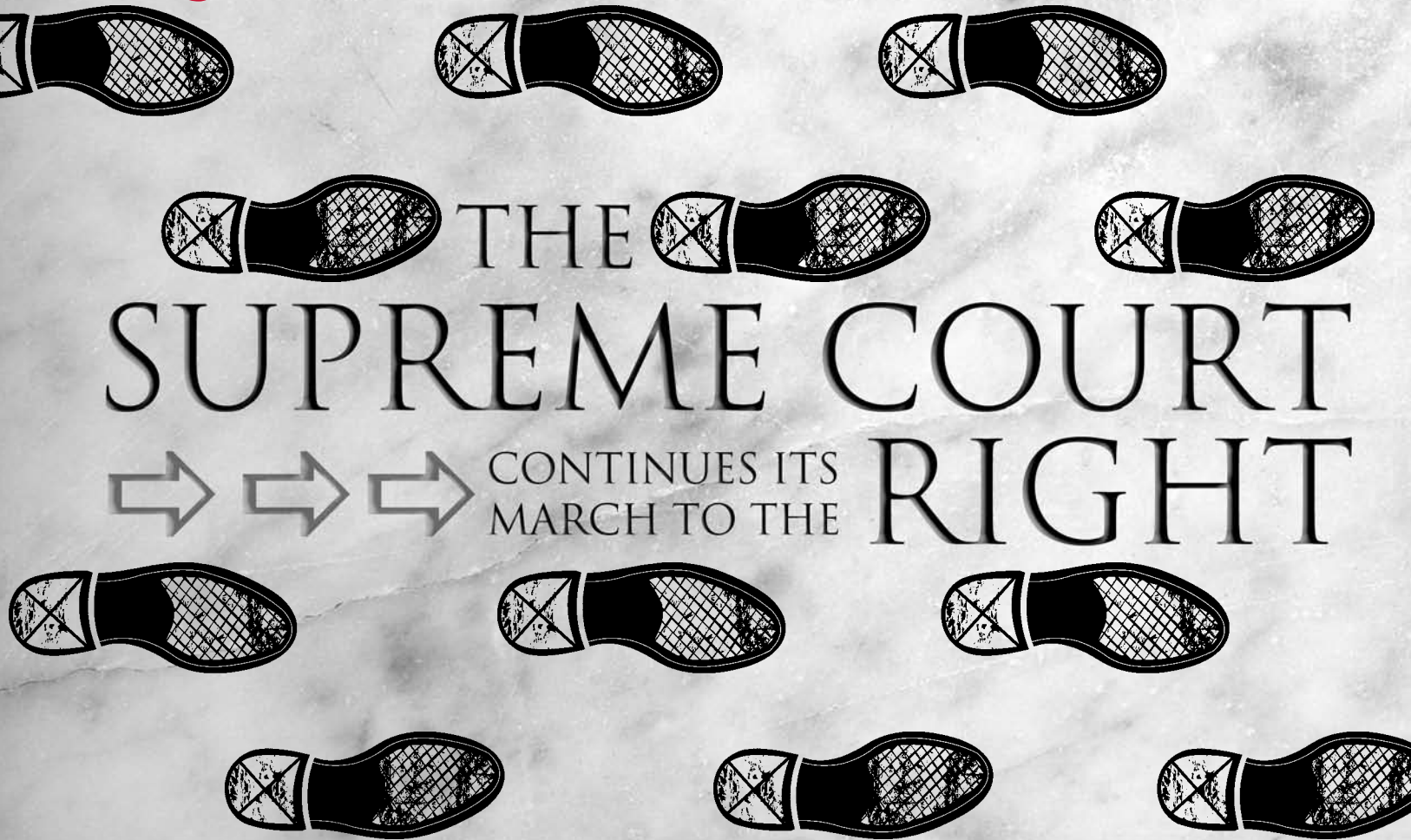


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The *Olmstead* Decision at Ten



