

Administration for Community Living

Celebrating 10 years of advancing independence, integration and inclusion

ACL was built on the fundamental principle that all people, regardless of age or disability, should be able to live independently and fully participate in their communities. By advocating across the federal government for older adults, people with disabilities, and families and caregivers; funding services and supports provided by networks of community-based organizations; and investing in training, education, research, and innovation, ACL helps makes this principle a reality for millions of Americans.

The Administration for Community Living (ACL) was established on April 18, 2012, bringing together federal advocacy for older adults and people with disabilities, along with most federal human services programs for older people and people of all ages with intellectual and developmental disabilities. The agency grew quickly, with the transfer of programs with similar missions from other agencies, including independent living, assistive technology, and traumatic brain injury programs; paralysis and limb-loss resource centers; programs that help people navigate their Medicare benefits and the health care system; and the federal government's primary disability research organization.



As one agency, ACL's programs are better able to leverage learnings and best practices for meeting the similar needs of people with disabilities and older adults. Joining forces in one agency also gave the disability and aging communities a larger voice – together, they are better able to ensure that the unique needs of people with disabilities and older adults are considered in policies, programs, and planning. At the same time, ACL continues to advocate for and develop and manage programs related to the issues that affect only older adults or only people with disabilities.

This work has never been more important. There are more than 77 million people who are 60 or older, and 61 million people with disabilities living in the United States, and both populations are growing. Community living is overwhelmingly preferred by older adults and people with disabilities, and people are generally happier and healthier when they live in their own communities. Expanding community living also is critical to lowering health care costs – in most cases, it costs less to provide the services and supports people need to live in the community than it costs to provide institutional care. Finally, this work affects all of us – more than two-thirds of us will need assistance with daily activities as we age, and one in seven of us is providing that support to an older adult or person with a disability living in the community. At some point in our lives, nearly all of us will either need or provide the assistance that makes community living possible.

In celebration of ACL's 10th anniversary, we've pulled together some of the most significant milestones, accomplishments, and shaping events from our first decade, as well as some highlights of the work we are doing today.



Founding Milestones

- On April 18, 2012, Secretary of Health and Human Services Kathleen Sebelius combined the Administration on Aging, the HHS Office on Disability, and the Administration on Developmental Disabilities to form the Administration for Community Living.
- In the FY 2014 annual appropriation, Congress transferred to ACL the State Health Insurance Assistance Program from the Centers for Medicare & Medicaid Services and the Paralysis Resource Center from the Centers for Disease Control and Prevention (CDC).
- The Workforce Innovation and Opportunity Act (WIOA) of 2014 transferred the National Institute
 on Disability, Independent Living, and Rehabilitation Research and the Independent Living and
 Assistive Technology programs to ACL from the Department of Education in FY 2015. That same
 year, the Limb Loss Resource Center was transferred from CDC to ACL.
- In the FY 2016 annual appropriation, Congress transferred the Traumatic Brain Injury Program from the Health Resources and Services Administration to ACL.

COVID-19 Response and Recovery

People with disabilities and older adults have been disproportionately impacted by the COVID-19 pandemic. In addition to significantly increased risk of serious illness and death, many faced the serious threat of being forced to move from their homes into nursing homes and other institutional settings when they were cut off from the services they need to live independently due to physical distancing measures and workforce shortages. Many who contracted the virus were unable to return home following a hospitalization for the same reason.

Those who remained in the community faced increased social isolation and barriers to accessing health care, including COVID-19 testing, treatment, and vaccinations. All of these effects were even more pronounced for people with disabilities and older adults who face additional barriers due to race, ethnicity, sexual orientation, gender identity, income, language spoken, or other factors.

The following are just a few examples of how ACL and the aging and disability networks have been working together to address these issues since the start of the pandemic.

Providing critical services and support to make it possible for older people and people with disabilities to continue living in the community

• As the pandemic took hold, the disability and aging networks quickly adapted programs and formed new partnerships to continue to meet the pressing needs of people who had received services before the pandemic. They also found ways to meet increased needs created by the closure of locations that provide services in the community and difficulties families faced in supporting loved ones due to physical distancing requirements. For example, the network significantly increased the number of home-delivered meals and created "grab-and-go" meals that could be picked up from congregate nutrition sites. They established virtual services, such as wellness checks and telephone reassurance, and employed video-teleconferencing services to promote face-to-face interaction for program participants with family members and program staff.



