



**CONSORTIUM FOR CITIZENS
WITH DISABILITIES**

April 24, 2020

The Honorable Frank Pallone
Chair, House Energy and Commerce
Committee
2125 Rayburn House Office Building,
Washington, DC 20515

The Honorable Greg Walden
Ranking Member, House Energy and
Commerce Committee
2322A Rayburn House Office Building,
Washington, DC 20515

The Honorable Lamar Alexander
Chair, Senate Health, Education, Labor and
Pensions Committee
428 Dirksen Senate Office Building,
Washington, DC 20510

The Honorable Patty Murray
Ranking Member, Senate Health, Education,
Labor and Pensions Committee
648 Hart Senate Office Building,
Washington, DC 20510

The Honorable Chuck Grassley
Chair, Senate Finance Committee
219 Dirksen Senate Office Building,
Washington, DC 20510

The Honorable Ron Wyden
Ranking Member, Senate Finance Committee
219 Dirksen Senate Office Building
Washington, DC 20510-6200

Dear Chairmen Pallone, Alexander, and Grassley and Ranking Members Walden, Murray, and Wyden:

Thank you for your leadership in addressing the unprecedented COVID-19 crisis for all Americans, including those who are at high risk for the virus – people with developmental disabilities. We greatly appreciated the 6.2% increase in the Medicaid federal medical assistance percentage (FMAP) in the Families First Coronavirus Response Act (FFCRA) and expect this amount to be increased in the next package.

The undersigned members of the Consortium for Citizens with Disabilities (CCD) Task Force on Developmental Disabilities, Autism, and Family Support urge you to include the funding for the following programs, which cut across your committees, in the next COVID-19 bill. The mission of the task force is to advocate for federal public policies that directly relate to individuals with developmental disabilities, autism spectrum disorders, family supports, and the prevention of child abuse and neglect.

The programs described below were not included in previous COVID legislation and demand for the services they provide have increased dramatically in the last several weeks, leaving them unable to meet the needs of people with developmental disabilities and their family caregivers.

DEVELOPMENTAL DISABILITIES (DD) ASSISTANCE AND BILL OF RIGHTS ACT PROGRAMS

The DD Act established programs in [every state and territory](#) to improve the lives of people with developmental disabilities through capacity building, systems change, advocacy, and the enforcement and protection of civil rights. With a long history of bipartisan congressional support for funding within the Administration for Community Living (ACL), these programs have decades of experience meeting the needs of people with intellectual and developmental disabilities.

Title I – State Developmental Disabilities Councils (DD Councils)

While the Coronavirus Aid, Relief, and Economic Security (CARES) Act provided \$955 million for the Administration for Community Living (ACL), only 9% of the funding supported ACL programs for people with disabilities and none of the funding was directed to people with intellectual and developmental disabilities. We request an additional \$100 Million for DD Councils to provide a quick infusion of funds directly to local organizations that are filling gaps in services for people with intellectual and developmental disabilities created by the COVID-19 emergency.

DD Councils are positioned to expand their work to provide emergency grants and cooperative agreements to trusted state and local organizations (for profit and nonprofit) in their extensive network of sub-grantees already working on these issues. Using the DD Council's existing grantmaking authority, DD Councils can quickly fund local programs to:

- 1) Bridge the digital divide by providing devices and increasing connectivity for people with intellectual and developmental disabilities so they can access healthcare, education, and the workforce during the emergency;
- 2) Provide support for caregivers by funding training and microgrants for personal protective equipment for providers, families and natural supports;
- 3) Fill gaps in emergency communications including creating accessible and plain language materials for ongoing updates on the emergency for people with intellectual and developmental disabilities in English and other languages; and
- 4) Update state emergency plans and provide funding to meet the needs of people with intellectual and developmental disabilities not covered by the existing plan.

Title I – Protection and Advocacy for Individuals with Developmental Disabilities (PADD)

Protection and Advocacy (P&A) agencies comprise the nationwide [network of 57](#) congressionally created and mandated, legally based disability rights agencies. P&A agencies have the authority to provide legal representation and other advocacy services, under federal laws, to **all** people with disabilities.

Congress gave P&A agencies the ability to protect people with disabilities through programs such as the Protection and Advocacy for Individuals with Developmental Disabilities (PADD) program no matter their disability, where they may live, work, or

receive services. In these uncertain times, the work of the P&As to ensure that the rights of people with disabilities are not violated is more important than ever and P&As are working to fulfill this critical mandate and support the disability community.

COVID-19 related issues P&As are seeing right now include: concerns about the spread of the virus in congregate facilities (including nursing homes, prisons and juvenile detention facilities); medical rationing; how to access assistive technology devices and services for use in remote education and employment; changes in voting processes and requirements due to the pandemic, and violation of individual rights around Do Not Resuscitate orders.

When the pandemic ends we know that there will be numerous issues to address inclusive of the items listed above, but also: employment discrimination issues; ensuring people that lived in the community are able return to those living arrangements; inaccessibility issues impacting people with disabilities in the elections later this year, and reconnecting people with disabilities to needed services and supports including health care, employment supports, assistive technology, educational services, and home health care.