Sargent Shriver National Center on Poverty Law



## The *Olmstead* Decision at Ten: Directions for Future Advocacy

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June 2009 marked the tenth anniversary of the U.S. Supreme Court's decision in *Olmstead v. L.C.*, making this an apt time to take stock of the decision's impact on service systems for individuals with disabilities and of directions for *Olmstead* advocacy.<sup>1</sup> The unnecessary institutionalization of people with disabilities is a form of discrimination prohibited by the Americans with Disabilities Act of 1990 (ADA), and a public entity must administer services to individuals with disabilities in the most integrated setting appropriate to their needs unless doing so would fundamentally alter the entity's service system, the Court held in *Olmstead*.<sup>2</sup>

As a result of the *Olmstead* decision and subsequent litigation, many states have been taking advantage of temporary federal incentives to expand community-based services for individuals with disabilities—for example, federal Nursing Home Transition grants, Real Choice Systems Change grants for community infrastructure development, and the Money Follows the Person initiative providing a one-year increased Medicaid match for individuals transitioning to community settings.<sup>3</sup> States have also been continuing to expand Medicaid home- and community-based waivers to enable

<sup>1</sup>*Olmstead v. L.C.*, 527 U.S. 581 (1999) (Clearinghouse No. 52,203). For additional discussion of *Olmstead*, see Jennifer Mathis, *Where Are We Five Years After Olmstead?*, 38 CLEARINGHOUSE REVIEW 561 (Jan.–Feb. 2005), and *Community Integration of Individuals with Disabilities: An Update on Olmstead Implementation*, 35 *id.* 395 (Nov.–Dec. 2001); Ira Burnim & Jennifer Mathis, *After Olmstead v. L.C.: Enforcing the Integration Mandate of the Americans with Disabilities Act*, 33 *id.* 633 (March–April 2000).

<sup>2</sup>*Olmstead*, 527 U.S. at 596–98; Americans with Disabilities Act of 1990, 42 U.S.C. §§ 12101 *et seq.*

<sup>3</sup>Nursing Home Transition grants helped about 1,900 individuals move to community settings from 1998 to 2000 in nine states that reported data (out of twelve grantee states), and Real Choice Systems Change grants helped the twenty-three grantee states and ten grantee independent-living centers move about 3,600 individuals to community settings from 2002 to 2003 (Audra T. Wenzlow & Debra J. Lipson, Mathematica Policy Research, *Transitioning Medicaid Enrollees from Institutions to the Community: Number of People Eligible and Number of Transitions Targeted Under MFP [Money Follows the Person]*, REPORTS FROM THE FIELD, Jan. 2009, at 1–2, <http://bit.ly/1kiEzu>; Jennifer Gillespie, National Academy for State Health Policy, *Nursing Facility Transition Grantee Annual Report Data 1–2* (June 2005), <http://bit.ly/55Wxe>). The Money Follows the Person initiative, which is more ambitious in scope, aims to help about 34,000 people transition to community settings (Debra J. Lipson & Susan R. Williams, Mathematica Policy Research, *Implications of State Program Features for Attaining MFP Transition Goals*, REPORTS FROM THE FIELD 3 (June 2009), <http://bit.ly/1KCw1V>). In the thirty-one grantee states, however, more than 1.3 million people were institutionalized in 2004 (Wenzlow & Lipson, *supra*, at 2, 3). The 1.3 million estimate does not include many institutionalized individuals, such as those in board-and-care homes.

individuals to move to more integrated settings from nursing homes and from institutions for individuals with developmental disabilities. These state efforts, however, generally result in small, piecemeal expansion of community settings rather than large-scale systemic change.

