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CCD Marks the 25th Anniversary of the Supreme Court *Olmstead v Lois Curtis* Decision, Calls for Listening to the Voices and Needs of Disability Community Members

The Consortium of Constituents with Disabilities (CCD) Emergency Management, Health, Housing, International, Long Term Services and Supports, Rights, and Transportation Task Force Co-Chairs celebrate the twenty-fifth anniversary of the landmark Supreme Court decision of *Olmstead v. Lois Curtis*. The June 22, 1999 decision held that unnecessary institutionalization and segregation of people with disabilities is discrimination prohibited by the Americans with Disabilities Act (ADA) and Section 504 of the Rehabilitation Act of 1973. The highest court in our nation recognized the right of people with disabilities to be treated as equal members of our society, to live and work in their communities, and receive services in the most integrated setting, which is almost always outside of an institution.

The *Olmstead* decision stemmed from the bravery and steadfast advocacy of Lois Curtis and her co-plaintiff Elaine Wilson.¹ Curtis and Wilson, women with mental and intellectual disabilities, were approved to get services in the community and wanted to live in the community but remained in a state-run psychiatric unit in Georgia due to a lack of community-based services.

The late Supreme Court Justice Ruth Bader Ginsburg wrote the plurality opinion in a six-to-three ruling that Title II of the ADA requires local and state governments to ensure persons with disabilities can live and receive services in their communities when appropriate, the affected person does not oppose community-based treatment, and community-based services can be reasonably accommodated. The Court held that unjustified segregation, which “perpetuates unwarranted assumptions that persons so isolated are incapable or unworthy of participating in community life,” is a form of discrimination under the Americans with Disabilities Act. The Court recognized that “confinement in an institution severely diminishes the everyday life activities of individuals, including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment.”

While the *Olmstead* decision has improved lives, 25 years later much work remains. More than 268,980 people with intellectual and developmental disabilities live in congregate, institutional settings or are on waitlists for services and residential programs, and hundreds of thousands of people with mental health disabilities are involuntarily detained each year.² People with disabilities who remain in other types of institutions, such as prisons, long-term care hospitals, residential treatment facilities, and the roughly 1.2 million adults living in nursing homes are often under-counted and not included in these numbers.³ Multiply marginalized communities, including Black, Brown, and LGBTQI+ disabled people, are disparately impacted by the harms of institutionalization.

The rights of people with disabilities to live their lives to their fullest in the setting of their choice must be zealously enforced and reflected in policies, practices, and programs at every level of government. If we are to fully realize the promise of *Olmstead*, we ask policymakers to listen to the voices and needs of disability community members in the following areas:

Health

Access to quality, affordable, and timely healthcare services is essential for people with disabilities to maintain their independence and self-determination. However, people with disabilities still face numerous obstacles to obtaining and utilizing healthcare services, including inaccessible facilities and equipment and persistent biases from medical professionals. Additionally, chronic underfunding of the Medicare and Medicaid programs severely limits access through restrictive eligibility, extensive service authorization requirements, and inadequate provider networks. To address these issues, we support:

- Robust enforcement of the recently issued HHS 504 and Section 1557 rules, which prohibit discrimination based on disability, sex, gender or gender identity, race, sexual orientation, or national origin, and requires medical facilities and equipment to be accessible;
- Expansion of Medicaid in the 10 states that have refused federal incentives to do so, leaving many people with disabilities without access to healthcare;
- Mandatory competency training for medical professionals on how to interact with patients with disabilities;
- Permanent coverage of telehealth services for all qualified, enrolled providers by the Medicare and Medicaid programs to increase access to care for people with disabilities;
- Medicaid coverage of dental and oral healthcare;
- Improvement and expansion of Medicaid buy-in programs by substantially increasing income eligibility thresholds so that people with disabilities can work without losing access to Medicaid-funded services and supports.

Housing

People with disabilities are still heavily impacted by segregation and institutionalization because institutional bias is intact, and federal and state governments have never invested in a commensurate supply of service-ready, integrated, affordable, and accessible housing. The federal government can invest in programs that work and legislate new disability-forward housing solutions that ensure disabled people, particularly those who need support in their own homes, can live and thrive in homes and communities they choose. The following federal action is needed:

- Fully fund HUD Section 811 Project-based Rental Assistance (PRA) to be available in all states and territories. As such an effort is advanced, fully fund all Section 811 PRA renewals and appropriate at least \$500 million for new PRA for FY25.
- For HUD Section 811 Capital Advance, fund existing projects and implement proposed recommendations, including RAD and amending program criteria to ensure that no new dollars fund congregate, segregated settings.
- Fully fund the Housing Choice Voucher program, including the Mainstream Voucher Program, to all eligible people. As such efforts are advanced, fully fund all vouchers and spend \$100 million for new vouchers to ensure people with disabilities, including those stuck in institutions and those experiencing homelessness, can secure safe, decent housing in the community.
- Invest and strengthen HUD's commitment to fair housing enforcement and compliance across all programs because HUD fails to adequately address the onslaught of discrimination complaints based on disability submitted annually. In addition, HUD continues to have documented failures in meeting people with disabilities' requests for reasonable accommodations.
- Invest in effective and innovative housing and services partnerships, as evidenced by the Housing and Services Resources Center.
- Expand and reform the Low-Income Housing Tax Credit to ensure that all housing is rehabbed and produced in accordance with Section 504 of the Rehabilitation Act.

