Legislative Request

As Congress works to advance additional legislation to address the health and economic difficulties resulting from the COVID-19 crisis, NDSS is requesting that it include the provisions identified below to help address the challenges facing people with Down syndrome.

Background and Summary

The COVID-19 crisis has created health and economic challenges for all Americas, but especially so for people with disabilities. People with Down syndrome, for example, are more likely to have one or more of the medical conditions that put them at higher risk than those without Down syndrome. These can include ongoing heart defects (heart disease), chronic respiratory problems or lung disease or a history of severe respiratory infections, sleep apnea, lower immune function, cancer/leukemia and diabetes.

Recent legislation enacted by Congress to protect community health and provide financial relief during the economic slowdown have exposed gaps in the way people with Down syndrome and other disabilities are treated in the delivery of home and community based services, access to educational supports, and in the non-discriminatory provision of health care, among other things.

In April 2020, NDSS surveyed the Down syndrome community by asking about the issues and struggles people are facing during this difficult period. The responses identified three key issues in need of Congressional consideration and action:

Financial Relief for All Dependent Children with Down Syndrome – Under the Coronavirus Aid, Relief and Economic Security (CARES) Act passed by Congress on March 25, adults with Down syndrome who get Supplemental Security Income (SSI) are not eligible for stimulus money if they can be claimed as a dependent by someone else. The “All Dependent Children Count Act” (H.R. 6420) and the “All Dependents Count Act” (S. 3652) are bills in the House and Senate that seek to address the lack of financial relief for individuals who are claimed as dependents under the CARES Act. The bills allow for cash payments to be extended to dependents with disabilities of all ages as well as those younger than 19 and students ages 24 and under.

Funding for Medicaid Home and Community-Based Services (HCBS) – Increased funding for Medicaid HCBS is needed to ensure that people with disabilities have access to the health care and caregiving services they need to continue to live safely and independently in the community during the pandemic. Many people with Down syndrome require valuable assistance from caregivers, including assistance with activities of daily living (such as eating,
bathing, and dressing) and instrumental activities of daily living (such as preparing meals, managing medication, and housekeeping). Additional Medicaid HCBS funding would allow HCBS caregivers to be compensated for the essential work they are providing in the face of increased health risks associated with COVID-19.

**Funding for Compensatory Services** – Since the onset of COVID-19, students have moved to distance learning (also known as virtual learning) at home for the remainder of the 2019-2020 school year. This transition, while necessary to ensure student and teacher safety, has created new challenges for people with disabilities and has illuminated inequities pervasive to our school systems, both public and private. Due to the unforeseen and unavoidable nature of COVID-19, many special education services have not been delivered. Therefore, NDSS strongly encourages Congress to allocate additional funding for compensatory educational services for students who qualify for special education services under the Individuals with Disabilities Education Act (IDEA), and who had an individualized education plan (IEP) during the 2019-2020 school year. These compensatory services will aid in bridging the gap between what IEP teams determine is necessary to provide a Free and Appropriate Public Education (FAPE) and what was provided via distance learning during the COVID-19 pandemic.

On May 15, 2020, the U.S. House of Representatives passed [H.R. 6800](https://www.congress.gov/bill/116th-congress/house-bill/6800), the Health and Economic Recovery Omnibus Emergency Solutions (HEROES) Act. This $3 trillion public health and economic relief package includes two of the three policy priorities outlined above. Specifically, it:

- **Addresses the issue of adult dependents who missed out on the stimulus payment from the CARES Act** – Many individuals with Down syndrome are claimed as dependents as adults, so people with Down syndrome who are 17 or older (and their families) missed out on these initial stimulus payments. The HEROES Act expands the definition of “qualifying dependent” to include anyone who can be claimed as a dependent on someone’s tax return. This would allow all taxpayers with dependents age 17 and older to be eligible for the $500 dependent credit under the CARES Act, as well as the Economic Impact Payments provided for in the HEROES Act.

- **Includes increased Medicaid funding targeted at Home and Community-Based Services** – This funding includes an increase in compensation and personal protective equipment for direct support professionals, providing HCBS to those on waiting lists, personal protective equipment for family care providers, and more.