Millions of people with disabilities remain institutionalized although, with new service approaches, people with even the most challenging needs can now be served in integrated community settings.<sup>4</sup> The heavy reliance on institutions continues in part because of states' reluctance to close institutional beds and reallocate dollars to more integrated settings.<sup>5</sup> Such reliance continues also because the privately operated facilities, such as nursing homes and board-and-care homes, on which states rely typically operate on a for-profit basis and have little incentive to identify residents as qualified for more integrated care.<sup>6</sup> Neither these facilities nor states are making much effort to give residents information about more integrated settings. Often these private facilities—particularly board-and-care homes—receive little attention in state *Olmstead* planning efforts because they have been labeled as “in the community” even though many are large,

segregated facilities serving hundreds of residents with disabilities.<sup>7</sup> Even smaller board-and-care homes have features of larger institutional settings, diminishing residents' opportunities to interact with people without disabilities.<sup>8</sup>

Here we envision future *Olmstead* litigation and policy efforts to achieve real change and ensure that people with disabilities have opportunities to live in settings that maximize their integration into community life. To drive disability service systems in this direction, *Olmstead* implementation efforts should focus on ensuring that

- institutional beds are closed and funding is reallocated to develop integrated community settings;
- privately operated facilities used as part of disability service systems are included in *Olmstead* compliance efforts;
- people with disabilities are truly integrated into community life, through technologies such as scattered-site supportive housing, and not resegregated in private facilities or housing projects; and
- people with disabilities have meaningful and informed choices about where to live.

<sup>4</sup>Wenzlow & Lipson, *supra* note 3, at 2, 3 (millions of people with disabilities remain institutionalized); see also NATIONAL COUNCIL ON DISABILITY, *OLMSTEAD: RECLAIMING INSTITUTIONALIZED LIVES (ABRIDGED VERSION)* 11–18 (2003), <http://bit.ly/id8nD> (hundreds of thousands of individuals with disabilities segregated in developmental disabilities institutions, nursing facilities, psychiatric institutions, and board-and-care homes; most of these individuals could be supported in their own homes in community).

<sup>5</sup>In many states, county authorities control the organization and administration of disability service systems. For the sake of simplicity, we discuss state disability service systems, but *Olmstead* applies equally to local government entities.

<sup>6</sup>See, e.g., CHARLENE HARRINGTON ET AL., *NURSING FACILITIES, STAFFING, RESIDENTS AND FACILITY DEFICIENCIES, 2001 THROUGH 2007*, at 20 (2008), <http://bit.ly/1553Mh> (in 2007 only 5.9 percent of Medicaid- and Medicare-certified nursing facilities in United States were government-operated); Center for Mental Health Services, Substance Abuse and Mental Health Administration, U.S. Department of Health and Human Services, *Transforming Housing for People with Psychiatric Disabilities Report 11* (2006) (more than three out of five licensed board-and-care homes are operated for profit). Board-and-care homes are living arrangements that give residents shelter, food, personal care services, and twenty-four-hour supervision or oversight (Center for Mental Health Services, Substance Abuse and Mental Health Administration, *supra*, at 6). Board-and-care homes provide a lower level of care than nursing homes (NATIONAL COUNCIL ON DISABILITY, *supra* note 4, at 18).

<sup>7</sup>See, e.g., *Disability Advocates Incorporated v. Paterson*, 598 F. Supp. 2d 289, 320 (E.D.N.Y. 2009) (summary judgment decision describing state's argument that residents of “adult homes” with more than 120 beds primarily serving individuals with psychiatric disabilities are “‘integrated’ community-based settings”) (see box for update on posttrial decision); National Council on Disability, *Inclusive Livable Communities for People with Psychiatric Disabilities 21* (2008), <http://bit.ly/15FthC> (although some “would describe the person living in a board-and-care home or a mental health community residence as being ‘in the community,’ the examples cited in this paper show that the person is living a segregated life and has very little meaningful interaction with people other than mental health clients or staff”).

<sup>8</sup>See, e.g., Center for Mental Health Services, Substance Abuse and Mental Health Administration, *supra* note 6, at 2 (“Even many smaller board and care homes operate like institutions,” requiring residents to line up for medications and to receive disability checks, affording little privacy and little choice concerning roommates, meals, or activities and expending little effort to help residents get jobs or job training and no effort to help residents find more integrated housing).

