

Disability Policy Priorities 2021

The Association of University Centers on Disabilities (AUCD) supports and promotes a national network of university-based interdisciplinary programs. AUCD's mission is to advance policies and practices that improve the health, education, and 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.

COVID-19 Relief

Individuals with disabilities and their families have been disproportionately impacted¹ by the dual public health and economic crises spurred by the COVID-19 pandemic. The various health, education, employment, and social service systems that support individuals with disabilities are in desperate need of financial relief to continue meeting the needs of this vulnerable community.

Priority Action Steps:

- 1. Include individuals with disabilities among priority populations in Phases 1 and 2 of federal, state, and local COVID-19 vaccine allocation and distribution plans.
 - Expand definition of underlying conditions that cause "significantly higher risk" of severe COVID-19 symptoms and death in COVID-19 vaccine guidance to include individuals with intellectual and/or developmental disabilities^{2,3}.
 - b. Include both paid and unpaid⁴ caregivers (e.g. DSPs, therapists, family members) in Phases 1 and 2 of COVID-19 vaccine allocation to protect both the caregivers and individuals with disabilities.
 - c. Provide all information regarding COVID-19 and COVID-19 vaccine allocation and distribution in accessible^{5,6}, clear, and consistent language.

¹ https://ajp.psychiatryonline.org/doi/full/10.1176/appi.ajp.2020.20060780

² https://www.nih.gov/news-events/news-releases/people-intellectual-developmental-disabilities-disproportionately-affected-covid-19

³ https://www.acpiournals.org/doi/10.7326/M20-4986

⁴ https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7151363/

⁵ https://www.aucd.org/conference/template/page.cfm?id=50214

⁶ https://www.plainlanguage.gov/about/definitions/

- Secure additional, emergency funding for Home- and Community-Based Settings (HCBS) services to meet the needs of people with disabilities living in the community.
 - Continue to transition individuals with disabilities from congregate care settings where risk of COVID-19 infection is higher to safer HCBS, including long-term or permanent authorization of Money Follows the Person.
 - b. Ensure that workforce, economic, and public health systems are supporting the safe return to work for people with disabilities.
 - c. Invest in the systems that employ paid and unpaid caregivers to increase access to personal protective equipment (PPE), hazardous duty pay during COVID-19, and other measures for worker health and safety⁷.
 - d. Continue to push for federal and state agency collection on COVID-19 positivity counts and fatalities for both residents and staff in congregate care settings, including group homes, Intermediate Care Facilities, etc.
- 3. Maintain the full rights and protections afforded to students with disabilities through the Individuals with Disabilities in Education Act (IDEA) throughout the public health crisis (e.g. access to Least Restrictive Environment, Individualized Education Plans).
 - a. Dedicate emergency education funds at the State Education Agencies and Local Education Agencies levels to IDEA services to ensure funding supports Individualized Education Plan services designed for students with disabilities⁸ and Section 504 services for at-risk students.
 - Address the academic, social, and emotional impacts of interruptions to instruction caused by suspension of in-person education, and provide compensatory services as needed⁹.

Healthcare

Individuals with disabilities across the lifespan face considerable barriers and disparities in healthcare access, care, and outcomes¹⁰. The rights and protections secured by the Affordable Care Act (ACA) are integral to the health of individuals with disabilities and to their and their families' quality of life.

Priority Action Steps:

1. Further invest in Medicaid, Medicare, and the Children's Health Insurance Program (CHIP) to improve access and quality of care for individuals with disabilities¹¹.

⁷ https://ici-s.umn.edu/files/iJphkG6fcN/dsp-covid-survey-results

⁸ https://www.congress.gov/bill/116th-congress/senate-

bill/4112/text?q=%7B%22search%22%3A%5B%22murray%22%5D%7D&r=2&s=6

⁹https://www2.ed.gov/about/offices/list/ocr/frontpage/faq/rr/policyguidance/Supple Fact Sheet 3.21.20 FINAL.pdf

¹⁰ https://www.cdc.gov/ncbddd/disabilityandhealth/relatedconditions.html

¹¹ https://www.kff.org/report-section/medicaid-financial-eligibility-for-seniors-and-people-with-disabilities-findings-from-a-50-state-survey-issue-brief/

