



July 22, 2022

Senator Patrick Leahy
Senate Appropriations Committee
Washington, DC 20510

Senator Richard Shelby
Senate Appropriations Committee
Washington, DC 20510

Representative Rosa DeLauro
House Appropriations Committee
Washington, DC 20515

Representative Kay Granger
House Appropriations Committee
Washington, DC 20515

Senator Jeanne Shaheen
Senate Appropriations Committee
Subcommittee on Commerce, Justice,
Science and Related Agencies
Washington, DC 20510

Senator Jerry Moran
Senate Appropriations Committee
Subcommittee on Commerce, Justice,
Science and Related Agencies
Washington, DC 20510

Representative Matt Cartwright
House Appropriations Committee
Subcommittee on Commerce, Justice,
Science and Related Agencies
Washington, DC 20515

Representative Robert Aderholt
House Appropriations Committee
Subcommittee on Commerce, Justice,
Science and Related Agencies
Washington, DC 20515

Dear Senators Leahy, Shelby, Shaheen, Moran and Representatives DeLauro, Granger, Cartwright, and Aderholt:

The Collaboration to Promote Self-Determination (CPSPD) writes with serious concern regarding report language that has been included in the Fiscal Year (FY) 23 House Commerce, Justice, Science, and Related Agencies (CJS) Subcommittee Appropriations Bill Report and in the Labor, Health and Human Services, Education, and Related Agencies (L-HHS-ED) Appropriations Bill Report regarding the Supreme Court decision in *Olmstead v. L.C.* (1999). The report language as written is incorrect legally speaking, contrary to the rights of people with disabilities, and wrongfully decenters the opinions and needs of the individuals with disabilities themselves.

Founded in 2007, the Collaboration to Promote Self-Determination (CPSPD) is a national advocacy coalition of organizations representing people with intellectual, developmental, and other disabilities and their families, disability service agencies and individuals who have come together to bring about a significant modernization of the

federal adult system of services and supports for persons with disabilities. The mission of CPSD is to push for major systemic reform of the nation's disability laws and programs to advance economic security, enhance integrated community participation, and increase opportunities for people with disabilities so that they can lead self-determined lives. To that end, CPSD advocates for comprehensive, innovative public policy reform that prioritizes: access to health and long-term services and supports that people need to work; ensuring quality transition services from school to adult life through modernized education policies and practices; leading efforts to eliminate Section 14(c) of the Fair Labor Standards Act (FLSA) and building the capacity of service systems that lead to competitive, integrated employment (CIE) and economic advancement.

The report language we are concerned with is the following:

House CJS Report Language (pg. 68 of report)

Deinstitutionalization. —The Committee is aware of concerns about displacement of vulnerable persons from institutional programs as the result of litigation or the threat of litigation. The Committee also notes that in *Olmstead v. L.C.* (1999), a majority of the Supreme Court held that the Americans with Disabilities Act does not condone or require removing individuals from institutional settings when they are unable to handle or benefit from a community-based setting, and that Federal law does not require the imposition of community-based treatment on patients who do not desire it. The Committee is also aware of concerns that the approach taken by both Federally-supported Developmental Disabilities Assistance and Bill of Rights Act programs and the DOJ in its related prosecutorial discretion may in some instances adversely impact individuals who may be unable to handle or benefit from community integration and do not desire such care. The Committee strongly urges the Department to ensure that the Civil Rights Division properly accounts for the needs and desires of persons with intellectual and developmental disabilities in licensed intermediate care facilities, their families, caregivers and legal representatives, and the importance of affording patients the proper setting for their care, in its enforcement of the Americans with Disabilities Act and the 'Olmstead' decision.

House L-HHS-ED Report Language (pg. 217 of report)

The Committee notes that the Supreme Court decision in *Olmstead v. L.C.* (1999) held that the Americans with Disabilities Act (ADA) does not require removing individuals from institutional settings when they are unable to handle or benefit from a community-based setting and that the ADA does not require the imposition of community-based treatment on patients who do not desire it. The Committee notes that actions to close intermediate care facilities for individuals with intellectual disabilities may impact some individuals who do not meet the criteria for transfer to a community-based setting. The Committee urges HHS to

ensure that programs properly account for the needs and desires of patients, their families, and caregivers and the importance of affording patients the proper setting for their care.

In 1999, the United States Supreme Court held in *Olmstead v. L.C.* that unjustified segregation of persons with disabilities constitutes discrimination in violation of title II of the Americans with Disabilities Act (ADA). In a speech to The National Conference of State Legislators, then Secretary of the U.S. Department of Health and Human Services, Donna Shalala stated “*The Court ruled [in Olmstead] that when a professional determines that a disabled individual can live in the community -- and can be served there effectively -- the person must be given the **choice** of doing so.*” At its core, the *Olmstead* decision is about giving people with disabilities the choice to live in the community of their choosing. This landmark decision has helped people with disabilities leave institutions and other segregated settings of their own accord when previously it was believed that segregated settings were the only appropriate settings for people with disabilities. There is no doubt that thousands of people with disabilities have benefited from *Olmstead*.