### Reallocation of Funds Is at the Heart of *Olmstead's* Integration Mandate

Many states' *Olmstead* planning does not consider closure of institutional beds or reallocation of funds to develop more integrated settings. Budgeting funds for *Olmstead* compliance is viewed as a drain on budgets rather than an opportunity for cost savings.<sup>9</sup> When new money must be found to develop additional community-based settings, development remains modest. As long as individuals with disabilities have insufficient community options, they will continue to be placed in or steered toward institutional settings.

Even though states tend not to do so, tying development of community-based services to closure of institutional beds is at the heart of *Olmstead's* analysis. The Court made clear that the possibility of closing institutional beds and reallocating funds must be considered as part of the fundamental alteration defense.<sup>10</sup> In determining whether requested relief would be a fundamental alteration, cost savings from closing institutional beds must be analyzed and quantified.<sup>11</sup> Indeed, the integration mandate would be hollow if states were allowed to keep unneeded institutional beds instead of reallocating funding to expand community settings. If a state cannot demonstrate

that closing institutional beds and shifting resources to community-based services would compel cutbacks in services to other individuals with disabilities, then shifting resources in this way is not a fundamental alteration.<sup>12</sup>

To achieve the promise of *Olmstead*, state service systems must commit to closing institutional beds and reallocating funds to develop more integrated settings.

### Private Facilities Must Be Part of *Olmstead* Compliance Efforts

Increasing numbers of individuals with disabilities are served in privately operated facilities, including nursing homes and board-and-care homes.<sup>13</sup> Often these facilities are considered permanent-living settings, and no discharge planning is done for residents.<sup>14</sup> Some states insist that *Olmstead* does not apply to individuals in such facilities; they argue that *Olmstead* and the statutory provision that it interprets (the ADA's Title II, which prohibits state and local government entities from discriminating based on disability) apply only to government-operated facilities.<sup>15</sup> Courts have consistently rejected this position when the private facilities are part of a larger, publicly planned and financed system of

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<sup>9</sup>Theoretically a state could comply with *Olmstead* without closing any institutional beds if the state found sufficient new funding to offer integrated settings to all individuals who are qualified. As a practical matter, finding sufficient new funding is unlikely to occur especially because all states have too many institutional beds and funding needless institutional beds is a drain on state funding.

<sup>10</sup>*Olmstead*, 527 U.S. at 604–5 & n.15.

<sup>11</sup>*Id.*

<sup>12</sup>See, e.g., *Townsend v. Quasim*, 328 F.3d 511, 518–20 (9th Cir. 2003) (rejection of state's argument that requiring it to extend Medicaid home- and community-based services waiver to higher-income group of Medicaid recipients would be fundamental alteration simply because such an extension would change how state chose to structure its programs); *Fisher v. Oklahoma Health Care Authority*, 335 F.3d 1175, 1182–83 (10th Cir. 2003) (rejection of state's arguments that eliminating its limit of covering only five prescriptions per month for individuals in Medicaid home- and community-based services waiver would be fundamental alteration simply because reducing services in optional Medicaid program was "reasonable" and because state was experiencing fiscal crisis).

<sup>13</sup>See, e.g., Center for Mental Health Services, Substance Abuse and Mental Health Administration, *supra* note 6, at 5 (states' increasing reliance on private-sector board-and-care homes is response to downsizing of hospitals).

<sup>14</sup>See, e.g., *Disability Advocates*, 598 F. Supp. 2d at 300 ("Plaintiff's experts have observed that adult homes are permanent placements, and that 'comprehensive discharge planning is non-existent'"); Kenton Robinson, *Thousands with Psychiatric Disabilities Locked Away in Nursing Homes*, NEW LONDON DAY, Dec. 19, 2004, A1, A11 (operator of nursing homes with locked units for individuals with psychiatric disabilities quoted as saying that "[t]here are some residents that may not leave, so they don't have treatment plans").