 To support that work, ACL distributed more than \$3.2 billion in supplemental funding in FY 2020 and FY 2021.

Upholding the civil rights of people with disabilities and older adults

• Throughout the COVID-19 pandemic, ACL has worked closely with the HHS Office for Civil Rights (OCR) and our grantees to protect the civil rights of the populations we serve. For example, ACL worked closely with OCR on <u>guidance related to crisis standards of care</u> to ensure that people with disabilities and older adults do not face discrimination in accessing lifesaving care. ACL's networks have been at the forefront of the fight when discrimination has occurred, bringing issues to OCR's attention, providing legal assistance and other support to individuals who were unable to access care, and providing technical assistance to help health care systems correct discriminatory policies and practices.

Accelerating vaccination of older adults and people with disabilities

- In the spring of 2021, ACL, in partnership with CDC, <u>awarded nearly \$100 million in grants</u> to the aging and disability networks to support outreach, education, and direct assistance to help older adults and people with disabilities get vaccinated. With these grants, the networks provided assistance with scheduling vaccine appointments, transportation to vaccine sites, direct support services needed to attend vaccine appointments, connection to in-home vaccination options, education about the importance of receiving the vaccine to people with disabilities and older adults, and more.
- This funding also increased the capacity of the <u>Eldercare Locator</u>, a national hotline that connects older adults and caregivers to services and resources in their communities, allowing the service to offer vaccine information to more than 63,000 people. It also allowed ACL to launch a similar resource for people with disabilities the national <u>Disability Information and Access Line (DIAL)</u>. Launched on June 1, 2021, DIAL has helped more than 40,000 people find the services and resources they need.

Promoting access to masks and COVID-19 tests

- Through a partnership between ACL and the Health Resources and Services Administration
 (HRSA) announced in February 2022, HRSA-funded community health centers and rural health
 clinics and ACL's aging and disability networks are working together to distribute at-home test kits
 and N95 masks to underserved and hard-to-reach older adults and people with disabilities.
- The Disability Information and Access Line also is helping connect people with disabilities to free tests and masks. For people who can use an at-home test, DIAL operators are available to assist with ordering free tests; understanding instructions for test administration and test results; or providing alternative instructions for those unable to access, read, or understand the manufacturer's version. For those who cannot use an at-home test, DIAL operators can assist individuals with ordering tests to collect a specimen that can be mailed back for results. For individuals who cannot use either an at-home test or an alternative "swab and send" test, DIAL operators can assist callers with locating their state or local health department and/or disability and aging resources for additional assistance with other testing options that may be available in



their community, including identifying potential in-home testing options, or assistance with transportation or companion support to visit a community-based testing site.

Sharing lessons learned and preparing for the future

- Expanding the public health workforce in the aging and disability networks: In January 2022, ACL <u>began distributing \$150 million</u> in public health workforce funding provided through the American Rescue Plan to ACL's networks to expand the capacity of the public health system to meet the needs of people with disabilities and older adults.
- Addressing the needs of people with long COVID: ACL is playing a leading role in the wholeof-government effort to meet the needs of people with long COVID. ACL is working closely with
 partners such as the HHS Office of Civil Rights and the Departments of Justice, Labor, and
 Education to raise awareness of long COVID as a potential cause of disability, protect people
 with COVID-related disabilities from illegal discrimination, and connect people with long COVID
 to the resources and supports they need.
- Supporting research about the impacts of the COVID-19 pandemic on the disability
 community: ACL's National Institute on Disability, Independent Living, and Rehabilitation
 Research has supported a number of projects that have explored the disproportionate effects of
 the COVID-19 pandemic on people with disabilities. That work has illuminated the need for further
 research and will inform the development of interventions to better support people with
 disabilities, both during national emergencies and in daily life.

Looking to the Future: Strengthening the Community Living Infrastructure

The pandemic both demonstrated the critical importance of the 20,000 community-based organizations that make up ACL's networks and laid bare the fragility of our nation's system of supporting older adults and people with disabilities to live in the community. The impact of the longstanding shortages in the workforce that provides paid care, our dependence on volunteers, and the extent to which family caregivers must fill the gaps when services are not available quickly became clear. The pandemic also exacerbated the challenges of family caregiving. Balancing work, family, and caretaking became even more difficult, and in many cases, caregivers had to completely leave the workforce.