Emergency Management

Disasters are a critical juncture where people with disabilities are institutionalized in nursing facilities and other institutions. In order to interrupt the disaster-to-institution pipeline, as well as to protect the rights of people with disabilities over all, Congress reintroduced the Real Emergency Access for Aging and Disability Inclusion for Disasters Act (READI) (S. 1049) (H.R. 2371). The READI for Disasters Act will divert disabled people from institutions during disasters by creating training and technical assistance centers which will support disabled people in remaining in the community in disasters. It will also fund projects of national significance that will utilize innovative solutions to prevent institutionalization during disasters. Passage of READI will equip the nation to provide more disabled disaster survivors services in the most integrated setting that meets their needs as mandated by Olmstead.

International

There are more than 1 billion children and adults with disabilities worldwide, many are still segregated from society in abusive institutions with no autonomy and very little contact with their families and communities. Advocates for deinstitutionalization around the world have learned from the Olmstead decision and the services and support being provided to adults and families with disabilities through Home and Community-Based Services.

Long Term Services and Supports

Medicaid currently has an institutional bias -- institutional services like nursing facilities are mandatory and home and community-based services (HCBS) are optional. As a result, people with disabilities and older adults who prefer to receive services in their own homes and communities often must wait on years-long waitlists for HCBS, while others live in states where the services they need are simply not offered. To rectify this, we support:

- Increasing funding for HCBS in the short term, and making HCBS a mandatory Medicaid benefit in the long term;
- Addressing the direct care workforce crisis, so that individuals have meaningful access to the HCBS they are entitled to;
- Opposing legislation and Medicaid demonstrations that incentivize the use of institutions for adults and youth with mental health needs; and
- Making permanent successful programs such as Money Follows the Person and Spousal Impoverishment protections, to help rebalance spending towards HCBS, and eliminating practices that discourage people who need HCBS from utilizing it, and that are punitive, such as estate recovery.

Rights

States and localities continue to face a severe shortage of voluntary home- and community-based resources to meet the needs of people with disabilities, which places people in danger of unnecessary and harmful institutionalization. To advance the ADA's four key goals of equality of opportunity, full participation, independent living, and economic self-sufficiency, we call on our elected representatives to:

- Strengthen regulatory and sub-regulatory guidance and resources to promote civil rights protections for people with disabilities, including in the contexts of alternatives to guardianship, equal access to healthcare, community integration, parents with disabilities, and equal educational opportunities.
- Pass federal legislation that will improve the lives of disabled people, eliminate subminimum wages for people with disabilities, increase funding for home- and community-based services, increase diversion from institutions and the criminal legal system, expand access to health insurance and public benefits for disabled immigrants, and increase tax credits to promote greater access to all aspects of community living.
- Advance public policy around people with disabilities and the criminal legal system, including in the areas of crisis response, home- and community-based services and supports, and diversion at each stage of the criminal process. Institute systems that reduce interactions between law enforcement and people with disabilities, as well as avoid needless incarceration.

- Consider and center the voices of people with disabilities, especially multiply marginalized people with disabilities, in the development of new legislation and public policy at every level of government.
- Recognize the dignity and autonomy of all people, including people with disabilities, and that disability rights are civil rights and human rights and should be treated as such.

Transportation

To fully live independently in the community, people with disabilities need access to accessible transportation. Transportation connects individuals to medical and vital services, employment, social and recreational activities, and is, ultimately, necessary to live independently in the community. Congress must continue to pass laws that further accessible transportation and promote accountability with federal law compliance. Such actions include passing legislation that increase transparency in Amtrak’s progress to comply with the Americans with Disabilities Act and confirm a disability advocate for the Amtrak Board of Directors; ensure all autonomous vehicles are accessible for people with disabilities, including wheelchair users, and not limit their use for public transportation; and pass all legislation that expands accessible public transit and accessible, safe public rights of way, such as sidewalks and crosswalks. Only with accessible transportation can the purpose of *Olmstead v. L.C.* be achieved.

The undersigned applaud the decision and the then-Justices for their role in promoting integration for people with disabilities. CCD commits to continuing Lois Curtis and Elaine Wilson’s legacy, to raising expectations and continuing the fight for the right to live full lives outside of all institutions, and to advocating for the services and supports needed to make this right possible.

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¹ See the 2022 Statement from the CCD Board of Directors on the Passing of Lois Curtis: <https://www.c-c-d.org/fichiers/CCD-Board-Statement-on-Lois-Curtis-Passing-110922.pdf>.

² CSH I/DD Estimated Supportive Housing Need - 269,000 Homes, https://www.csh.org/wp-content/uploads/2019/05/IDD_web.pdf; <https://www.cbsnews.com/news/16000-people-disabilities-institutions-no-place-like-home-cbs-reports/>; Gi Lee and David Cohen, *Incidence of Involuntary Psychiatric Detentions in 25 U.S. States*, PSYCH. SERVS. (Nov. 3, 2020), <https://ps.psychiatryonline.org/doi/10.1176/appi.ps.201900477>

³ KKF, Total Number of Residents in Certified Nursing Facilities (2023). <https://www.kff.org/other/state-indicator/number-of-nursing-facility-residents/?currentTimeframe=0&sortModel=%7B%22colId%22:%22Location%22,%22sort%22:%22asc%22%7D>