<sup>15</sup>Americans with Disabilities Act of 1990 tit. II, 42 U.S.C. §§ 12115, 12132.

services.<sup>16</sup> Title II covers all programs, services, and activities of a state or local government entity “without any exception.”<sup>17</sup> Hence the ADA applies to the way a state plans and administers its service systems for individuals with disabilities. In planning, organizing, and funding service systems, states must comply with the ADA’s integration mandate.

*Disability Advocates Incorporated v. Paterson* contains an extensive and thoughtful discussion of *Olmstead*’s application to private facilities.<sup>18</sup> The plaintiff—a nonprofit organization that advocates the rights of people with disabilities—challenged under *Olmstead* New York’s use of large, segregated “adult homes” as service settings for individuals with mental illness.<sup>19</sup> The state argued that *Olmstead* did not apply because the homes were private and the state played no role in admission and discharge decisions.<sup>20</sup> The court rejected New York’s argument and held that “[t]he statutory and regulatory framework governing the administration, funding, and oversight of New York’s mental health services—including the allocation of State resources for the housing programs at issue here—involves ‘administration’ on

the part of defendants,” to which the ADA applies.<sup>21</sup> The court found that the plaintiff’s *Olmstead* claims did not challenge the conduct of the adult-home operators but rather “the State’s choice to plan and administer its mental health services in a manner that results in thousands of individuals with mental illness living and receiving services in allegedly segregated settings.”<sup>22</sup> The court barred the state from evading its obligation to comply with the ADA by using private entities to deliver services.<sup>23</sup>

The court also rejected New York’s contention that Title II was inapplicable because the state did not require that anyone live or receive services in an adult home and individuals were free to move out or receive services elsewhere.<sup>24</sup> As the court explained, the state determines the settings in which it will provide and fund mental health services: “Defendants do so by controlling the State’s funding for services in various settings, including adult homes and [the more integrated setting of] supported housing, and effectively control how many adults receive services in any particular setting.”<sup>25</sup>

<sup>16</sup>See, e.g., *Disability Advocates*, 598 F. Supp. 2d at 313–16 (*Olmstead* applies to state’s administration of service system for individuals with mental illness including its use of privately operated “adult homes” to serve individuals who could live in more integrated settings); *Martin v. Taft*, 222 F. Supp. 2d 940, 946, 981 (S.D. Ohio 2002) (*Olmstead* “liability does not hinge upon whether the setting in question is owned or run directly by the State”); *Rolland v. Cellucci*, 52 F. Supp. 2d 231, 237 (D. Mass. 1999) (immaterial for purposes of *Olmstead* claim against state that many of plaintiffs lived in private rather than public nursing homes); see also *Radaszewski v. Maram*, 383 F.3d 599, 614 (7th Cir. 2004) (Clearinghouse No. 55,873) (“If the state would have to pay a private facility to care for [plaintiff] ... and the cost of that placement equaled or exceeded the cost of caring for him at home, then it would be difficult to see how requiring the State to pay for at-home care would amount to an unreasonable, fundamental alteration of its programs and services.”). Other courts have also applied *Olmstead* in cases challenging states’ use of private facilities to deliver services to people with disabilities (see, e.g., *Townsend*, 328 F.3d 511; *Fisher*, 335 F.3d 1175; *Long v. Benson*, No. 4:08cv26-RH/WCS, 2008 WL 4571904 (N.D. Fla. Oct. 14, 2008)).

<sup>17</sup>*Pennsylvania Department of Corrections v. Yeskey*, 524 U.S. 206, 209 (1998) (Clearinghouse No. 52,082).

<sup>18</sup>*Disability Advocates*, 598 F. Supp. 2d at 313–16.

<sup>19</sup>Adult homes are residential adult care facilities licensed by New York to provide long-term care and supervision to people with disabilities or mental illness or both.

<sup>20</sup>*Disability Advocates*, 598 F. Supp. 2d at 313.

<sup>21</sup>*Id.* at 318.

<sup>22</sup>*Id.*

<sup>23</sup>*Id.* The court also noted that, while the institution at issue in *Olmstead* was state-operated, the state’s community service system, also included in the Supreme Court’s analysis, relied on private providers (*id.* at 316).

