

The Next 25 Years of Community Living Under the ADA

On July 26, 2015 we honor the 25th anniversary of the Americans with Disabilities Act (ADA), one of the most important pieces of legislation ever created by Congress. Everyone knows someone who is protected under the ADA: a cousin with autism, a neighbor who uses a service dog, or a veteran injured in Iraq. The ADA changed the lives of millions of Americans by increasing options and decreasing barriers for them to fully participate in their communities.

As Americans we take for granted that we have the right to choose where we want to live, determine what we consider a home, and define community in our own terms. This has not been true for persons with intellectual or developmental disabilities (I/DD). Fifty years ago, supports services could not be accessed easily in communities and institutionalization was the most likely option for someone with I/DD.

One of the most significant tests of the ADA occurred 16 years ago in *Olmstead v. L.C.* in which the U.S. Supreme Court found that two women in an institution in Georgia had been denied their right to supports in a residential setting in the community. The Court ruled that, under Title II of the ADA, states cannot discriminate against individuals with disabilities and withhold access to community-based services for persons with disabilities.

In almost two decades since *Olmstead*, self-advocates, parents, legislators and others have worked together to change regulations, laws and develop new ways of thinking about support services so individuals with disabilities can have more choices and control of their lives.

Coalition for Community Choice (CCC; www.coalitionforcommunitychoice.org) is a national collaboration of more than 125 organizations, providers and advocates who want to increase options and decrease barriers to housing and employment choices.

Today, individuals with I/DD may have the option to live alone or with roommates in their own home or apartment, in a group home, in an adult foster care home, on a farmstead or ranch, or on a supportive living campus setting, all with supports they need to be able to interact with the greater community to the fullest extent possible. But four years from now this may not be true.

Recent changes in federal and state regulations may limit what constitutes an integrated residential setting. The Centers for Medicare and Medicaid Services (CMS) issued new requirements about housing and employment settings that states have five years to implement through State Transition Plans. For a person with I/DD, these changes may have the unintended consequences of reducing the options available and increasing barriers to that individual's right to choose his or her preferred setting.

Affordable, supportive housing will be one of the most acute areas to be addressed in the next 25 years of the ADA, and it may prove to be a frustratingly elusive target. A snapshot of the statistics sizes the challenge:

- There are 4.9 million adults with I/DD in the U.S.
- Of the 4.9 million, 3.5 million live with family caregivers, and 853,000 of these family caregivers are 60 years of age or older and may soon need their own caregivers
- 77 percent of the 3.5 million receive no residential supports
- Only 244,195 additional residential placements were funded from 1994-2011



Rather than mitigate the housing crisis, in the 25 years since the ADA and 16 years following the *Olmstead* decision, the number of adults with I/DD on a waiting list for, but not receiving, residential services has increased more than 66 percent.

CCC and its member organization are working together to educate and advocate for persons with I/DD, families, legislators and advocates in five major areas:

- **Choice.** People with I/DD have the human and civil right to choose from the broadest range of home, workplace, and community supports and settings.
- **Fund the Person.** Medicaid funding of supports and services should be person-centered and available to all people with I/DD based on the individual's preferred settings, support needs, and meaningful life goals.
- **Housing Innovation and Public/Private Partnerships.** "One size fits all" in housing doesn't work for people with I/DD any more than it does for nondisabled people. Affordable, accessible planned communities that combine best practices in design with creative public-private funding can increase system capacity, reduce waiting lists, and provide an array of new options.
- **Focus on the Real Issue.** The physical characteristics of a setting is not the issue. Full inclusion in a community can be achieved in a planned community or farmstead just as it can in an individual home or apartment. How settings are designed, managed and staffed is the greatest determinant of optimal outcomes and experiences.
- **Workforce and Professional Development.** The job market for skilled direct support professionals who supports individuals with I/DD to live in the home of their choice is one of the fastest-growing over the next 25 years. Low wages, shrinking reimbursement rates, lack of training, and appropriate certifications must be improved to make this a desirable career field.

As the first 25 years of the ADA has shown, person-centered policy and collaborative advocacy can open doors to choices and opportunities. We call upon all stakeholders at state and federal levels to continue to put the rights of individuals with I/DD first in the next 25 years of the ADA.

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