

The Unintended Consequences of *Olmstead v. L.C.*

Mark L. Olson

Chairperson, Community Living & Employment Subcommittee, Nevada Commission on Autism Spectrum Disorders; President & CEO, LTO Ventures, a 501(c)(3) non-profit company that develops live/work/play communities for adults with Autism Spectrum Disorders (www.ltoventures.org); and, parent of a 16 year old daughter with Autism.

Proposed changes to the Medicaid Home and Community-based Services Waiver and what qualifies as “community living” have fractured the disability community in a highly-emotional debate over recipient “choice” versus implementation of a landmark US Supreme Court ruling and ultimately could result in disastrous public policy that affects the future of essential residential and supportive services for millions of disabled Americans.

At the heart of the debate is the 1999 decision in *Olmstead v. L.C.* [527 U.S. 581] and how each side interprets the terms “home” and “community” in that ruling. Efforts at the Centers for Medicare & Medicaid Services (CMS) since 2009 to redefine those terms and constrain eligibility and access to funding are a case study in how good intentions can have unintended consequences.

The *Olmstead* ruling held that unnecessary segregation and institutionalization of persons with disabilities is a form of discrimination and prohibited under the Americans with Disabilities Act. The decision was a giant step forward to advance choices in housing and services for millions of people with disabilities. In the Court’s opinion Justice Ruth Bader Ginsburg wrote: “*we recognize...the States’ need to maintain a range of facilities for the care and treatment of persons with diverse mental abilities, and the States’ obligation to administer services with an even hand.*”

Disabled individuals want the freedom to choose where they live, but this battle is also about money, specifically billions of Medicaid dollars. Medicaid is the primary funding safety net for persons with disabilities through its Home and Community Based Services (HCBS) Waiver. Under the HCBS waiver Medicaid pays only for services, not room and board. However, CMS requires those services be provided in a CMS-approved setting. This is where the “choice” versus “*Olmstead*” debate really starts to heat up.

The “choice” side -- disabled persons, their families, caregivers and providers – argue that funding for services should not be tied to a CMS-approved setting because if the recipients are worthy of services, they should be worthy of services wherever they receive them. They fear that if the Final Rule from CMS includes the proposed restrictions, an estimated 25 percent of existing eligible residential settings would no longer meet the new CMS criteria, and tens of thousands of disabled individuals would be forced out of their residences.

They also argue that narrowing the definition of an eligible setting would have a chilling effect on innovation in housing models and financing mechanisms, public and private, would severely impact the development of residences suitable for the tens of thousands of adults with Autism, intellectual, developmental and other disabilities who need them, and would balloon already bloated waiting lists nationwide.

Almost 123,000 people were on waiting lists in 2009 for Medicaid-eligible residential services for intellectually and developmentally disabled persons. This is an increase of almost 71% over the same waiting lists in 2000, the first year after the Supreme Court *Olmstead* decision. In many states, the length of time eligible individuals have languished on waiting lists exceeds ten years. And it is projected to get much worse. Data from the Centers for Disease Control and Prevention and Autism Speaks estimate that more than 500,000 individuals under 22 years of age with an Autism Spectrum Disorder will reach adulthood by 2024 and join the market for housing and services.

CMS Administrator Donald M. Berwick and disability advocates, including the independent protection and advocacy system created by Congress, contend they are only following their obligations under *Olmstead*. They maintain that only living situations that closely or exactly mirror those of “typical” persons fulfill the intention of the Supreme Court and the Americans with Disabilities Act, and that federal and state funding under HCBS waivers should only be used for such settings.

(Interestingly, agencies and officials responsible for administering the Medicaid program in 14 states filed a joint public comment opposing the changes proposed by the federal office of CMS.)

Both sides claim to be devoted supporters of “choice,” yet the two sides have strikingly different ideas about what “choice” means and who gets to decide. “Choice” advocates consistently argue an all-inclusive position that the consumers of these services and their families and care team should be the ones to decide, or considered more broadly, to let the market decide.

“*Olmstead*” advocates, however, consistently argue for choice, but clearly delineate that by “choice” they mean only those settings that *they* deem suitable according to their exclusive interpretation of “home” and “community.” Alarming, this means they also go out of their way to condemn some of the most innovative, person-centered settings existing and planned.

The rule-making process and this debate should produce an outcome that expands inventory and choices and removes barriers to innovation and investment in residential settings desired by adults with autism and intellectual, developmental and other disabilities. At the very least CMS must “do no new harm” and choose not to include proposed new paragraphs to the Medicaid HCBS Waiver regulation.

President Obama, in commemorating the tenth anniversary of the Supreme Court decision said: “*The Olmstead ruling was a critical step forward for our nation, articulating one of the most fundamental rights of Americans with disabilities: Having the choice to live independently.*”

The operative word here is “choice.” CMS should adopt policies and regulations that facilitate development of the broadest range of choices to address the varied needs and desires of the disabled Americans they are mandated to serve, and let the market decide what settings should prosper.