<sup>24</sup>*Id.* at 318–19.

<sup>25</sup>*Id.* at 319. New York, where the *Disability Advocates* case occurred, distinguishes between scattered-site housing for people with mental illness, such housing being labeled “supported housing,” and housing where people with mental illness live in an apartment building for only or primarily people with disabilities, typically with services on-site, such housing being labeled “supportive housing.” Many states do not distinguish between the two types of housing and use the term “supportive housing” to refer to both models. Because of the term’s prevalence, we use “supportive housing” here except in quotations from and discussions about the *Disability Advocates* case. We use this term to describe scattered-site housing that is not conditioned on compliance with treatment for people with mental illness.

Despite the clear application of *Olmstead* to states' use of privately operated facilities as part of their disability service systems, large numbers of these private facilities remain outside state efforts to promote compliance with *Olmstead*.

### Compliance with *Olmstead's* Integration Mandate Is Best Achieved Through Supportive Housing

*Olmstead* is frequently described as requiring states to offer individuals living in "institutions" the opportunity to live "in the community." However, this characterization does not fully capture *Olmstead's* meaning. *Olmstead* and the ADA's integration mandate require that states administer services to individuals with disabilities in the most integrated setting appropriate to their needs.<sup>26</sup> The attorney general's regulations implementing Title II define the "most integrated setting" as "a setting that enables individuals with disabilities to interact with non-disabled persons to the fullest extent possible."<sup>27</sup> The *Disability Advocates* decision concluded that the regulations "mean what they say," and the court set forth the proper inquiry.<sup>28</sup> The decision rejected New York's argument that *Olmstead* required simply an inquiry into whether individuals had any opportunities to interact with nondisabled individuals.<sup>29</sup>

The plaintiff in *Disability Advocates* sought to compel New York to make "supported housing" available to individuals residing in large, segregated adult homes. This type of housing is permanent housing where individuals with disabilities live in their own apartments or homes, with the rights and responsibilities of tenants and with services delivered according to the individuals' preferences and needs.<sup>30</sup> Such housing typically provides a rental subsidy as well as a flexible array of services varying with the individual's needs. One important aspect of integrated supportive housing programs is that the housing is not conditioned on the individual's compliance with treatment—an approach known as "housing first."<sup>31</sup> Another is that the housing units are "scattered site"—that is, units are scattered throughout the community rather than congregated in a single building where all tenants are people with disabilities.<sup>32</sup>

The plaintiff in *Disability Advocates* sought "supported housing" because it was the most integrated setting for its constituents (individuals with mental illness living in adult homes), is effective in serving even people with the most challenging needs, and is less costly than other alternatives.<sup>33</sup> Having one's own home is a powerful motivator for people to seek and continue treatment.<sup>34</sup> Supportive housing gives people their own

<sup>26</sup>*Olmstead*, 527 U.S. at 596–98; 28 C.F.R. § 35.130(d) (2008).

<sup>27</sup>28 C.F.R. § 35.130(d), app. A (2008). The National Council on Disability, an independent federal agency, observed that "the most integrated setting" is generally understood to be (1) "a place where the person exercises choice and control," (2) a "home of one's own shared with persons whom one has chosen to live with, or where one lives alone," or (3) "living in the community with everyone else like everyone else" (NATIONAL COUNCIL ON DISABILITY, *supra* note 4, at 9).

<sup>28</sup>*Disability Advocates*, 158 F. Supp. 2d at 320, 321.

<sup>29</sup>*Id.* at 320–22.

<sup>30</sup>See, e.g., Sam Tsemberis & Ronda F. Eisenberg, *Pathways to Housing: Supported Housing for Street-Dwelling Homeless Individuals with Psychiatric Disabilities*, 51 PSYCHIATRIC SERVICES 487, 488–89 (2000).

