

## EXAMPLE EMAIL

**From:** Lauren Blachowiak <lblachowiak@AUCD.ORG>  
**Sent:** Thursday, July 2, 2020 10:59 AM  
**To:** abigail\_welborn@cotton.senate.gov  
**Cc:** Rylin Rodgers <rroddgers@AUCD.ORG>  
**Subject:** COVID impact on home and community-based supports for people with disabilities

Good morning Abigail,

We are grateful for your continued efforts and those of your boss as you work to address the impacts of COVID-19. I wanted to share the results of a [z.umn.edu/dsp-covid19]Direct Support Workforce and COVID-19 National Survey 2020 .We believe that this first national survey provides critical evidence about the experiences of direct support professionals (DSPs) during the COVID-19 pandemic and informs your immediate work to ensure that a relief package meets the needs of people with disabilities.

### **Background:**

The direct support workforce provides critical supports, making it possible for people with intellectual and developmental disabilities (IDD) to live, work and thrive in their communities. Providing home and community-based supports for people with IDD, however, requires specialized skills and competencies that are not reflected by the low wages these workers generally receive due to underfunded Medicaid-reimbursement rates, limited access to benefits, and lack of respect afforded to this essential workforce.

### **Key Findings:**

- 96.8% of DSPs self-identified as essential workers, though when the pandemic hit in the U.S., states were slow to identify direct support workers as essential
- DSPs experienced significant schedule changes due to COVID
  - 34% working more hours
  - 29% working in different settings
  - 26% reported they were more short-staffed than before the pandemic
- **The pandemic is leading to DSPs leaving the workforce:**
  - 42% knew someone in the DSP workforce who left their job due to the pandemic.
  - 34% feared becoming infected
  - 25% had childcare issues
  - 13% feared infecting others
  - 9% left after testing positive for COVID-19
  - Other reasons for leaving included caring for family members, being furloughed or laid off when a program closed, having hours cut, mental strain, or receiving more income elsewhere

### **Needs for Package 4**

1. Fund Home and Community Based Services and the Direct Support Workforce to meet the emergency needs of people with disabilities living in the community.

- a. *Justification:* People with disabilities rely on a network of services to remain in their homes and communities. Currently, they are being asked to stay home, yet this results in avoiding the community organizations that serve them. Investment is needed in systems and in the DSP workforce to safely provide care and supports.
- b. *Total funding:* \$20 billion to Centers for Medicare and Medicaid, Home and Community Based Services
- c. *Action:* See Sec. 202 of [S. 3544](#) and HR. [6305](#)

I have attached the full survey for your reference along with AUCD's detailed asks for package 4. I would be happy to have a call to talk more about how COVID-19 is impacting the disability community.

Rylin Rodgers  
Director of Public Policy  
[rrodgers@aucd.org](mailto:rrodgers@aucd.org)  
Direct: 240.821.9381  
Cell: 765.891.0075

Lauren Blachowiak  
Disability Policy Fellow  
[lblachowiak@aucd.org](mailto:lblachowiak@aucd.org)  
240-821-9386

Association of University Centers on Disabilities (AUCD)  
[www.aucd.org](http://www.aucd.org)



## Priority Needs for COVID-19 Response

The mission of the Association of University Centers on Disabilities (AUCD) is to advance policies and practices that improve the health, education, social, and economic well-being of all people with developmental and other disabilities, their families, and their communities by supporting our members in research, education, health, and service activities that achieve our vision. This work has never been more critical. Our network is on the front lines in every state and territory.

### Critical Priorities

1. Fund Home and Community Based Services to meet the emergency needs of people with disabilities living in the community.
  - a. *Justification:* People with disabilities rely on a network of services to remain in their homes and communities. Currently, they are being asked to stay home, yet this results in avoiding the community organizations that serve them. Investment is needed in systems for home care workers to safely provide care and supports.
  - b. *Total funding:* \$20 billion to Centers for Medicare and Medicaid, Home and Community Based Services
  - c. *Action:* See Sec. 202 of [S. 3544](#) and HR. [6305](#)
2. Fund the systems that support people with disabilities, especially those with intellectual and developmental disabilities, including UCEDDS and LENDS. Resources are needed to address critical emerging demands. Disabled Americans are among those most at risk and while our existing systems have shifted to meet new and growing needs, they can't meet needs the need.
  - a. *University Centers for Excellence in Developmental Disabilities Education, Research, and Service (UCEDD):*
    - i. *Justification:* A network of 67 centers authorized under Section 156 of the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (P.L. 106-402, Subtitle D) continues 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 share.
- ii. *Total funding:* \$20 million to Administration for Community Living, Office of Intellectual and Developmental Disability Programs
  - b. *Leadership Education in Neurodevelopmental and Related Disabilities (LEND):*
    - i. *Justification:* 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.
    - ii. *Total funding:* \$20 million to Health Resources and Services Administration (HRSA), Autism and other Developmental Disabilities
  - c. *Disability and Health Programs:*
    - i. *Justification:* An underfunded existing state-based program at the Center for Disease Control (CDC), National Center on Birth Defects and Developmental Disabilities (NCBDDD), the Disability and Health Programs must be leveraged to respond to the emergent health threat of COVID-19 and to provide coordination of outcomes and significantly improve plans for the future. Action is needed to fund all states and major jurisdictions to contribute to a national surveillance system at CDC regarding data for people with disabilities, build state- and local-based networks to prepare, maintain, and distribute critical health communications for people with disabilities in all necessary formats, and ensure state and local response capacity is prepared to provide public health services to people with disabilities in an urgent public health response.
    - ii. *Total Funding:* \$100M to CDC, NCBDDD, Disability and Health Programs
3. Increase SNAP and Meals on Wheels funding and expand eligibility to include people with disabilities.
- a. *Justification:* Like many Americans, people with disabilities are not able to work or have lost their jobs during this crisis. Access to food is life sustaining and life-saving during this time.