The pandemic has created a new urgency and momentum for ACL's work: Improving the availability and quality of home and community-based services, supporting families and other informal caregivers, advancing the inclusion of people with disabilities and older adults in all aspects of American life – in other words, strengthening the infrastructure of community living.

Advancing Equity for Older Adults and People with Disabilities

Advancing equity is at the core of everything ACL does. Our work advances inclusion, integration, and independence throughout life, which includes ensuring equitable opportunities for education, employment, self-determination, and all other elements of American life. Most of our programs focus on those in greatest need, which often includes people who – in addition to being marginalized due to age and/or disability –



face additional barriers due to race, ethnicity, sexual orientation, gender identity, poverty, language spoken, or other factors.

In support of President Biden's Executive Order 13985 Advancing Equity and Support for Underserved Communities through the Federal Government, ACL also has launched several new efforts focused specifically on advancing equity. These include:

- Older Adults' Equity Collaborative (OAEC): The Older Adults' Equity Collaborative includes five
 ACL-funded national Minority Aging Technical Assistance and Resource Centers that each focus
 on serving a unique community. Together, they work to ensure access and equity across aging
 services programs by providing technical assistance to the aging services network. To promote
 and support collaboration, coordination, and cross-cutting efforts among the OAEC organizations,
 ACL also funds a coordinating center administered by the Center for Healthy Aging at The New
 York Academy of Medicine.
- Promoting employment opportunities for researchers from underrepresented populations: ACL's National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) has long emphasized the importance of applicants' employment of people with disabilities and others who have traditionally been underserved and/or underrepresented in the research workforce. In March 2022, NIDILRR proposed to amend its regulations to include updated criteria to better evaluate the extent to which grant applicants conduct outreach to and hire people with disabilities and people from other groups that traditionally have been underserved and underrepresented. With this change, NIDILRR seeks to strengthen true inclusion of people with disabilities in every aspect of the disability research enterprise.
- Center for Equity, Disability, and Intersectionality: ACL will award a new grant in September 2022 to establish a national resource center to increase the inclusion of people with disabilities and to improve the cultural competency of supportive services and other resources for people with disabilities.
- Advancing equity in disability research: In April 2022, ACL announced funding opportunities to establish three new Rehabilitation Research and Training Centers (RRTC) focused on equity one in each of the research domains funded by the National Institution on Disability, Independent Living, and Rehabilitation Research (Employment, Health and Function, and Community Living and Participation). Each will conduct research to generate new knowledge to support development and implementation of evidence-based policies, practices, or interventions for achieving more equitable outcomes among the heterogeneous population of people with disabilities. In addition, the three Equity RRTCs will coordinate and share information with each other and with ACL's other equity resource centers: the Center for Equity, Disability, and Intersectionality and the Older Adults' Equity Collaborative.

Expanding Access to Home and Community-Based Services (HCBS)

A key priority of ACL is to expand access to services provided in people's homes and communities to help people with disabilities and older adults live in the community instead of in institutions.



- Affordable, accessible housing and supportive services: In partnership with the Department of Housing and Urban Development (HUD) and in collaboration with Centers for Medicare & Medicaid Services (CMS), the HHS Assistant Secretary for Planning and Evaluation (ASPE), and the Substance Abuse and Mental Health Services Administration (SAMHSA) within HHS, ACL launched the HHS-HUD Housing and Services Resource Center (HSRC) in December 2021. The goal of the HSRC is to coordinate federal resources and facilitate state and local partnerships between state Medicaid, disability and aging agencies; ACL's disability and aging networks; public housing agencies and authorities; and homeless, disability, and aging service providers.
- Supporting transitions from institutions to home: As opportunities to expand access to HCBS grow through Money Follows the Person, supplemental services, and other value-based health care programs, ACL is supporting the disability and aging networks' ability to partner with nursing homes and hospitals to safely transition individuals to home with services and supports. ACL is working in partnership with CMS and HUD to provide technical assistance to states to strengthen partnerships among the disability and aging network agencies, state Medicaid agencies, and housing agencies to help people transition out of institutions, braid funding, and secure home and community-based services and housing to live in the community.
- Strengthening and expanding the direct care workforce: Direct care workers (DCWs) provide vital services to help people with disabilities and older adults live independently in the community. Demand for these essential professionals is at an all-time high as the result of growth in home and community-based services and an increase in the number of people with disabilities and older adults who need support to live at home. With an average turnover rate of 45% and significant challenges to recruiting and retention, however, the demand has far exceeded supply for many years. The workforce shortage worsened during the COVID-19 pandemic, as direct care workers were quarantined or left the workforce. Without an adequate number of direct care workers, many people are unable to obtain the services they need, which limits full participation and true inclusion in society.