- Remove Medicaid's Institutional Bias in Long Term Services and Supports (LTSS), which favors nursing facility care over Home- and Community-Based Settings¹².
- b. Expand offerings and coverage for services provided in HCBS.
- c. Improve coverage for LTSS to support individuals with disabilities across the lifespan.
- d. Secure permanent flexibility and reimbursement for telehealth services to better meet the needs of individuals with disabilities living in HCBS.
- e. Ensure equitable access to telehealth services for individuals with disabilities and their families through improved wifi access, digital literacy training, etc.
- f. Expand the number of and funding level for Disability and Health Grantees from the Centers for Disease Control and Prevention (CDC).
- 2. Lower the cost of prescription drugs to reduce health disparities for individuals with disabilities who require them.
 - Adopt cost-lowering measures that do NOT index prescription drug cost to Quality-Adjusted Life Years (QALYs), which is a discriminatory policy toward individuals with disabilities¹³.
- 3. Promote influenza, COVID-19, and routine vaccines for individuals with disabilities, their families, and the professionals who support them.
 - a. Provide all information on influenza and routine vaccines in accessible, clear, and consistent language.
 - b. Address common vaccine misconceptions and hesitancies in the disability community through community partnerships and targeted messaging.
- 4. Increase health outcomes and reduce health inequities by improving capacity of health and community organizations to address social determinants of health as related to individuals with disabilities and their families¹⁴.
- 5. Increase access to and coverage for mental health services for individuals with disabilities.
 - a. Expand funding for Children's Mental Health Champions¹⁵ administered by the CDC.

Education

Quality education services for students with disabilities are necessary to securing stable employment and financial independence as adults. The services, rights, and protections afforded by the Individuals with Disabilities in Education Act (IDEA) and the Higher Education Act (HEA) provide long-term benefits to individuals with disabilities, their families, and their communities.

¹² https://www.aarp.org/content/dam/aarp/ppi/2017-01/Stretching%20Medicaid.pdf

https://aucdpolicytalk.org/2019/11/08/what-is-a-galy/

¹⁴ https://www.tfah.org/wp-content/uploads/2020/08/SDOH-bill-fact-sheet.pdf

¹⁵https://www.aucd.org/template/news.cfm?news_id=14854&parent=505&parent_title=Archived%20News&url=/template/page.cfm?id%3D505

Priority Action Steps:

- 1. Pass the Keeping All Students Safe Act (KASSA)¹⁶ to end harmful restraint and seclusion practices in schools. These practices are disproportionately applied to students with disabilities and students of color¹⁷.
- 2. Fully fund and enforce IDEA.
 - a. Fund training and technical assistance to the childcare workforce on developmental monitoring and interventions through IDEA Part C.
 - Protect the civil rights of all students with disabilities with the support of the U.S. Department of Education's Office of Civil Rights.
 - c. Work with the U.S. Department of Education leadership on regulations, guidance, and initiatives related to least restrictive environment, inclusion of students with significant disabilities, disciplinary practices, etc.
- 3. Fully fund and support post-secondary programs for students with disabilities, including Think College and Transition and Postsecondary Programs for Students with Intellectual Disabilities (TPSIDs).
 - a. Ensure post-secondary students with disabilities receive necessary accommodations through the HEA.
- 4. Reauthorize the Assistive Technology Act of 1998.
 - a. COVID-19 highlighted the disparities in access to technology and gaps in Accessible Technology (AT) for students and workers with disabilities. Reauthorization should place an emphasis on coordination between AT programs, State Education Agencies, state/workforce labor agencies, and employee/employer organizations.

Workforce and Employment

Employment rates continue to lag for adults with disabilities compared to adults without disabilities. While some states have begun to transition toward competitive, integrated employment, progress is inconsistent. Over 100,000 individuals with disabilities continue to work in sheltered, segregated workshops for subminimum wages¹⁸.

- 1. Accelerate state and territory transition to competitive, integrated employment and supports in pursuit of ending all sheltered, segregated workshops.
 - a. Support the passage of the Transformation to Competitive Employment Act (introduced in the 116th Congress as <u>H.R.873</u>, <u>S.260</u>) or similar legislation that ends subminimum wages for individuals with disabilities through a multi-year phase-out.
 - b. Create federal incentives for states and territories to increase opportunities in and support systems for competitive, integrated employment for individuals with disabilities.

