

Integrated Housing for People with Intellectual and Developmental Disabilities: Know the Facts

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In the past several decades, the public, policymakers and the disability community have benefited from an increasing recognition that people with disabilities are entitled to normal lives in the community. Through the hard work of self-advocates, families, and legal advocates, over 850,000 people with disabilities are now living in community settings with home- and community-based services and supports.*

Research shows that this trend has resulted in better life outcomes for people with disabilities. Compared with people with disabilities who live in larger congregate settings or institutions, people with disabilities who live in small community settings have a higher overall quality of life, more friends, more opportunities to make choices about their lives, more opportunities to develop and maintain skills, and higher satisfaction with their living arrangements.† Data from the National Core Indicators project, a multi-state program that provides a systematic approach to performance and outcome measurements for state intellectual and developmental disability systems, indicates that smaller setting size is positively correlated with enhanced choice and autonomy across every level of intellectual disability.‡

In order to fulfill the promise of community living for people with disabilities, it is crucial that community living options for people with disabilities remain truly integrated in the community instead of merely replicating institutional environments in smaller buildings. Policymakers must focus on providing people with disabilities access to “scattered-site” housing in neighborhoods and apartment buildings that are not primarily occupied by people with disabilities. Access to housing should not be contingent on adherence to treatment, daily regimens, or lifestyle restrictions beyond those required of nondisabled tenants, and choice of service providers and types of

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* Peebles, V. & Bohl, A. (2013, August). The HCBS Taxonomy: A New Language for Classifying Home- and Community-Based Services. *Mathematica Policy Research*. Available at http://www.mathematica-mpr.com/~media/publications/PDFs/health/max_ib19.pdf.

† National Council on Disability, *Deinstitutionalization Toolkit: Community inDETAIL* (“Community inDETAIL”), pp. 13-14 (2012), available at <http://www.ncd.gov/publications/2012/DIToolkit/Community/inDetail/>.

‡ Lakin, C., Doljanac, R., Byun, S., Stancliffe, R., et al. (2008). Choice-Making Among Medicaid HCBS and ICF/MR Recipients in Six States. *American Journal on Mental Retardation*, 113(5), pp. 325-342.

services should be independent of housing choices.

As a result, states should not invest in models that link service-provision and real estate and instead invest in models that decouple services from housing providers. In addition, states should not fund services provided in “gated communities” and similar segregated, congregate settings, or service providers who restrict people’s rights or otherwise imitate characteristics of an institutional environment. In short, public funds should never support segregation.

The *Olmstead* Decision and the Right to Integration

In 1999, the Supreme Court issued a landmark decision* finding that segregation of people with disabilities constituted discrimination under the Americans with Disabilities Act. As a result, when states provide services to people with disabilities, they must offer those services in the most integrated setting appropriate to their needs. The Court therefore held that the two plaintiffs, women with intellectual disabilities, were entitled to receive supports and services that they needed to move out of the institution where they lived and into the community.

Unfortunately, implementation of the Supreme Court’s decision in *Olmstead* has been slow and incomplete. Although the United States Senate Health, Education, Labor, and Pensions Committee has found that “virtually all people with disabilities can live in their own apartment or house with adequate supports” and that “for virtually all people with disabilities, the most appropriate integrated setting is their own home,” many Americans with developmental disabilities remain in institutions or congregate settings, such as group homes, in which real estate and service-provision are linked and restrictions on basic rights occur. Policymakers must focus both on shifting away from smaller congregate models and preventing the re-emergence of large congregate settings similar to the ICF settings and other large-scale institutions that have largely been eliminated.

Why Avoid Congregate Housing?

In September 2010, the Autistic Self Advocacy Network (ASAN), Self-Advocates Becoming Empowered (SABE), and the National Youth Leadership Network (NYLN) conducted a survey of 72 individuals with developmental disabilities attending a self-advocacy conference, in order to determine which features made a housing placement truly “integrated” into the community. Participants responded that “gated communities, farmsteads, and clusters of group homes,” as well as other settings housing four or more unrelated individuals with disabilities who have not specifically chosen to live together, were not community-based settings as they deprived residents of opportunities to participate in community life and interact with nondisabled individuals who were not staff members.†

Following their survey, ASAN, SABE, and NYLN concluded that the scattered-site supported housing model provided the greatest access to community life. This model permits individuals with disabilities to live in the community on the same terms as

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* *Olmstead v. L.C.*, 527 U.S. 581 (1999).

† Autistic Self Advocacy Network, *Keeping the Promise: Self-Advocates Defining the Meaning of Community Living* pp. 6-7 (2012), available at <http://autisticadvocacy.org/wp-content/uploads/2012/02/KeepingthePromise-SelfAdvocatesDefiningtheMeaningofCommunity.pdf>.

individuals without disabilities. Key features of scattered-site supported housing truly integrated in the community include:

- The residence is embedded in the community. If it is a house, it is in a neighborhood where people without disabilities also live. If it is an apartment, it is in a building that is populated primarily by people without disabilities.
- The residential provider does not impose restrictions on individuals' daily activities, comings and goings, ability to have guests, sexual activities, adherence to treatment, or other everyday choices above and beyond the responsibilities of a regular tenant or homeowner.
- The individual's residence is not linked to a specific service provider or level of services. Rather, the individual and his or her support team determine the type of services the individual will receive and who provides those services.