There are multiple reasons for difficulties in recruiting and retaining DCWs, including low wages, lack of benefits, lack of training and supportive supervision, few promotion opportunities, and competition with other higher paid jobs. In 2022, ACL, in collaboration with the Department of Labor, and CMS and ASPE within HHS, will launch a resource and technical assistance center to help states begin to address these challenges and to strengthen and grow the direct care workforce. The center will provide resources, technical assistance and, through learning collaboratives, opportunities for states and providers of direct care services to share successful strategies and learn from each other.

Collaboration to improve the quality of home and community-based services: HCBS are
primarily funded by Medicaid, and ACL has a very close working relationship with the Centers for
Medicare & Medicaid Services (CMS). ACL is working closely with CMS on implementation of the
HCBS Settings Rule, which for the first time set standards to ensure that all people receiving
HCBS have access to the full benefits of community living. ACL and CMS also are collaborating
on initiatives around HCBS quality, strategies to strengthen the direct care workforce, and
institutional diversion and transition.



Aligning health care and social services and addressing the social determinants of health:
 Since 2012, ACL has worked with public and private partners to build the business skills and
 enhance the effectiveness, efficiency, and sustainability of the aging and disability networks.
 More recently, these efforts have evolved to support expanding and strengthening the capacity of
 ACL's networks to effectively and efficiently partner with the health care sector to address social
 needs. ACL also is working with partners across HHS to develop a department-wide Social
 Determinants of Health Action Plan and to accelerate the formation of community-level
 infrastructure to provide holistic, person-center services that support overall health and well being.

Supporting Families and Caregivers

Families and other informal caregivers have long been the backbone of America's caregiving infrastructure. Each year, more than 53 million people provide a broad range of assistance to support the health, quality of life, and independence of someone close to them. With the populations of both older adults and people with disabilities growing, supporting family caregivers is a critical public health issue that affects everyone, and is a key focus for ACL.

- National Family Caregiving Strategy: In 2021, ACL delivered two reports to Congress on issues facing family caregivers and recommendations for addressing them: the Recognize, Assist, Include, Support, and Engage (RAISE) Family Caregiver Act report to Congress and the Supporting Grandparents Raising Grandparents (SGRG) Act report to Congress. ACL is now working with the RAISE and SGRG advisory councils and federal partners to develop a national caregiving strategy, which will be delivered to Congress in fall 2022.
- Building dementia-capable communities: More than 5 million Americans are currently living
 with Alzheimer's disease and related dementias (ADRD), and researchers expect that number to
 double within the next three decades. Most people with ADRD will need day-to-day assistance
 from family members in order to retain their independence, quality of life, and well-being. ACL is
 working to expand dementia capability of communities across the nation, including tribal
 communities, and to increase training and support for caregivers.
- Lifespan respite: Respite care offers caregivers temporary relief from the daily routine and stress that can come with providing care. Respite can play a critical role in strengthening family stability and maintaining the health of the family caregiver. Through the Lifespan Respite Care program, ACL is working with states to enhance and strengthen their respite systems, improve coordination and dissemination of respite services, streamline access to respite programs, fill gaps in services, and improve the overall quality of respite services.
- Advanced care planning for people with intellectual and developmental disabilities (I/DD):
 Nearly one million families in the U.S. include adults with I/DD living with aging caregivers and
 that number is expected to grow in the coming years. About two-thirds of these families do not
 have advanced care plans in place, and families often are concerned with what will happen to
 their loved ones with I/DD when they are no longer able to care for them. To build capacity across
 the disability and aging networks to support people with I/DD and their families, particularly in
 advanced care planning, in Oct 2021, ACL launched a new initiative to bring together State
 Councils on Developmental Disabilities, state developmental disability agencies, and state aging
 agencies.

