



October 10, 2023

The Honorable Bob Casey
393 Russell Senate Building
Washington, DC 20510

Dear Senator Casey,

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 write today in strong support of the passage of the Home and Community Based Services (HCBS) Relief Act.

The act seeks to address the need for long-term funding for HCBS by proposing an increase in the Federal Medical Assistance Percentage (FMAP) for State Medicaid programs for HCBS during fiscal years 2024 and 2025. Through increased funding, states can stabilize and streamline state HCBS delivery networks and reduce waiting lists for services. Additionally, service providers can recruit and retain qualified direct care workers and meet the long-term services and supports (LTSS) needs of eligible Medicaid beneficiaries.

Under this act, increased funding is conditional upon states meeting certain requirements, including an application detailing plans to implement activities to improve home and community-based services. States are required to submit reports to the Secretary regarding the use of funds, the number of eligible individuals served, and other relevant information. The Department of Health and Human Services (HHS) is tasked with evaluating the implementation and outcomes of the act and disseminating its findings to state Medicaid directors and relevant congressional committees.

A 2022 report revealed that a significant shortage of direct care workers exists, with over 70 percent of service providers unable to fill vacancies for LTSS workers. The shortage of direct care workers and instability in provider networks puts a strain on families who rely on home care services, forcing them to make difficult choices in caring for their loved ones at home. By assisting states for a two-year period, this act will address the needs of individuals and families by allowing workers and service delivery agencies to increase their rates, provide paid leave, and improve job stability.

NDSS strives to ensure all individuals with Down syndrome are assured their human rights and valued by a more inclusive society. We encourage Congress to dedicate funds to support people with disabilities by more fully funding HCBS. Thank you for your leadership in addressing this critical issue.

Sincerely,

A handwritten signature in black ink that reads "Kandi Pickard". The signature is fluid and cursive, with a large loop at the end of the name.

Kandi Pickard
President and CEO
National Down Syndrome Society