

State Advocacy Talking Points

In utilizing the state talking points, you know what will resonate best with your state leadership, pick and choose to adapt a message that works for you.

- The decision to restructure the federal Department of Health and Human Services, including the Administration on Community Living, is reckless and misinformed.
- People with intellectual and developmental disabilities will suffer, as this
 restructuring threatens to erode vital services offered by Developmental Disability
 Councils, University Centers of Excellence in Developmental Disabilities, and
 Protection and Advocacy networks across the country.
- In [STATE NAME], our [NUMBER OF] Centers for Independent Living and [NUMBER OF] Area Agencies on Aging provide crucial services that allow people with disabilities and older adults to stay in their communities, preventing expensive institutional care.
- Institutional care costs are higher than the costs of home and community-based services (HCBS). Average <u>HCBS program expenditures are generally lower</u> than states' estimated costs for serving beneficiaries with intellectual or developmental disabilities in institutional settings.
 - In 2022, 2.5 million HCBS users accounted for \$17.0 billion in HCBS spending, while about 100,000 institutional users in the same age range accounted for \$3.5 billion in institutional spending (CMS).
- These services are cost-effective and life-saving—labeling the gutting of these programs as a "cost-saving transformation" is not only misleading, but also harmful.
- People with disabilities have the right to live in the community—to be treated equally and be seen as equal participants in society.
- ACL is an integral part of the network of state, local, and federal government agencies that work to fulfill the spirit of the Olmstead decision and the promise of the Americans with Disabilities Act, protecting the hard-won civil rights that people with disabilities fought for.
- This move to dismantle ACL and restructure HHS is a clear step backward, not forward.



Program Specific Talking Points

UCEDDs

- The mass staffing reductions and reorganization announced at HHS will affect the capacity and expertise at ACL, especially the plan to eliminate the ACL and split its functions across three other agencies.
- The University Centers for Excellence in Developmental Disabilities Education, Research, and Service get core funding from the Administration on Community Living (ACL) within HHS. They have played key roles in every major disability initiative over the past four decades.
- UCEDDs are a vital national resource for addressing issues, finding solutions, and advancing research related to the needs of people with disabilities and their families.
- Without UCEDDs, people with disabilities, members of their families, state and local government agencies, and community providers will lose a vital connection to a program that produces impactful research, services, and training.
- People with disabilities have long fought for the right to live in the community.
 Decimating the systems that support them jeopardizes their health and safety and threatens their hard-won civil rights.

LENDs

- Consolidating HRSA into the Administration for a Healthy America (AHA) with Office of the Assistant Secretary for Health (OASH), Substance Abuse and Mental Health Services Administration (SAMHSA), Agency for Toxic Substances and Disease Registry (ATSDR), and National Institute for Occupational Safety and Health (NIOSH) while also cutting staff across HHS will come at the cost of losing the expertise and support that HRSA and MCHB provide to LENDs.
- In the face of already existing workforce shortages for qualified professionals who serve children with disabilities, HHS cuts to staff and potential future cuts to funding will only further exacerbate these shortages.
- Leadership Education in Neurodevelopmental Disabilities (LEND)
 Programs improve the lives of people with disabilities by providing high-quality, interdisciplinary training to health care providers and other professionals that address the needs of children and youth with autism and other developmental



disabilities.

- LEND Programs prepare trainees to assume leadership roles and help meet the complex needs of children with autism and other developmental disabilities.
- In the absence of LEND Programs, there will be detrimental workforce shortages of qualified professionals able to screen, refer, and provide services to children and youth with autism and other developmental disabilities.

IDDRCs

- AUCD's Intellectual and Developmental Disabilities Research Centers (IDDRCs)
 membership organizations are funded by NIH *Eunice Kennedy Shriver* NICHD to
 advance our understanding of the biological processes that contribute to brain
 health across the life span.
- The IDDRC Network amplifies the overall impact and reach of NIH Research Projects through their invaluable capacity-building and infrastructure support.
- The IDDRCs' scientific and clinical findings are key to developing cutting-edge
 tests for detecting and diagnosing brain health, creating new behavioral,
 biological and biochemical therapies, and improving assistive technologies so
 that people with disabilities can live independently and fully participate in their
 communities.
- In the absence of IDDRCs, there will be a gap in discoveries and technologies that have been essential for advancing healthcare for people with disabilities as well as the loss of an ecosystem that advances participation of people with disabilities within the research enterprise.

Federal Advocacy Talking Points

- ACL manages and distributes federal funding for services such as home care, nutrition assistance, and caregiver support. ACL ensures that older adults and people with disabilities can meet their most basic needs.
 - At a time when the vast majority of aging adults, and nearly all disabled people want to live in their communities, this disruptive change threatens to increase rates of institutionalization, homelessness, and long-lasting economic hardships.
- ACL streamlines programs and services for people with disabilities spreading it across agencies is actually inefficient.



- ACL was created by unifying agencies serving seniors and people with disabilities to build efficiencies across populations cutting unnecessary bureaucracy and improved coordination, directing more resources to actually delivering services and supports to people with disabilities and their families.
- The current proposal to split up ACL across other agencies in HHS will directly counter its purpose as a hub across HHS and with other Departments to coordinate services and supports critical to disabled people and older adults, such as Long-term Services and Supports and affordable housing, facilitating federal, state and local cross-sector partnerships focused on efficient use of limited resources.
- ACL has coordinated many interagency initiatives like the National Strategy to Support Family Caregivers and the Interagency Coordinating Committee on Healthy Aging and Age-Friendly Communities
- Cuts across the federal government already have been shown to cause less efficiency. Similarly, mass staffing cuts to HHS will directly impact the services people with disabilities rely on.
 - <u>Example</u>: Staff in the Department of Education's seven OCR regional offices that were recently closed were working on 6,896 cases leaving thousands of students in potentially unsafe learning environments—or out of school entirely—and without any clear plan for resolution. Caseloads are expected to explode to an estimated 86 cases per investigator—an increase of 206 percent.
- The Administration has announced its intention to move significant work supporting students with disabilities under the Individuals with Disabilities Education Act (IDEA) and other education services from the Department of Education to HHS. Cuts to HHS personnel and agencies expected to now serve those same individuals with disabilities in both education and health services can only overburden the agency and personnel, and harm services to people with disabilities.
- Without Federal programs and funding, the state you (policymaker) represent will have to make up funding differences with its own budget or lose the programs and services people with disabilities and their families rely on.
 - o If federal funding for these services is cut, states will need to make up the difference or reduce services available to seniors and people with disabilities, endangering their ability to live independently in the community.



 The work of HHS is not wasteful, fraudulent, or abusive. In many ways, agencies in HHS coordinate and streamline federal programs that support people with disabilities. Thoughtlessly slashing and restructuring the agency will only harm people with disabilities and will not serve the purpose of "efficiency."

Plain Language Talking Points

- People with disabilities and their families are worried about the cuts the Administration is making to agencies and programs that work for people with disabilities.
 - We are worried about special education and cuts at the Department of Education because we don't want students with disabilities to lose their supports at school. We are worried students with disabilities are going to have fewer protections in school and become isolated from students without disabilities.
 - We are worried about the restructuring of HHS, and how ACL going away will hurt people with disabilities and their right to live and work in the community.
 - We are worried about staffing cuts at Social Security that will make it harder for people with disabilities to access SSI or SSDI.
- Programs that serve people with disabilities are important and should not be considered wasteful.
- HHS does important work that supports people with disabilities living in the community. It helps us get healthcare and home and community-based services.
- We do not want to go back to living in institutions. We want to live in the community, work in the community, and be treated equally.