¹⁶ https://edlabor.house.gov/imo/media/doc/BEYER 142 xml.pdf

¹⁷https://www.aucd.org/template/news.cfm?news_id=15101&parent=1068&parent_title=Disability%20Policy%20 News%20Archive&url=/template/page.cfm?id%3D1068

¹⁸ https://www.usccr.gov/files/2020-09-17-Subminimum-Wages-Report.pdf

- c. Include employees with disabilities in economic recovery efforts and climate-reform jobs.
- 2. Support federal and state efforts to professionalize the direct support professional (DSP) workforce.
 - a. Financially invest in the DSP workforce to promote workforce stabilization through efforts such as increasing pay, increased state reimbursement rates, and/or implementing a national credentialing system¹⁹.

Social Justice

The disability community includes individuals of all races, ethnicities, genders, sexual orientations, and other identities. Individuals with disabilities that have intersecting minority identities, such as Black, Hispanic, and/or American Indian, face significant, additional systemic barriers related to health, education, employment, and financial security²⁰.

Priority Action Steps:

- 1. Engage in and promote anti-racist efforts at the national, state, and local levels.
 - a. Support the passage of the Voting Rights Advancement Act (introduced in the 116th Congress as <u>H.R.116-317</u>), which builds upon the protections afforded in the Voting Rights Act of 1965.
- 2. Invest in national data collection, monitoring, and dissemination on the systemic disparities and inequities related to race and disability across the lifespan.
 - a. Identify disparate health, education, employment, family, and financial outcomes and needs of individuals with disabilities across racial and ethnic groups to inform systemic interventions²¹.
- 3. Include disability-specific considerations in federal policies, programs, and trainings.
 - a. The rights and needs of individuals with disabilities must be addressed in, but not limited to, efforts in:
 - i. Voting;
 - ii. Criminal Justice System;
 - iii. Domestic and sexual violence, and abuse and neglect;
 - iv. Housing;
 - v. Transportation;
 - vi. Climate change policy and clean energy investments;
 - vii. Emergency preparedness;
 - viii. Nutrition;
 - ix. Gender, sexuality, sex, and and reproductive health education;

¹⁹https://www.nasddds.org/uploads/documents/Moving from Crisis to Stabilization Credentialing Report.pdf

²⁰ https://www.nationaldisabilityinstitute.org/wp-content/uploads/2020/08/race-ethnicity-and-disability-financial-impact.pdf

²¹ https://www.cdc.gov/ncbddd/disabilityandhealth/materials/infographic-disabilities-ethnicity-race.html

- x. Mental health wellness;
- xi. Allied health and public health professional training.

Appropriations

All AUCD network centers and programs are affected by the annual federal Budget and Appropriations process.

Priority Action Steps:

- 1. Fund the University Centers of Excellence in Developmental Disabilities authorized under The Developmental Disabilities Assistance and Bill of Rights Act of 2000 (DD Act) (P.L.106-402) through Fiscal Year 2022²².
- Fund the Leadership Education in Neurodevelopmental and Related Disabilities (LENDs) authorized under the Autism Collaboration, Accountability, Research, Education, and Support (CARES) Act (P.L.116-136) through Fiscal Year 2022²³.
- 3. Fund Intellectual and Developmental Disabilities Research Centers (IDDRCs), which receive core funding through the Eunice Kennedy Shriver National Institute for Child Health and Human Development (NICHD).
- 4. Fund the Projects of National Significance (PNS) authorized under Section 162 of the DD Act (P.L.106-402) through Fiscal Year 2022²⁴.
- 5. Fund the Transition Programs for Students with Intellectual Disability (TPSID) and the TPSID National Coordinating Center through Fiscal Year 2022²⁵.

²² https://www.aucd.org/docs/UCEDD%20Issue%20Brief%20FY%202021%20.pdf

https://www.aucd.org/docs/LEND%20Issue%20Brief%20FY%202021%201.pdf

²⁴ https://www.aucd.org/docs/PNS%20Issue%20Brief%20FY%202021.pdf

https://www.aucd.org/docs/FY2021%20Draft%20TPSID%20approps%20edited1.131.pdf