The U.S. Senate is unlikely to consider the House legislation in its current form and, instead, is expected to move its own additional relief legislation sometime in the coming weeks. NDSS will be working with our advocates and their Senators and Representatives to build support for including all three provisions that are priorities for our community in any final legislation that is enacted.

For more information and to see bill text, actions, cosponsors and more, you can visit:

Key Messages

→ Individuals with Down syndrome and their families have been significantly impacted by COVID-19. Many of lost their jobs and providing care for someone with complex medical needs is costly. The economic stimulus payments provided as part of coronavirus relief legislation should not be denied to those who need it most.

→ Increased Medicaid funding dedicated to Home and Community-Based Services is needed to provide sufficient support to direct care workers (support professionals, home health workers, and personal care attendants) who are critical to keeping people with disabilities in their homes and getting the necessary support they need. The HCBS workforce needs the additional resources to keep themselves safe, and to be compensated for the essential work they are providing. This includes increases in pay for direct support professionals, home health workers, and personal care attendants to recruit, retain and reward them for their critical work.

→ The Individuals with Disabilities Education Act (IDEA) requires public schools to provide every student with special needs a free appropriate public education. This means that children with special needs have the right to receive educational services appropriate to their needs at public expense. Parents who comply with federal and state guidelines for social distancing to ensure student and teacher safety during the pandemic should not have to forfeit their rights. Therefore, compensatory services should also be awarded due to the unavoidable school closures which forced schools to transition away from face-to-face learning.

Answers to Questions about COVID-19 Relief Legislation

1. Why were adults with Down syndrome who get Supplemental Security Income (SSI) not eligible for stimulus money under the CARES Act?

   Under the CARES Act, a household could receive an additional $500 for each qualifying child, defined as a child under the age of 17. This is the same definition of a qualifying child for the Child Tax Credit. People with disabilities who get Supplemental Security Income are eligible under the law, unless they can be claimed as a dependent by someone else, a factor that disqualifies many adults with Down syndrome. Changing definition of “qualifying dependent,” as provided for in the HEROES Act, will rectify an inequity that prevented such individuals from receiving any payment as part of the CARES Act.

2. Congress already boosted Medicaid funding as part of the Families First Coronavirus Response Act passed by Congress on March 18, 2020. Why is additional funding for HCBS necessary?

   Congress did provide a temporary 6.2 percent increase in federal Medicaid payments to the states for the duration of the COVID-19 pandemic. However, Governors are given significant flexibility on how those funds are allocated. Much of the funding has appropriately gone to people in nursing homes. But people with disabilities receiving home and community-based services (HCBS) are also at increased risk of adverse health outcomes from COVID-19 due to chronic illness as well as from unmet daily needs due to workforce and medical supply shortages.
during the crisis. Expanding HCBS during the public health emergency is critical to preventing outbreaks in this community.

3. What are compensatory educational services and how are they awarded?

When special education services are not delivered under an Individualized Educational Plan (IEP), students may be entitled to receive compensatory services. These may include such things as academics, speech therapy, language, physical therapy, occupational therapy, social work, and any other related service or therapy. Compensatory services are done in a variety of ways, but almost exclusively done outside of the school day, depending both the type of service and the level of service (hours needed).

Traditionally, compensatory services are awarded to a student due to a school/districts failure to provide a Free and Appropriate Public Education (FAPE) as guaranteed under the Individuals with Disabilities Education Act (IDEA). As the Department of Education noted in its Questions and Answers on Providing Services to Children with Disabilities During the Coronavirus Disease 2019 Outbreak:

“If an LEA continues to provide educational opportunities to the general student population during a school closure, the school must ensure that students with disabilities also have equal access to the same opportunities, including the provision of FAPE. (34 CFR §§ 104.4, 104.33 (Section 504) and 28 CFR § 35.130 (Title II of the ADA)).”

This means FAPE as outlined in the student’s IEP must be delivered, in this case many students will be owed “make up” services from the 2019-2020 school year in order for FAPE to be provided.

Resources


Resources on how to stay healthy during the pandemic, if you or someone you know with Down syndrome has been denied health services due to scarce COVID-19 resources, making the transition to home and digital learning, working from home, and what to do if a loved one has been hospitalized and you have been told you are unable to visit – https://www.ndss.org/covid-19-fact-sheet.
