national down syndrome society
ndss®

June 4, 2025

The Honorable Seth Moulton
1126 Longworth House Office Building
Washington, DC 20510

The Honorable Joseph Morelle
570 Cannon House Office Building
Washington, DC 20510

The Honorable Brian Fitzpatrick
271 Cannon House Office Building
Washington, DC 20510

The Honorable Debbie Dingell
102 Cannon House Office Building
Washington, DC 20510

Dear Representatives Moulton, Fitzpatrick, Morelle, and Dingell:

The National Down Syndrome Society (NDSS) empowers individuals with Down syndrome and their families by driving policy change, providing resources, engaging with local communities, and shifting public perceptions. We strongly support the passage of H.R. 3409, the *Healthcare Extension and Accessibility for Developmentally disabled and Underserved Population* (HEADs UP) Act which would direct the Health Services and Resources Administration (HRSA) to designate people with Intellectual and Developmental Disabilities (I/DD) as a Medically Underserved Population.

People with Down syndrome and other intellectual and developmental disabilities often experience a myriad of health challenges throughout their lifetime. Being included as a Medically Underserved Population would expand access to government programs and agencies and help ensure that individuals with I/DD have access to the healthcare they need and deserve.

Many individuals with Down syndrome and other intellectual and developmental disabilities struggle to find primary care providers and specialists that understand their disability and can provide appropriate care. Only about 5% of the 212,000 families in the U.S. who have loved ones with Down syndrome live in an area where they can visit a Down syndrome specialty program.[1] Further training and support for providers, like the support that this bill would make available, is critical to ensure that the Down syndrome community has increased access to high quality care from providers who understand their unique needs.

This bill would also have a significant impact on coverage for care as it incentivizes physicians to treat the I/DD community through higher reimbursement rates from the Centers for Medicare and Medicaid Services (CMS). Medicaid is the nation's primary health insurance for people with disabilities, covering over 10 million Americans with disabilities.[2] Unfortunately, many in our

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[1] https://www.dsc2u.org/organizations

community often experience issues with CMS coverage of the care and services they need. By increasing the reimbursement rates for services delivered to individuals with I/DD, this bill would work to guarantee that providers are appropriately reimbursed for the specialized care they provide, thus increasing quality and access for the patient with I/DD.

Lastly, this bill would incentivize new research at the National Institutes of Health (NIH), an important step towards future medical advancements for the Down syndrome and broader I/DD community. Since 2018, Down syndrome has been primarily studied through the work of the INvestigation of Co-occurring conditions across the Lifespan to Understand Down syndrome (INCLUDE) Project at NIH. Since its inception, the INCLUDE Project has made significant advances in the health and quality of life for the Down syndrome community; however, there is still more work to be done. The preference given to Medically Underserved Populations in federal research, including at the NIH, would help ensure that the Down syndrome and greater disability community continues to be included in and prioritized in the lifesaving research being conducted.

NDSS strives to ensure all individuals with Down syndrome are guaranteed their human rights and valued by a more inclusive society. The passage of H.R. 3409 will make important progress toward both of those goals. We urge Congress to take action on this issue, and we thank you for your leadership regarding this important piece of legislation.

Sincerely,

Kandi Pick

Kandi Pickard
President and CEO
National Down Syndrome Society