

Background

Every person has the right to receive quality, accessible, and affordable healthcare. Persons with disabilities face significant barriers, disparities, and discrimination in access to and receiving quality healthcare. The comprehensive healthcare improvements achieved in the Patient Protection and Affordable Care Act (ACA) must be maintained. The ACA is integral to ensuring quality and affordable healthcare. A competent healthcare professional workforce is essential to reducing health disparities and improving quality of life for persons with disabilities. Knowledgeable, culturally responsive, sensitive, and respectful healthcare providers should not only provide quality services but also holistic and preventive services that would result in greater patient satisfaction and lower healthcare costs. Support, privacy, and self-determination are key policy principles that are essential for healthcare decision-making.

Research

The National Center for Disability, Equity, and Intersectionality, a project led by three University Centers for Excellence in Developmental Disabilities, and members of AUCD's national Network including Cincinnati Children's Hospital/University of Cincinnati, Georgetown University National Center for Cultural Competence, and Maryland Center for Developmental Disabilities at Kennedy Krieger Institute as well as Morehouse School of Medicine and the Autistic Self Advocacy Network examines how multiply marginalized people with disabilities experience compounded discrimination and barriers in healthcare. One example of a significant finding is that nearly 30 percent of Black and Hispanic adults with disabilities went without healthcare due to cost, compared to only 17.1 percent of Black and 15.7 percent of Hispanic adults without disabilities.

The Workgroup on Advocating for Access to Genomic Testing, which is part of the Intellectual and Developmental Disabilities Research Centers, a member of AUCD's national Network, conducted a study to examine US-based policy and recommendation guidelines related to equitable genetic testing for people with neurodevelopmental disabilities. The findings identify several gaps and variable practices in society guidelines that have the potential to further exacerbate barriers to access and inequities in healthcare for people in multiply marginalized communities.

AUCD and AUCD's Network collaborators—including the Autism Intervention Research Network on Physical Health, the Leadership Education in Neurodevelopmental Disabilities Program at the University of California, Los Angeles and the University of California, Riverside, and the Disability Experience Expert Panel of the Ohio State University Nisonger Rehabilitation Research and Training Center—conducted a pilot study to report on the perception versus reality of what inclusion of people with disabilities represent in “inclusive” training curricula for medical and dental school faculty and administrators. The study identified gaps in inclusive training practices including meaningful engagement of people with disabilities in curricula goal setting and evaluation. Only a fraction of curricula included the social model of disability, reproductive health, or diagnostics in topics covered.

During the 119th Congress, AUCD will work to:

- Ensure persons with disabilities have access to quality, accessible, and affordable healthcare, including medical, dental/oral health, hearing, vision, behavioral/mental health, prescriptions drugs, habilitation, and durable medical equipment through the ACA, Medicaid, Medicare, and CHIP.
- Protect, enhance, and fully fund the ACA and its regulations; in particular, protect the provisions that provide for quality, accessible, appropriate, comprehensive, affordable, portable, and non-discriminatory coverage and benefits.
- Protect, enhance, and fully fund the Mental Health Parity and Addiction Equity Act and its regulations and the behavioral/mental health and substance use services provisions in the ACA.
- Ensure that there is transparency in health plan selection and that plans have an adequate network of providers.
- Ensure that laws, regulations, and policies protect against abuse and discrimination on the basis of disability in medical decision-making such as physician-assisted suicide, stem cell research, end-of-life care, and organ transplants, and ensure that persons with disabilities are included in all aspects of research with human subjects.
- Reduce healthcare disparities by improving data collection on disability status, race and ethnicity, gender identity, socioeconomic status, and other demographics to understand the full scope of healthcare disparities.
- Recognize persons with developmental and other disabilities as medically underserved populations.
- Expand opportunities and funding for the training of medical, habilitation, and behavioral/mental health and other healthcare providers about the needs of children and adults with disabilities, including the transition to adult care.
- Ensure that persons with disabilities have access to a full range of accessible information about healthcare including sexual and reproductive care.
- Protect, enhance, and fully fund the Autism Collaboration, Accountability, Research, Education, and Support (CARES) Act and ensure more research and training on autism and other neurodevelopmental disabilities across the lifespan and in diverse populations.