The report language included in both bills is contrary to the rights of people with disabilities--the people who are most impacted by *Olmstead*. The language mischaracterizes the impact of *Olmstead* by indicating that people are forced into community settings against their will and against clinical judgment regarding their treatment needs. These statements are in direct conflict with the 3-prong test the Supreme Court created in *Olmstead* to determine when the ADA requires placement of people with disabilities in community settings rather than in institutions. Community-based services are required as alternatives to institutional placement when “(1) the State’s treatment professionals determined that such placement is appropriate, (2) the affected person does not oppose such treatment, and the (3) placement can be reasonably accommodated, taking into account the resources available to the state and the needs of others.” *Olmstead v. L.C.*, 527 U.S. 581, 606 (1999).

Relatedly, the regulations for the ADA require that a public entity administer its program, services, and activities in the “most integrated setting *appropriate* to the needs of qualified individuals with disabilities.” 28 C.F.R. § 35.130(d). The report language regarding deinstitutionalization and choice is contrary to well established law. People with disabilities are not moved to community placements against their will, nor against clinical judgment as to an *appropriate* setting. Despite multiple attempts by families of individuals to assert a “right to institutionalization” under *Olmstead*, this theory has been routinely dismissed by courts.

In regard to the CJS language specifically, we totally reject the suggestion that the approach taken by the Federally-supported Developmental Disabilities Assistance and Bill of Rights Act (DD Act) programs in its related prosecutorial discretion may in some instances adversely impact individuals who may be unable to handle or benefit from community integration and do not desire such care. We are unaware of the nature of

these concerns or any specific concerns that have been brought before the Committee. The CJS subcommittee has no jurisdiction over the DD Act programs and should not be asserting itself over these programs. The L-HHS-ED subcommittee does have jurisdiction over the DD Act programs yet makes no mention of these programs in their report language. It is inappropriate for the CJS subcommittee to weigh in on concerns about the DD Act programs, especially when they are unsubstantiated.

The report language also infers that individuals are offered little or no choice of setting during deinstitutionalization activities. However, choice plays an important role in supporting people with disabilities in exercising their rights, including to community inclusion. The report language is premised on the idea that people with disabilities are being forced out of preferred institutional settings to community settings against their will, against clinical advice, against the preferences of their families and caregivers, and at risk to themselves; and that the DD Act programs and the Department of Justice (DOJ) are the perpetrators of this forced deinstitutionalization. This could not be further from the truth. Both federal and non-governmental enforcers of the ADA, such as the Protection & Advocacy Agencies, are laser focused on enforcing integration mandates centered on choice. For example, the DOJ Statement Enforcement of the Integration Mandate of Title II of the Americans with Disabilities Act and *Olmstead v. L.C.* explicitly focuses on individual choice and maximizing those choices. In addition, people using Medicaid waiver services for the alternative to institutionalization have to be offered informed choice of the feasible alternatives to facilities, with again the focus being on the “at the choice of such individuals”. 42 U.S.C. § 1396n(c)(2)(C). In summary, the suggestion in the report language that community integration is being forced upon individuals is at a minimum a mischaracterization of *Olmstead* and at worst a legally incorrect interpretation.

The report language also suggests that the opinions and needs of individuals with disabilities themselves are not paramount in determining where they will live, perpetuating the same wrongs that the ADA, Section 504 of the Rehabilitation Act, and the *Olmstead* case are meant to correct. While family and caregivers are often important people in the lives of people with disabilities, as they are for people without disabilities, the choice of where to live and what type of life to have is that of the actual individual with disabilities. The interests of family and caregivers are not always in alignment with that of the individual with a disability. This report language puts outsized emphasis on the opinions of others when, in fact, the right to determine the type of setting in which they wish to live rests solely with the individual in question, regardless of disability status.

The ADA and *Olmstead* highlighted that unjustified institutional isolation perpetuates unwarranted assumptions that people are incapable or unworthy of participating in community life and that isolating people severely diminishes everyday life activities, including family relations, social contacts, education, work, and cultural enrichment. This report language by its very design discriminates against people with disabilities, which

in and of itself is contrary to the obligation of the federal government under Section 504 of the Rehabilitation Act. The federal government cannot preference the wants and needs of families over the actual individuals with disabilities any more than can individual states.

As our mission states, our organizations work to increase opportunities for people with disabilities so that they can lead self-determined lives. This report language is legally incorrect and will potentially work to close opportunities for people with disabilities. This language sets us back in terms of ensuring that people with disabilities can live the life they want to live. The *Olmstead* decision has been settled and while challenges to the ruling continue, it is very alarming to us that Congress would attempt to erode settled law of the land. We urge you to abandon this incorrect and inaccurate language. Should you have any questions or if you wish to discuss this further, please do not hesitate to contact Cyrus Huncharek (Cyrus.Huncharek@ndrn.org).

Sincerely,

Allies for Independence

Applied Self Direction

Association of People Supporting Employment First

Autism Society

Autistic Self Advocacy Network

Community Options

Marc Gold Associates

National Association of State Directors Of Developmental Disabilities Services (NASDDDS)

National Disability Institute

National Disability Rights Network (NDRN)

National Down Syndrome Congress

National Organization on Disability (Ridge Group)

Williams Syndrome Association

Association of University Centers on Disabilities (AUCD)

Center for Public Representation

National Alliance for Direct Support Professionals

Association of Programs for Rural Independent Living (APRIL)

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