

Where Are We Now?

The Olmstead decision 25 years later

Summer 2024 marks 25 years since the Supreme Court Decision *Olmstead v. L.C.*¹. This decision, recognized under Title 2 of the Americans with Disabilities Act and Section 504 of the Rehabilitation Act, states that people with disabilities have a right to get services and support in their communities. As a result, [much of home- and community-based services \(HCBS\) spending moved from institutions to community-based settings.](#) Although this was a positive outcome that changed the lives of many people with disabilities, we still have more work to do. As a person living with a disability, I'll share my perspective on the work that still needs to be done to support the vision of the Olmstead decision.

The problem with Home- and Community-Based Services (HCBS)

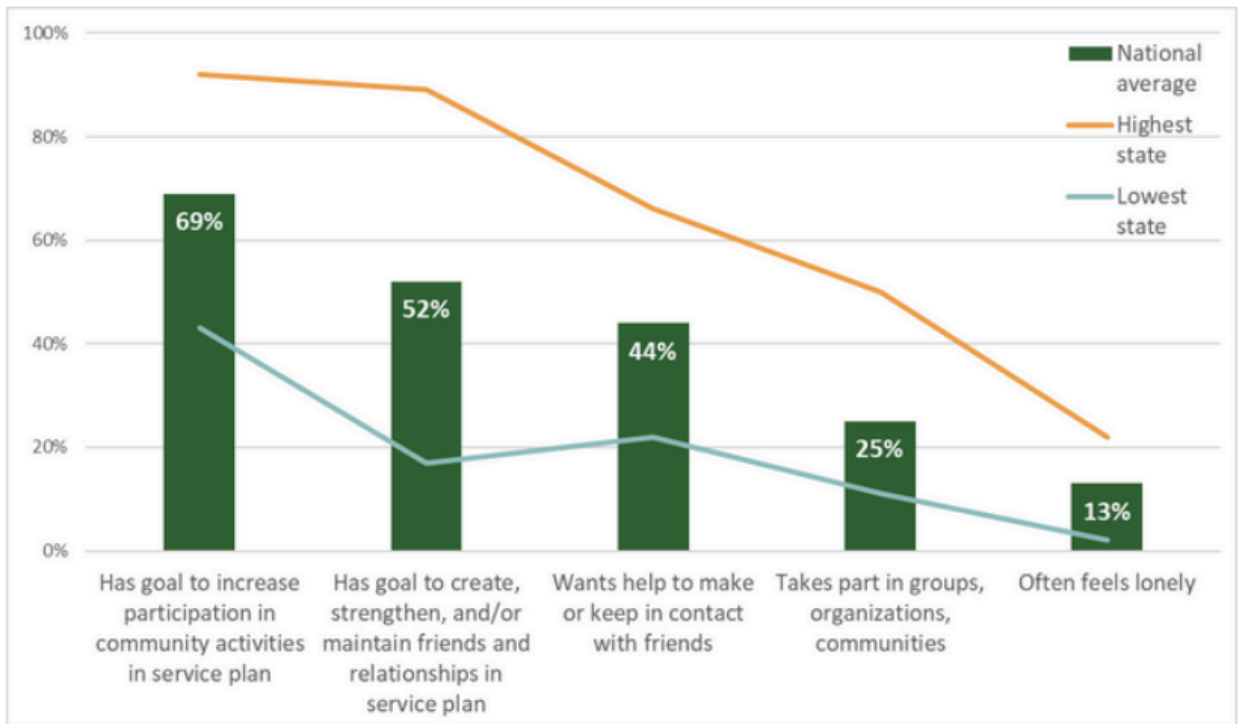
HCBS is challenging to obtain, and often, one needs to be in crisis to get services. I believe our HCBS system must be transformed so that it is more proactive. Right now, it is an entitlement for people with disabilities to live in institutions, but not

¹ "L.C." refers to Lois Curtis, an artist with developmental disabilities who was born in Georgia in 1947. In 1995, the Atlanta Legal Aid Society demanded in a lawsuit that Curtis be moved out of an institution and into the community.

an entitlement to live in the community and get HCBS support. HCBS is an optional service unlike institutional settings.

According to data from a recent National Core Indicators (NCI)² Aging & Disabilities survey, out of those people with disabilities who live in communities, 55% report that health limitations prevent them from participating in as many activities as they'd like. In the same survey, we learn 39% of people with disabilities don't take part in activities with others as much as they want (in-person or virtually). Community participation is not just a desire but a need. In fact, according to NCI's Intellectual and Developmental Disabilities (IDD) In-person Survey, two out of three participants aim to increase participation in their communities. Still, just one in four participants participate in groups, organizations, or communities. For more information, see this graph on social connections among people with IDD from NCI.

² National Core Indicators – Aging & Disabilities In-person Survey, 2022-2023.



Ideally, anyone with a disability who has poor adaptive functioning would be able to sign up for services, even if they are not at the level of nursing home care or in crisis. For instance, if I qualified for an HCBS waiver, my health issues and financial wellbeing would undoubtedly improve, and I'd have more opportunities to participate in my community. Creating a personal support program for anyone with a disability to receive support to live independently would also be a step in the right direction. This is especially important for adults with autism who can fall through the cracks. If people on the so-called "mild/moderate" end of the spectrum had access to even a modest level of support, then we

would have better health, mental health, employment and other life outcomes.

Being proactive: how HCBS can improve

One way HCBS can be more proactive is by making it easier to access services. We can prioritize accessibility by:

1. Requiring everyone to buy into long-term HCBS support via payroll tax or a fee based on income to pay for the cost of HCBS' expansion.
2. Requiring everyone to buy into Medicaid HCBS by paying a small monthly fee (as we do in some states with Medicaid Buy In).
3. Allowing Medicaid HCBS waivers to be portable from state to state. Allowing the portability of HCBS support will make our lives easier and ease the stress of raising kids with disabilities. It will give us more freedom and independence.
4. Reduce the administrative paperwork needed to apply for HCBS, Medicaid, Long-Term Care Medicaid, and other public benefits. Developing accessible online portals that are easy for anyone to use would make our lives easier (and save trees!).

Ultimately, support for people with disabilities must shift from system-centered to person-centered. We are more than a label, and our needs and wants—from reducing paperwork to participating in our communities—deserve to be met. Investment in a robust person-centered HCBS system is essential to ending health disparities, achieving better employment outcomes, and improving quality of life. Let's hope that in the next 25 years, we'll transform the vision of the Olmstead decision into reality.

About the author:

Nicole LeBlanc has a keen ability and interest in public policy and excels at communicating the needs of people with developmental disabilities to public officials. In April 2019, Nicole joined [Human Services Research Institute](#) (HSRI) as the coordinator of the Person-Centered Advisory and Leadership Group (PAL-Group) in the National Center on Advancing Person-centered Practices (NCAPPS). Nicole completed a 10-week internship at the Administration on Intellectual and Developmental Disabilities through the Washington Center in Washington, D.C., and has a professional studies certificate from the University of Vermont. Most recently, Nicole finished the Vaccine Education Initiative

Grant with the Autism Society of Maryland. Nicole is the winner of the 2019 David Joyce Advocate of the Year Award and 2022 Steven Bartlett Award for policy advocacy. Her personal motto is “control your own destiny or someone else will.”