Supporting people with behavioral and mental health conditions

- I/DD and co-occurring behavioral and/or mental health conditions: People with I/DD who have co-occurring behavioral and/or mental health conditions have tremendous unmet needs due to system fragmentation and a general lack of qualified mental health professionals who can provide specialized services to this population. In 2021, ACL awarded five National Training Initiative (NTI) grants to University Centers for Excellence in Developmental Disabilities to collaborate with state stakeholders to improve systems integration to more effectively address these barriers. In 2022, ACL will award a five-year grant to create a national resource center to provide integrated and culturally competent mental health services and home and community-based services to people with I/DD, their families, and others in their support systems.
- Older Adults Mental Health Awareness Day: Mental health is critical to well-being at every age.
 Since 2018, ACL has partnered with the Substance Abuse and Mental Health Services
 Administration (SAMHSA) to present the Older Adult Mental Health Awareness Day, a day-long symposium on meeting the mental health needs of older adults. The event has grown each year, and registration for the 2022 event tops 4,000.
- Research on Mental Health: For 30 years, ACL's National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) has partnered with SAMHSA to fund research related to disability and mental health. Two prominent research tracks have focused on youth and young adults with serious mental health conditions, and adults with serious mental illness. The research, training, and technical assistance that NIDILRR has co-funded over the years has helped to both solidify the research-to-practice pipeline and to establish a number of evidence-based practices and approaches, including Wellness Recovery Action Plan (WRAP), a process for creating action plans to achieve goals and support health and wellness; Helping Youth on the Path to Employment (HYPE), a career development program designed for young adults with mental health conditions to enhance long-term vocational outcomes; and more.
- Commit to Connect: To tackle the challenge of combatting social isolation during COVID-19 and beyond ACL pulled together partners from across federal government, the aging and disability networks, philanthropy, and industry. Together, we created the Commit to Connect campaign, a public-private partnership that challenges each of us to do our part to connect and engage ourselves, reach out to others to help them to do the same, and work together to create tools and resources.

Protecting Rights and Preventing Abuse and Neglect

Abuse and neglect rob people of their fundamental human rights, erode equal opportunity, and harm health and well-being; equity and inclusion cannot be achieved in the face of abuse. Preventing abuse, neglect, and exploitation of older adults and people with disabilities has been a priority for ACL since its inception.

Elder Justice Coordinating Council: In 2012, then-Secretary of Health and Human Services Kathleen Sebelius and then-Attorney General Eric Holder convened the first meeting of the Elder Justice Coordinating Council (EJCC). In the years since, ACL has convened the EJCC on behalf of the HHS Secretary. The EJCC provides national policy and program leadership on protecting the rights and preventing the abuse of older adults.



