conference on April 28-30, 2025. This three-day conference will allow advocates to receive information and training on important policy issues for our community and, through a day on Capitol Hill, offers the chance to speak with Members of Congress face-to-face and express support for legislation that improves the lives of people with Down syndrome.

NDSS believes in amplifying the voices of individuals with Down syndrome and provides tickets to self-advocates at no charge. There is also an option to sponsor a self-advocate by covering their costs to attend DSAC. Register before February 20, 2025, to receive our early registration price! Learn more at: ndss.org/down-syndrome-advocacy-conference



national down syndrome society®

Down Syndrome Advocacy Conference



For more information visit ndss.org/advocacy
or contact us at policy@ndss.org