



Long Waiting Lists for Community Services Deny ADA Rights

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Both the Americans with Disabilities Act (ADA) and the Supreme Court's related *Olmstead* decision support an individual's right to receive long-term care in the least restrictive manner possible. Yet when families ask if Medicaid can help them pay for home and community-based services (HCBS), the answer is overwhelmingly "no." How is that possible?

Medicaid, established 25 years before the 1990 passage of ADA, contains a strong institutional bias. To receive federal Medicaid funds, states must make nursing home care available to individuals who meet certain medical and financial criteria. But providing the same services within the mainstream community is *optional*. States are also permitted to cap the number of openings for such "waiver" programs, which have repeatedly suffered budget cuts. This is despite evidence that it's far less expensive to provide medical treatment, day care and personal care outside an institutional setting.

While *Olmstead* marked a victory for social inclusion, its focus was on plaintiffs who were *already* institutionalized, not the rights of those wanting to avoid placement in a nursing home. The result is that in most states, the only way to avoid decades-long waiting lists for community services is to first be receiving Medicaid Long-Term Care benefits in an institution for at least 30 days. The sad reality is that, once there, residents tend to stay—either because their condition deteriorates or they experience *transfer trauma*. Fragile individuals who have once been uprooted and forced to adjust to a nursing home are unlikely to handle well the upheaval involved in another major move.

The situation in Maryland, where I practice elder and special needs law, is a case in point. With over 30,000 people in the state's community services backlog, only 150 slots were made available during the first half of 2015. At that rate, it would take a century to satisfy everyone *currently* standing in line. Another problem is our state's shortage of the "supports planners" who help people with disabilities of all ages navigate the Medicaid system—a problem created by unreasonably low salaries.

Not surprisingly, suits protesting ADA infractions have been filed throughout the country. Indeed, the U.S. Department of Justice has declared that an "*Olmstead* violation" occurs whenever government fails "to provide community services or its cut to such services will

likely cause a decline in health, safety or welfare that would lead to the individual's eventual placement in an institution."

The Solution

The best way to solve this nationwide dilemma would be to revise the federal Medicaid law, but one barrier is what's known as the "woodwork effect." Little data exists about the actual number of people needing Medicaid-funded community services, and states fear that liberalized eligibility standards would result in unmanageably large numbers of applicants "coming out of the woodwork." For that reason, legislation should require research to determine just how great the need is, then establish funding streams and realistic enrollment caps.

A 1994 report from the GAO, addressing Oregon's experience with expanded Medicaid funding of community services found that while expenditures initially rose, the state eventually saved money. In Maryland, the cost of a waiver slot is 40 percent that of a nursing home placement. Because states work with a 12-month budget cycle, while federal budgets use a 10-year horizon, it would make sense to allocate federal funds to help states withstand short-term cost increases.

A number of bills are being drafted by Congress to address this crisis, including the Disability Integration Act of 2015, recently introduced by Senator Charles Schumer (D-NY). That legislation would require public entities and long-term services and supports (LTSS) insurance providers to provide community-based services to anyone "who would otherwise qualify for institutional placement provided or funded by the public entity or LTSS insurance provider." States would be required review and analyze funding sources to determine how to provide "reasonable and timely access" to such services and would have 42 months to submit and begin implementing appropriate transition plans. States meeting approved annual objectives would receive increased federal funding.

Schumer's bill would also require the U.S. Department of Health and Human Services to research the extent to which individuals with disabilities remain institutionalized and to publish an annual report to Congress on progress towards deinstitutionalization, obstacles to community delivery of services and recommendations for additional legislative and executive action.

Across the nation, the rights of individuals of all ages with serious disabilities are being denied. It's time for ADA's promise to be fulfilled and for the states to cease their illegal segregation of individuals needing long-term care.

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