- Guardianship reform and advancing alternatives to guardianship: From the beginning, ACL has worked to uphold the right to self-determination, regardless of age or disability, through guardianship reform; development of an array of less restrictive options, such as supported decision-making; and programs that provide legal assistance and support to people subject to guardianship (including those who want to terminate their guardianship). ACL has been a key funder of the Working Interdisciplinary Networks of Guardianship Stakeholders (WINGS) project, through which states have created partnerships between courts and stakeholders to reform unnecessary and overbroad guardianship systems and to prevent, detect, and address guardianship abuse. Other ACL programs provide direct support to older adults and people with disabilities. One example is the Center on Youth Voice, Youth Choice, which helps young people with disabilities learn about and arrange alternatives to guardianship as they leave high school.
- Creating a "federal home" for Adult Protective Services (APS): Over the past decade, ACL has led federal efforts to support the critical work of APS programs through a variety of initiatives, including developing Voluntary Consensus Guidelines containing recommendations and best practices from the field and launching the first comprehensive national reporting system for APS programs, the National Adult Maltreatment Reporting System. In 2015, ACL awarded the first federal grants specifically designated for APS, awarding \$2.8 million to 11 APS programs. In FY 2021, ACL awarded \$180 million in grants to states to fund for the first time the federal APS program authorized by the Elder Justice Act in 2010. With those grants, states expanded remote work capabilities, improved reporting systems, improved responses to scams and fraud, provided direct services for APS clients, and more.
- Expanding and improving Long-Term Care Ombudsman services: In every state, long-term care ombudsmen are advocates for residents of nursing homes, board and care homes, assisted living facilities, and similar adult care facilities. They work to resolve problems of individual residents; bring about changes at the local, state, and national levels to improve care; and help residents and their families and friends understand and exercise rights guaranteed by law. Authorized in the Older Americans Act in 1972, the program has achieved two major milestones in ACL's first decade. In 2015, ACL published a long-awaited final rule to improve the consistency and quality of services provided to residents of long-term care facilities. In 2021, ACL provided funding to states to expand the reach of ombudsmen into assisted living facilities.
- Improving quality of home and community-based services and safety of group homes: With grants from ACL, eight states are currently developing, testing, and refining models for integrating systems for community-based monitoring of people living in group homes and other community settings and building capacity. The goal of this initiative is to provide states with a range of models and promising practices that can be used to improve quality of home and community-based services and strengthen protections against abuse and neglect of people with disabilities living in the community. This complements work that ACL is doing with the Centers for Medicare & Medicaid Services regarding quality measures, person-centered planning, and assurances that address health and safety.
- Mitigating the impact of the opioid epidemic on older adults: The opioid crisis has had a
 unique impact on many older adults. Because they are more likely to be prescribed opioids, they
 are at increased risk of abuse, neglect, and exploitation. Medication theft by caregivers can leave
 them with unmanaged pain, domestic disturbances caused by family members with opioid



addictions are causing older adults to be evicted from their homes, and addiction can drive family members to target the life savings of vulnerable elders to pay for drugs – and to become violent if denied. Later this year, ACL will award up to 20 two-year cooperative agreements to identify effective strategies and solutions for serving APS clients impacted by the opioid epidemic and by other substance use disorders. In addition, through our support of the Advisory Council to Support Grandparents Raising Grandchildren, ACL is also working to improve the lives of older adults who step in to raise grandchildren whose parents are misusing substances.

Expanding Access to Competitive Integrated Employment

Employment is a critical part of community inclusion for people with disabilities. Securing and maintaining employment helps many people to achieve independence and financial security in their communities.

- In 2021, ACL made strategic investments to expand access to competitive integrated
 employment through a Prize Competition and technical assistance support to its grantees. In
 October 2021, ACL announced the winner of the <u>Inclusive Talent Pipeline for American Business</u>
 <u>Prize Challenge</u>. The winner of the prize challenge was awarded \$100,000 to expand its inclusive
 technology recruitment platform to support employers and individuals with disabilities, particularly
 those with developmental disabilities.
- ACL's <u>Disability Employment Technical Assistance Center</u> is working with Centers for Independent Living, State Councils on Developmental Disabilities, Protection and Advocacy Systems, University Centers for Excellence in Developmental Disabilities, and grantees in ACL's Traumatic Brain Injury State Partnership Program to improve coordination and collaboration within the state systems that support people with disabilities in securing and succeeding in competitive, integrated employment. Through webinars, e-learning communities, and more, the Center is creating opportunities for programs to develop and share strategies.
- Strengthening Federal Partnerships to Jointly Advance Competitive Integrated Employment: As part of a federal interagency policy committee, ACL is working to address the systemic unemployment of Americans with disabilities. Last year, as part of our celebration of the anniversary of the Americans with Disabilities Act, HHS, the Departments of Labor and Education, and the Social Security Administration released a <u>fact sheet</u> on funding opportunities to help states expand access to competitive, integrated employment people with disabilities. The task force is working on additional interagency guidance that will be released later this year and recently held an interagency <u>webinar</u> on braiding, blending, and sequencing federal resources.

Ensuring Access to Democracy for Voters with Disabilities

Consistent with Executive Order 14019 on <u>Voting Access</u>, ACL <u>works to ensure that disabled and older Americans can participate in the electoral process</u>.

 The Voting Access Program authorized by the Help America Vote Act (HAVA) provides funding to Protection and Advocacy Systems to support their work to support people with disabilities in registering to vote, casting a vote, and accessing polling places.

