



The Olmstead decision & shifting resources to the community

The Challenge:

In 1999, the United States Supreme Court, in a case called “Olmstead v. L.C.,” ruled that unnecessary segregation of people with disabilities in institutions is a form of discrimination in violation of the Americans with Disabilities Act (ADA), which requires that people with disabilities receive services in the most integrated setting possible.

The decision required that people with disabilities be placed in community settings rather than institutions when: (a) the person prefers or does not oppose community services; (b) professionals determine that community services could be appropriately provided; and (c) community placement or services could be reasonably accommodated.

The Court also suggested that states could defend themselves against lawsuits by persons living in nursing homes, if they could demonstrate that they had a comprehensive, effectively working plan for placing qualified persons with disabilities in less restrictive settings, and a waiting list that moves at a reasonable pace not controlled by the

State’s endeavors to keep its institutions fully populated.

Since the decision, many states, including California have been bogged down identifying methods to overhaul a system of care based on the outdated institutional model. Further, implementation in many states has been tied solely to activities that are funded through federal grants.

California’s Olmstead plan

In late 2002, the State of California asked community groups to host public forums to discuss Olmstead implementation. The Long Term Care Council and the Department of Health and Human Services used the information from these forums to guide their creation of California’s Olmstead plan. In April 2003, the plan was finally released.

It stresses consumer choice and self-determination. The plan also acknowledges the need for cultural competency in the delivery of services and, the importance of **supporting individuals, rather than caring for them.**

Though California’s plan is a step in a right direction, it is only a starting point. Its success depends on a paradigm shift away from the medical model of care to a more consumer oriented approach. State and local decision makers will need to address many complex municipal and community service issues, such as housing and transportation to provide the social infrastructure that supports community-based care.

Barriers to implementation

The shift to community-based services is a considerable undertaking. Californians still remember when mental institutions were emptied in the 1960s without any increases in community services.

Because community-based care options were not funded, many wound up on the streets, never receiving the care they needed. We continue to suffer the consequences of those fateful decisions even today.

Funding continues to be a barrier the Olmstead plan must face. It cost more per person to care for an individual in an institutional setting than it does to care for that person in their home. Yet for decades, the bulk of government funding has flowed toward nursing homes and hospitals. The systemic bias toward institutional care has left consumers with few community-based options and even less money to pay for them. For example, in order to use Medi-Cal funds to live in the community, one needs to obtain a nursing home waiver, where there is a long waiting list.

Many persons with persons with disabilities living in the community complain of “funding silos” which are covered in red tape and are difficult to access. These limited funding streams don’t allow for much flexibility, let alone choice.

The continued failure of society to improve access to municipal services and community-based support options (affordable/ accessible housing, transportation, healthcare) are also barriers that the Olmstead decision requires us to overcome.

Housing - In almost all of the Olmstead forums held in 2002, the need for affordable and accessible housing was a top priority. More Section 8 vouchers need to be available and more Section 8 housing needs to be accessible. Affordable and accessible housing also needs to be located near public transportation and local services such as shopping, which also must be accessible, to maximize freedom and community integration for people with disabilities.

While communities and advocates address the need for affordable and accessible housing by building ramps and making home modifications for some, they must work to expand the accessible housing stock by educating builders and creating incentives for them to incorporate universal

design concepts. Such activity would eventually eliminate the need for expensive home modification later. Changing the way we build our homes will reduce the need for institutional care, by allowing more people with disabilities to remain in their own homes

Transportation - For many persons with disabilities, public transportation is an unmet necessity. Talk with people who use overburdened paratransit (Door-to-door transportation) services and stories abound regarding two-hour late pickups, more than 24 hours notice requirements, and an inability to get return rides. In order to implement an Olmstead plan, issues such as paratransit for non-medical emergencies, transportation across public jurisdiction and easier access to routes should be addressed.

Access to all forms of public transportation, not just paratransit services, needs to be improved to allow persons with disabilities to function in their communities. Accessible

vehicles, better routes and timetables will enable them to get to jobs, shopping, health care, etc.

Personal Assistance - The expansion and improvement of In-Home Support Services (IHSS), which provide personal services for the person with the disability is an integral part of implementing an Olmstead plan. There are several issues around the role of the caregiver, including pay, safety, assessment tools, coordination with county officials and state and federal funding sources that must be resolved.

Most caregivers are family members or workers paid at or just above minimum wage. As a result, high turnover rates, lack of responsibility, physical and financial abuse are problems that plague current IHSS consumers. Solutions include background checks, increased allowable hours for funded IHSS and greater consumer control.

Though community-based public authorities may be “employers of record,” consumers should be educated about their rights and be trained in

management skills such as hiring and firing to increase their safety and choice.

Assistive Technology - Without assistive technology (AT), one cannot move freely, breathe freely or live an independent lifestyle. Many persons with disabilities depend on wheelchairs, ventilators, canes and other forms of AT for their independence. Therefore, it will be important for lawmakers, advocates and consumers to place a priority on funding and obtaining AT and its role in Olmstead planning.

Multiculturalism - Because disability means different things in different cultures and different communities have different structures to support caregiving it would be in California’s best interest to understand and work with those strengths and needs in order to provide the best resources to the individual with a disability.

Many doors, single entry

People with disabilities and seniors must be able to easily find those community services they need to live independently. Therefore, information and referral that

can direct people to access points to connect with services should be available from many sources, including human services agencies, independent living centers, senior centers, 24 hour helplines and more.

Currently, it is usually assumed that if an individual can’t live in the community without personal assistance, the state and federal government will pay for nursing home placement. To implement Olmstead, we need to develop a process that will allow persons with a disability and/or seniors to determine what assistance they require to continue to live independently and then locate resources in their community for that assistance. Information and referral programs can help consumers make that comprehensive assessment. An advocate can assist with the coordination of services when needed.

Call to Action

Many believe California’s plan lacks teeth to effect real change. Without timelines, goals, and assigned responsibilities, it is merely a framework from which to start. And because many of

the decision makers who will help mold this shift to community-based care do not have disabilities, it is important that the Long Term Care Council appreciate the importance of community input and continue to seek it as they develop these plans.

As California struggles with its budget, it must strive to make the best use of all its resources, we cannot continue to fund the current system of institutional care and still meet our obligations under the Olmstead decision. While there will always be a need for skilled nursing homes, we must carefully consider who really needs that high level of care and who can best be served with community-based options. State funding needs to be shifted away from the institutional care system and into providing those services and programs that support community-based care options. The easiest way to implement such a shift is simply the “money follows the individual,” where Medicaid, Medicare and other government funding sources are linked to the person and how they choose to use it.

California’s Olmstead plan seeks to increase resource and funding options, including the reversal of the institutional bias of many Medicare and Medicaid programs. The new policy would specify that long term care services are to be provided in community settings whenever feasible.

From those who don’t want low-income people with disabilities living in their community to those who believe that people with disabilities should be “taken care of” or aren’t capable of making decisions about their own care, discrimination is a formidable foe.

However, discrimination can be minimized through education. Policy makers and the public must come to understand that implementation of the Olmstead plan is not an accommodation to a special interest group, rather it involves the reallocation of resources to best meet the needs of all citizens, disabled and able-bodied. 80% of Americans will experience a disability in their lifetime, either directly or indirectly through family or friends. This fundamental shift in how we deliver services to those with disabilities will improve the quality of life for all of us and make the best use of our tax dollars.

For more information contact your
local Independent Living Center:

Member,

**California Foundation for
Independent Living Centers**

www.cfilc.org

