

Congress of the United States
Washington, DC 20515

May 8, 2020

The Honorable Nancy Pelosi
Speaker of the House
United States House of Representatives
H-232, U.S. Capitol
Washington, D.C. 20515

The Honorable Kevin McCarthy
Minority Leader
United States House of Representatives
H-204, U.S. Capitol
Washington, D.C. 20515

The Honorable Mitch McConnell
Majority Leader
United States Senate
S-230, U.S. Capitol
Washington, D.C. 20510

The Honorable Charles Schumer
Minority Leader
United States Senate
S-220, U.S. Capitol
Washington, D.C. 20510

Dear Speaker Pelosi, Leader McCarthy, Leader McConnell, and Leader Schumer:

Thank you for your efforts over the last few weeks to pass essential legislation to combat the COVID-19 crisis, both to keep Americans healthy and to address the economic fallout of schools and businesses closing across the country. We particularly appreciate the additional Medicaid funds and state relief dollars included in the Coronavirus Aid, Relief, and Economic Security (CARES) Act. As you come together on future legislation, we respectfully request that you keep Americans with disabilities in mind.

We have all heard from constituents and families of individuals with autism spectrum disorders (ASD) and other developmental disabilities who are scared and struggling. While all Americans are facing unprecedented challenges, individuals with disabilities and their families often face additional burdens and needs. These individuals and families may face a severe “services cliff” without any warning or preparation as daily services they rely on have suddenly become unavailable. As such, we are requesting that steps be taken to protect individuals with disabilities and their families going forward. Specifically, we recommend increasing funding for Home and Community-Based Services (HCBS), increasing funding for Individuals with Disabilities Education Act (IDEA) services, and expanding telehealth.

Increased funding for Home and Community-Based Services (HCBS) is needed to support people with autism and other disabilities in their homes and communities. HCBS dollars will ensure staff are available to help support people who are quarantined or practicing social distancing and will help communities respond to and prevent the further spread of COVID. Specifically, we urge inclusion of an additional 15% increased FMAP for HCBS serving people with autism, intellectual and other developmental disabilities. States need this investment into the systems for home care workers to safely provide care and supports to people

with disabilities. This increase should allow states broad flexibility to use HCBS in a variety of ways but should focus on increasing available services, increasing provider payment rates and supporting emergency enrollment.

In addition, families and autistic individuals are searching for information and resources to help them during this time of crisis. Members of the autism community face a unique challenge during this time and are searching for information and resources across a wide range of domains – from health and safety to education and managing challenging behaviors during a time of crisis. Congress should allocate emergency funding to the Administration for Community Living to fund a national autism resource network and navigator program under Title II Family Support activities of the DD Act. This resource network would help ensure access to specially trained navigators who can provide person-centered case management across the lifespan and referrals to local providers, resources and information during this time and throughout the recovery.

Additionally, hundreds of thousands of students with autism have suddenly lost access to the individualized services and related supports that they rely upon as part of their daily education. The disruption to special education services has been catastrophic for families dealing with the current crisis. Congress must provide additional supports to ensure students and families have the resources they need to mitigate educational regression and maintain health and wellness. Furthermore, any legislation to support access to distance learning and other supports must address the unique needs of students with disabilities, including requirements under the Individuals with Disabilities Education Act (IDEA) and the Rehabilitation Act of 1973. Specifically, we urge funding to bolster IDEA system capacity, both under IDEA itself and through support for related programs such as the Assistive Technology Act. This supportive funding should enable local school districts to provide compensatory services and other supports to students with autism and other disabilities during the summer, extended breaks, and the next school year so that students with disabilities directly impacted by the COVID crisis can get back on track as soon as possible.

Finally, it is imperative that people with ASD continue to access healthcare services and much needed therapeutic intervention in order to maintain health and safety. We encourage continuing the success of expanding telehealth services available during this current crisis. Health Resources & Services Administration (HRSA) grants have led to the development of the ECHO Autism, an evidence-based tele-mentoring model which has successfully enabled autism specialty teams to support local clinicians in providing services to people with autism who may not have access to specialists in their home communities. The rapid shift to telehealth for assessment and treatment has a disproportionate impact on people with disabilities and their families. During this time of crisis, critical telehealth support is needed to develop and disseminate evaluation and treatment models for physical, mental, and behavioral healthcare needs.

Utilizing the ECHO Autism infrastructure that already exists through the HRSA-funded collaborative Autism Intervention Research Network on Physical Health (AIR-P)/Autism Treatment Network (ATN), we recommend that funds be appropriated to allow HRSA to provide emergency funding to repurpose and expand this existing infrastructure to address issues related to COVID-19. The ECHO Autism COVID-19 would quickly identify and disseminate best

practices and resources to providers and families across the country to help ensure that individuals with autism are receiving appropriate telehealth services during the pandemic. This “tele-mentoring” model allows health care providers across the country to access leading clinicians who can provide real-time information, improve their knowledge base, and improve the quality of care that individuals on the autism spectrum are receiving.

In addition, emergency funding for the Leadership Education in Neurodevelopmental and Related Disabilities (LEND) program would bolster the critical virtual services they are already providing to the autism community during this crisis. The 52 LEND sites across the country funded under Autism CARES Act provide an existing infrastructure that is pivoting to meet this need and has capacity, with emergency funds, to provide access to assessment and treatment for people with neurodevelopmental disabilities and their families.

We thank you for your consideration of these requests and ask that you reach out to our offices if you have any questions.

Sincerely,



Mike Doyle
Autism Caucus Co-Chair



Christopher H. Smith
Autism Caucus Co-Chair

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