During and after this pandemic, additional funding is vital to ensure that P&A agencies across the country can continue to protect and advocate on behalf of all people with disabilities. For this reason, we are requesting \$45 million for the PADD program.

In addition to the funding, we are seeking language similar to what was in the COVID 3 relief bill in three areas.

- Similar to the language in COVID-3 that reiterated the authority of the Long-Term Care Ombudsman, we request similar language around the P&A's authorities so as not to create delays in providing needed services or protections. That language would read as follows: Protection and Advocacy systems shall continue to have reasonable, unaccompanied access (directly or through the use of technology) to facilities for the purposes of investigation and monitoring (or other access through the use of technology) to long-term care facilities, to residents, and to appropriate records during any portion of the public health emergency relating to coronavirus beginning on the date of enactment of this Act and ending on September 30, 2021, to provide services described in 42 U.S. Code § 15043 et seq.
- Similar to the language in COVID-3, we believe the funding should be available to the P&A agencies from date of enactment until September 30, 2021 and would request that be explicitly stated. Given that we are already half way through the fiscal year, it is important that the P&As be given some additional time to expend these funds that are needed to provide services this fiscal year, but will also be needed to fund services in the next fiscal year.
- Similar to the language in COVID-3, we believe this funding should be designated as emergency funding.

Title I - University Centers for Excellence in Developmental Disabilities Education, Research, and Service (UCEDD):

A [network of 67 centers](#) continues to provide services modifying practices and adjusting policies as required to ensure the health and safety of the people with disabilities they serve. Emergency funds are needed to address emerging needs, including: support to state and local government, assistance to service providers, training and support to schools and others who have transitioned services to virtual delivery methods. In addition, funds are needed to collect data to evaluate the impact of COVID-19 services to ensure that the lessons learned related to pandemic response are collected and shared. We are seeking \$20 million for the Administration for Community Living, Office of Intellectual and Developmental Disability Programs.

Title II - Family Support activities

We urge Congress to allocate emergency funding to the Administration for Community Living to fund a National Autism and Other Developmental Disabilities Resource Network and Navigator Program. 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, and resources and information during this time and throughout the recovery. This program is needed to fill the gap in existing programs – namely, the Family-to-Family program (described below) which assists families of children with special health care needs with health care related issues, and the Parent Training and Information Centers under the Individuals with Disabilities Education Act (IDEA), which serves families of children and young adults needing assistance with issues related to early intervention, pre-school, elementary, and secondary education. A new navigator program would help meet the range of needs of *adults* with developmental disabilities who are not served by these other family support programs.

FAMILY-TO-FAMILY HEALTH INFORMATION CENTERS (F2Fs)

F2F programs are staffed by families of children and youth with special health care needs and disabilities (CYSHCN) to help families like themselves navigate the complex health care delivery and financing systems. There are [59 F2Fs](#), one in each state, DC, and five territories, plus three serving tribal families. Each receives federal funding of less than \$100,000 per year through the Health Resources and Services Administration (HRSA). The Coronavirus quarantine is making it much harder for families of CYSHCN to obtain the care, services, medications, and supplies that their children need, and they are turning to F2Fs for assistance and support. Examples of the pandemic-related problems that families are facing include: shortages of the masks, gloves, tubing, and other supplies that are regularly used to care for medically fragile children; difficulties obtaining extra refills of medications (as advised by CDC), particularly controlled substances that are often used for epilepsy or behavioral health conditions; problems using telehealth, including lack of translation services; loss of home health aides, either because families of medically fragile children do not want to risk having aides coming into their homes or because the aides are not available; and loss of school-based therapies that help children

maintain function. Additionally, millions of people are losing their jobs and health insurance. Those who have children with special health care needs are turning to F2Fs for help in keeping their children insured through Medicaid or private Exchange plans. To handle these increased demands for assistance, F2Fs will need additional staff. Therefore, we recommend an increase in F2F funding of \$6 million.

LEADERSHIP EDUCATION IN NEURODEVELOPMENTAL AND RELATED DISABILITIES (LEND)

As affirmed by the Congressional Autism Caucus on March 21, 2020, the rapid shift to telehealth for assessment and treatment has a disproportionate impact on people with disabilities and their families. Critical support is needed to continue access to evaluation and treatment. The [52 programs](#) funded under Autism CARES Act (P.L. 116-60) 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 request \$20 million to HRSA's Autism and other Developmental Disabilities program for the LENDS.

Thank you for your consideration of this request and for your continued attention to meeting the needs of people with developmental disabilities and their families. For more information, please contact Annie Acosta at acosta@thearc.org.

Sincerely,

American Music Therapy Association
Association of University Centers on Disabilities (AUCD)
Autism Society of America
Autistic Self Advocacy Network
Autistic Women and Nonbinary Network
CommunicationFIRST
Easterseals
Family Voices
National Association of Councils on Developmental Disabilities
National Center for Parent Leadership, Advocacy, and Community Empowerment (National PLACE)
National Disability Rights Network
National Down Syndrome Congress
National Respite Coalition
TASH
The Arc of the United States

CC:

The Honorable Nancy Pelosi, House Speaker

The Honorable Kevin McCarthy, House Minority Leader
The Honorable Mitch McConnell, Senate Majority Leader
The Honorable Charles Schumer, Senate Minority Leader