



Developmental Disabilities Act Network COVID-19 Funding Fact Sheet

Introduction

The State Councils on Developmental Disabilities (Councils), the University Centers for Excellence in Developmental Disabilities (UCEDDs), and the Protection and Advocacy (P&As) agencies are federally-funded programs under the Developmental Disabilities Assistance and Bill of Rights Act of 2000, collectively referred to as the DD Act Network. These three entities are charged with working to identify and solve the issues facing individuals with developmental disabilities in their communities. Additionally, they provide training and technical assistance to policymakers as they work to remove barriers that prevent individuals with developmental disabilities from having their voices heard. The 56 Councils, 57 P&As, and 67 UCEDDs across the United States also work closely with local, state, and federal governments to develop robust policy solutions aimed at empowering these individuals and promoting self-determination.

During the pandemic, these programs have rapidly stood up virtual platforms to ensure that the voices and needs of individuals with developmental disorders can be heard and met even as traditional healthcare and advocacy is interrupted. They continue to ensure that state and federal responses to the pandemic consider and account for the needs of individuals with developmental disabilities. However, this additional, critical work has jeopardized the ability of the Councils, UCEDDs, and P&As to appropriately respond to and meet the needs of those they serve in other non-COVID related areas as up to this point the DD Network entities have not received any additional federal funding from Congress as part of any COVID-19 relief bill.

Federal Partnership

Throughout the pandemic, the federal government has recognized the unique role the Councils, UCEDDs, and P&As play in mitigating the negative effects of the COVID-19 pandemic on people with developmental disabilities. For example, throughout the pandemic several agencies within the Department of Health and Human Services have recognized the access authority P&As have to monitor congregate settings.¹ As recently as February of this year, the Administration for Community Living (ACL) stated that their “work has become literally a matter of life and death”² and that it is crucial to support the DD Act networks². Again in March, ACL highlighted that the “ACL-funded DD network, including Protection & Advocacy agencies (P&As), State Councils for Developmental

¹ ACL Advocacy: Visitation in Congregate Settings | ACL Administration for Community Living. (2021). Retrieved from <https://acl.gov/news-and-events/acl-blog/acl-advocacy-visitation-congregate-settings>

² A Message from Acting Administrator and Assistant Secretary for Aging Alison Barkoff | ACL Administration for Community Living. (2021). Retrieved from <https://acl.gov/news-and-events/acl-blog/message-acting-administrator-and-assistant-secretary-aging-alison-barkoff>

Disabilities, and University Centers for Excellence in Developmental Disabilities (UCEDDs), have been advocating at the state and local levels on a range of issues impacting people with DD and supporting people in addressing the challenges created by the pandemic.”³

The Needs

A recent study published in the New England Journal of Medicine Catalyst, found, “that intellectual disability was second only to older age as a risk factor for dying from COVID-19. Yet, none of the billions of federal funding has specifically addressed mitigating risk for this population.”⁴ The DD Act Network have since the onset of the pandemic been on the front lines addressing numerous issues around COVID-19 for the developmental disabilities population, especially health disparities around treatment, and more recently on disparities on access to the vaccine. Discrimination around vaccine distribution continues to be a major issue that will require consistent attention as vaccines rollout across the country.

In order to build back, it is critical that we focus on the reintegration of people with disabilities into the community. This will require particular attention from our network to ensure that employment or housing discrimination against people with disabilities does not occur as people reenter the workforce and return to living in their communities. As the Administration continues to push for school reopening, education issues will come to the forefront including efforts to ensure compensatory education is provided which will require immediate attention to ensure parents and students are aware of their rights and are supported. There is no scarcity of work and the DD Act Network would be better positioned to meet the needs of the populations we serve with the appropriate federal funding supports.

Addressing the Continued Needs

As the Administration and Congress turn toward COVID-19 relief in the form of an economic recovery package, we once again reiterate our network’s request for additional funding. COVID-19 has highlighted the fragility of the systems that support people with developmental disabilities. From healthcare infrastructure to schools to employment opportunities, all of these sectors impact people with developmental disabilities and our network has a meaningful role to play to ensure this population has access to these vital services. As our network has already demonstrated, we are ready to meet the challenges posed by the virus but the financial strain continues to grow the longer additional federal funding is delayed.

³ Celebrating our Impact During DD Awareness Month | ACL Administration for Community Living. (2021). Retrieved from <https://acl.gov/news-and-events/acl-blog/celebrating-our-impact-during-dd-awareness-month>

⁴ After old age, intellectual disability is greatest risk factor for death from COVID-19, study finds. (2021). Retrieved from <https://www.sciencedaily.com/releases/2021/03/210305123809.htm>