

# A Quarter-Century Post-*Olmstead*, We're Still Waiting for Freedom

By Dom Kelly, Founder, President & CEO, New Disabled South

Twenty-five years ago, the Supreme Court's ruling in *Olmstead v. L.C.*<sup>1</sup> was seen as a victory for disability rights. Led by Georgia disabled advocates Lois Curtis and Elaine Wilson, the decision affirmed that disabled people belong in their communities, not in institutions. It was a powerful declaration: institutionalizing disabled people is discrimination. *Olmstead* was supposed to guarantee that no one would be forced into an institution simply because they needed care. The decision was meant to offer real autonomy, giving disabled people the chance to live at home, build relationships, and participate fully in society. But outrageously, both Lois and Elaine died without that promise being realized, and today, a quarter-century after the ruling, that promise still remains unfulfilled.

Today, [nearly 700,000 people](#) are waiting for Medicaid home- and community-based services (HCBS) waivers across the United States. These waivers allow disabled people to receive care in their own homes or communities rather than being forced into institutions or nursing homes. Some have been waiting for 10, 15, even 20 years. And without a waiver? Many are left with no choice but to enter a nursing home or survive without care.

In the American South alone, where my organization, [New Disabled South](#), focuses its work, nearly 75% of those 700,000 people are on waitlists. States with billion-dollar surpluses like Georgia, South Carolina, and Texas have the funds to clear these lists. However, year after year, lawmakers fail to act, leaving disabled people trapped in a system of institutional bias—the assumption that people have a right to receive care only in an institution, not in their own homes.

I know what it's like to need these services. I'm one of a set of triplets with cerebral palsy, and my parents relied on HCBS to get us the care we needed to stay at home rather than in an institution. Without that support, we could have been separated from our community and each other. But even with the waiver, my parents, like so many caregivers, faced enormous challenges—juggling work, caregiving, and simply trying to make ends meet.

Families waiting for HCBS waivers today are often forced into impossible situations. Many parents have no choice but to leave their jobs to care for their children, pushing them deeper into poverty. Caregiving shouldn't mean sacrificing everything else.

The situation is worsened by a care worker shortage fueled by poverty wages, as low as minimum wage. Many care workers, including those who are themselves disabled, can't afford to stay in these jobs, leaving families without the services they've waited years to receive. We can't rely on the small, incremental changes that have been the standard operating procedure in our states for years. State governments must commit to fully funding HCBS and paying care workers a livable wage to meet the growing demand.

As we reflect on 25 years since Olmstead, we need to confront the truth: the promise of this ruling remains unfulfilled. Disabled people deserve better than institutional bias and endless waitlists. We need lawmakers to prioritize funding HCBS and to ensure care workers earn the wages they deserve. No more excuses. No more inaction. The time for radical change is now. Every disabled person deserves the chance to live and thrive in their own home and community, with the support they need and the freedom to make their own choices. We owe it to the legacies of Lois and Elaine, and to the millions of disabled people waiting for care today, to fight for that future.

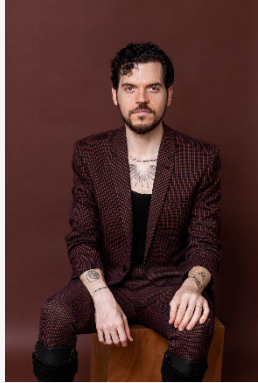
As readers of the Journal of Humanities in Rehabilitation, your voices are powerful. Together, we can advocate for the fulfillment of Olmstead's promise. Join us in demanding change—engage with local policymakers, spread awareness, and support initiatives that prioritize community-based care for all disabled individuals. The time for action is now; let's work together to make autonomy and freedom a reality.

To learn more about the work of the [New Disabled South](#) and for more resources for disability advocacy, please visit their website, including their project [Plain Language Policy Dashboard](#), which breaks down complex legislation into plain language to improve accessibility.

## References

1. U.S. Department of Justice. (n.d.). *Olmstead v. L.C.* Available at: [https://archive.ada.gov/olmstead/olmstead\\_about.htm](https://archive.ada.gov/olmstead/olmstead_about.htm). Accessed October 29, 2024.

## *About the Author*



Dom Kelly is the Co-Founder, President & CEO of New Disabled South, a 501(c)(3) nonprofit organization, and [New Disabled South Rising](#), its 501(c)(4) arm. He has been organizing in the South since 2009, committed to building a progressive future for disabled people in his region. His previous roles as a senior advisor and founding staff of Stacey Abrams' gubernatorial campaign, and as a lead fundraiser and advisor for her voting rights organization Fair Fight Action, both led him to make his vision for New Disabled South a reality.

Dom is one of a set of triplets born with Cerebral Palsy and has been a disability advocate since he was four years old. Starting when he was a young teenager, Dom and his brothers played around the world with their rock band A Fragile Tomorrow, touring and collaborating with artists like Indigo Girls, Joan Baez, Toad the Wet Sprocket, The Bangles and more and releasing 6 records over 15+ years.

He received a Master of Science in Nonprofit Leadership degree from the University of Pennsylvania's School of Social Policy and Practice where he also received the Excellence in Social Impact award. Additionally, he holds a bachelor's degree in music production, a master's degree in journalism, an executive certificate in social impact strategy, and a graduate certificate in interdisciplinary disability studies. Dom is a part of the 2025 global cohort of [Atlantic Fellows for Health Equity](#), was chosen as a [2024 Rockwood National Leading From the Inside Out Yearlong Fellow](#), and was one of ten winners of [The J.M. Kaplan Fund's 2023 Innovation Prize](#). He was a 2021 New Leaders Council fellow and currently serves as Chair for the board of [The Kelsey](#). Dom lives in Atlanta, Georgia with his wife Catie, their daughter Mahalia, and their dog Vivi.