Contrary to common assumptions that people with significant disabilities cannot live in their own homes, experts agree that the scattered-site housing model works for people with a range of disability-related support needs. Research has shown that, with the right supports, people with a wide variety of support needs – including persons with complex medical needs, people who have both developmental and psychiatric diagnoses, people with a history of involvement in the criminal justice system, and people who have spent many years in an institution – can live successfully in truly integrated community settings.*

Because scattered-site housing is the most integrated option for virtually all people with disabilities, the Department of Justice - which is tasked with enforcing *Olmstead* - has issued guidance to states that “congregate settings populated exclusively or primarily with individuals with disabilities” are segregated settings and thus inconsistent with *Olmstead's* integration requirements. States should avoid creating and operating such facilities, or financing placement of individuals with disabilities in these facilities.† Similarly, the United States Senate Health, Education, Labor, and Pensions Committee found that people with disabilities must have access to “scattered-site” community housing as opposed to merely group homes or multi-unit complexes that are primarily for people with disabilities.‡

Scattered-site housing provides, overall, a more cost-effective means of serving people with disabilities than congregate settings such as institutions and group homes.

* *Community inDETAIL* p. 19.

† United States Department of Justice, Civil Rights Division, *Statement of the Department of Justice on Enforcement of the Integration Mandate of Title II of the Americans with Disabilities Act and Olmstead v. L.C.*, p. 3, available at http://www.ada.gov/olmstead/q&a_olmstead.pdf.

‡ *Separate and Unequal* pp. 4, 14-16.

Making Funding Go Farther

Scattered-site housing provides, overall, a more cost-effective means of serving people with disabilities than congregate settings such as institutions and group homes. Cost savings result from higher flexibility in service levels, lower costs of housing, and greater access to federal matching funds to offset state expenditures.

Congregate environments, such as gated communities, group homes, and institutions, are associated with high fixed costs and limited flexibility due to the need to maintain buildings, staff, food service, and other such ongoing expenses. It may be difficult or impossible to reduce staff hours when residents acquire skills and need fewer services, or to reduce the size or number of buildings if residents move out.* The difficulty of adjusting service levels to an individual's changing needs can also result in unnecessary and costly transfers from one housing provider to another.

States also have fewer options to obtain federal matching funds for services provided in congregate environments. Like states, the federal government is required to administer its programs in a manner that does not have a discriminatory effect on people with disabilities.† As a result, following *Olmstead's* holding that segregation is a form of discrimination, federal agencies that oversee funding for state programs must ensure that the programs they fund provide integrated living options for people with disabilities.

The U.S. Department of Health and Human Services' Centers for Medicare and Medicaid Services (CMS), for example, have rejected other states' bids to use home-and community-based services waiver funding for placements in gated or other segregated "communities." In 2010, CMS rejected Missouri's petition to amend its HCBS waiver because the proposal would have used waiver funds to place individuals into "residential units clustered on the grounds of a large Stateoperated institution." CMS found that this setting was "segregated from and with restricted access to the larger community" and therefore not an appropriate use of waiver funds.‡

With the January 2014 promulgation of the CMS final rule on HCBS, CMS intends to prohibit use of Medicaid HCBS funds to pay for services in institution-like settings. The final rule requires that such services be provided in a setting that is "integrated in, and facilitates the individual's full access to, the greater community." Individuals must be able to choose which services and supports they receive and who provides those supports. Moreover, if the HCBS provider also owns or controls the individual's residential setting, the residence must be a place that the individual could have owned, rented or occupied without receiving services from the provider, and the individual must have the same rights and responsibilities as a regular tenant under state and local laws. Additionally, CMS has issued further subregulatory guidance intended to describe set-

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* National Council on Disability, *Deinstitutionalization: Unfinished Business, Companion Paper to Unfinished Business Toolkit* p. 43 (2012), available at <http://www.ncd.gov/publications/2012/Sept192012/>. For the purposes of its report, National Council on Disability considered all facilities of four or more people who did not choose to live together to be institutions.

† Rehabilitation Act, Pub. L. 93-112 (Sept. 26, 1973), codified as 29 U.S.C. § 701 *et seq.*, available at <http://www.law.cornell.edu/uscode/text/29/701>.

‡ Letter from Donald Berwick, Administrator, Centers for Medicare & Medicaid Services, to Ronald Levy, Director of Missouri Department of Social Services (Aug. 2, 2010), available at http://www.arkdisabilityrights.org/doc/2010/20100802cms_modss1915c-disapproval.pdf.

tings with institution-like characteristics.*

The Department of Housing and Urban Development also restricts states from using funding to finance development of congregate residential settings for people with disabilities. HUD has stated that, except where specifically authorized by the funding statute, recipients of HUD funding may not preferentially offer their units to people with disabilities except in the context of implementing *Olmstead's* integration requirements. HUD encourages recipients of HUD funding to create scattered-site developments for people with disabilities.†

Conclusion

All people with disabilities deserve the opportunity to live in their own homes and participate fully in their communities. Housing developments that are reserved primarily for people with disabilities, such as gated communities or group homes, serve to isolate people with disabilities through physical segregation and imposition of one-size-fits-all restrictions on residents' daily activities, meals, and social engagements. In contrast, housing models that maximize physical integration into the community - such as scattered-site housing - have proven to be viable and cost-effective means of serving people with disabilities, including those with complex needs. Moreover, these housing models provide opportunities for states to draw on sources of federal funding for housing and supports, such as HUD and Medicaid programs.

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* Centers for Medicare & Medicaid Services (2014). "Guidance on Settings that Have the Effect of Isolating Individuals Receiving HCBS from the Broader Community." Available at <http://www.medicare.gov/Medicaid-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Supports/Home-and-Community-Based-Services/Downloads/Settings-that-isolate.pdf>; Final Rule, 79 Fed. Reg. 2947-3039 (January 16, 2014).

† United States Department of Housing and Urban Development, *Statement of the Department of Housing and Urban Development on the Role of Housing in Accomplishing the Goals of Olmstead*, p. 7 (2013), available at <http://portal.hud.gov/hudportal/documents/huddoc?id=OlmsteadGuidnco60413.pdf>.