### **Non-Legislative Oversight Efforts**

- AUCD has provided comment to the administration (Secretary of Labor) seeking assurance that family caregivers who need to take time to provide care for adults with disabilities because of care provider closure or unavailability of direct care workers due to COVID-19 are eligible for emergency paid sick leave under the Families First Act.
  - *Action:* Congressional oversight letter to the Secretary of Labor on the access to paid sick leave for caregivers.

- AUCD was pleased by the release of the March 28, 2020, [bulletin from the U.S. Department of Health and Human Services \(HHS\)](#) affirming “persons with disabilities should not be denied medical care on the basis of stereotypes, assessments of quality of life, or judgments about a person’s relative “worth” based on the presence or absence of disabilities.”
  - *Action:* Congressional oversight letter to HHS’ Office of General Counsel on Public Readiness and Emergency Preparedness Act (PREP Act), regarding failure to provide immunity from civil rights laws.
- AUCD was pleased by the release of the March 21, 2020 [factsheet from the U.S. Department of Education](#) affirming “federal law should not be used to prevent schools from offering distance learning opportunities to all students, including students with disabilities.”
  - *Action:* The Coronavirus Aid, Relief, and Economic Security Act authorizes the Secretary of Education to report to Congress in 30 days with a list of waivers needed for Congress to provide. Congressional oversight of the adherence to IDEA and the Rehabilitation Act of 1973 is needed.
- AUCD is working with our network in every state and territory to ensure that The Coronavirus Aid, Relief, and Economic Security Act, including the \$150 billion Coronavirus Relief Fund, is leveraged to meet the needs of all including those with disabilities.
  - *Action:* Weekly calls, technical assistance, and social media to support states in this process to leverage existing emergency funds to support people with disabilities.

# AUCD Centers Serving Arkansas



**University Centers for Excellence in Developmental Disabilities (UCEDDs)** work with people with disabilities, members of their families, state and local government agencies, and community providers in projects that provide training, technical assistance, service, research, and information sharing, with a focus on building the capacity of communities to sustain all their citizens.

**Partners for Inclusive Communities**

Phone: 501-301-1100

Website: <http://uofapartners.uark.edu/>

**Leadership Education in Neurodevelopmental and Related Disabilities (LENDs)** interdisciplinary training, services, and care for people with disabilities across the lifespan.

**Partners for Inclusive Communities**

Phone: 501-301-1100

Website: <http://uofapartners.uark.edu/>

## Disability in Arkansas by the Numbers

**72,835**

Students age 3-21 receive special education supports<sup>1</sup>

**31.8%**

of people with disabilities are employed<sup>2</sup>

&

**34**

14c certificate holders paying subminimum wages<sup>3</sup>

**\$999,573,225**

Medicaid expenditures for LTSS institutional care<sup>4</sup>

vs

**\$1,086,255,418**

Medicaid expenditures for HCBS<sup>4</sup>

**523,554**

Individuals with disabilities living in communities<sup>5</sup>

## AUCD and Your Office

The Association of University Centers on Disabilities (AUCD) supports a national network of university-based interdisciplinary programs in every U.S. state and territory. We are a trusted resource on disability policy issues and stand ready to connect you to resources, research and expertise in both policy and constituent service.

1. IDEA Section 618 Data Products: Static Files. Part B. Retrieved from <https://www2.ed.gov/programs/osepidea/618-data/static-tables/index.html>.
2. Cornell University. Disability Statistics. Employment Rate. American Community Survey (ACS). Retrieved from <http://www.disabilitystatistics.org/reports/acs.cfm?statistic=2>.
3. Community Rehabilitation Programs (CRPs) List. Retrieved from <https://www.dol.gov/whd/specialemloyment/CRPlist.htm>.
4. Eiken, S. et al., 2018. Medicaid Expenditures for Long-Term Services and Supports in FY 2016. IBM Watson Health
5. U.S. Census Bureau. (2018). American community survey. In Lauer, E.A., Boege, S.L., & Houtenville, A.J.(Eds.), Annual disability statistics supplement: 2019 (Table 1.10-1.13). Durham, NH: University of New Hampshire, Institute on Disability. Data represents the civilian, noninstitutional population. Based on a sample and subject to sampling variability.