<sup>31</sup>See National Council on Disability, *supra* note 7, at 24–27 (describing "housing first" approach and recommending that housing for people with psychiatric disabilities "be based on consumer choice, provided in integrated settings, and be delinked from mental health programming"); OFFICE OF POLICY DEVELOPMENT AND RESEARCH, U.S. DEPARTMENT OF HOUSING AND URBAN DEVELOPMENT, *APPLICABILITY OF HOUSING FIRST MODELS TO HOMELESS PERSONS WITH SERIOUS MENTAL ILLNESS: FINAL REPORT 2–3* (2007), <http://bit.ly/2lFXXs>; Sam Tsemberis et al., *Housing First, Consumer Choice, and Harm Reduction for Homeless Individuals with a Dual Diagnosis*, 94 AMERICAN JOURNAL OF PUBLIC HEALTH 651 (2004).

<sup>32</sup>See National Council on Disability, *supra* note 7, at 27 (supportive housing should be provided in scattered-site apartments and houses where individuals are tenants rather than "mental health clients").

<sup>33</sup>For a comprehensive description of how supportive housing works, why it is effective for people with the most challenging needs, and why it is less costly than other alternatives, see Bazelon Center for Mental Health Law, *Supportive Housing: The Most Effective and Integrated Housing for People with Mental Disabilities* (n.d.), <http://bit.ly/hs3C>.

<sup>34</sup>Tsemberis et al., *supra* note 31, at 655.

home, where they can focus on recovery from mental illness and rebuild their lives.<sup>35</sup> Supportive housing participants choose their own apartments, in neighborhoods where they want to live, and receive services that they need and want. Participants' having housing and service choices correlates not only with satisfaction but also with greater housing stability.<sup>36</sup> "Housing first" programs produce more long-term housing stability than programs in which housing is conditioned on compliance with treatment.<sup>37</sup>

Supportive housing is also more cost-effective than other types of publicly financed housing for individuals with disabilities, even for people with significant needs.<sup>38</sup> Supportive housing reduces costs by using apartments or houses available for rent on the market, thereby eliminating the need for rehabilitation or construction costs. The use of scattered-site units avoids the difficulties and expense of fighting neighborhood opposition to siting of housing developments or group homes. Supportive housing also saves money by focusing on teaching participants independent-living skills and reducing their use of costly resources such as shelters, day programs, inpatient hospitals, prisons, and jails.<sup>39</sup>

Despite its successes, supportive housing remains unavailable to most people with disabilities because states have not developed sufficient amounts of supportive housing. Instead states rely on nurs-

ing homes, board-and-care homes, and traditional group homes as housing and service settings.<sup>40</sup> None of them is the most integrated setting for individuals with disabilities, and hence serving people in these settings represents a form of "transinstitutionalization" or moving individuals from one type of institution into another type of institution.<sup>41</sup>

Group-home settings were once considered state of the art. However, as our understanding of the capabilities of individuals with disabilities has evolved and as new service approaches have developed, we now know that even people with extremely significant needs can live in their own homes with appropriate supports. Congregate settings—those that house multiple people with disabilities—thus should no longer be considered the "most integrated setting" for individuals with disabilities. Because congregate settings amount to transinstitutionalization, some states are no longer developing new congregate capacity and are instead focusing on development of supportive housing.

With the development of supportive housing and the recognition that even people with the most challenging needs can be served in their own homes with services and supports, the answer to the question of what is the most integrated setting appropriate has changed. While nursing homes, board-and-care homes, and group homes may be more integrated

<sup>35</sup>National Council on Disability, *supra* note 7, at 23.

<sup>36</sup>Debra Srebnik et al., *Housing Choice and Community Success for Individuals with Serious and Persistent Mental Illness*, 31 COMMUNITY MENTAL HEALTH JOURNAL 139, 146, 149 (1995).

<sup>37</sup>Martha R. Burt & Jacquelyn Anderson, Corporation for Supportive Housing, AB2034 Program Experiences in Housing Homeless People with Serious Mental Illness 3 (2005), <http://bit.ly/4hgQIG>; Tsemberis & Eisenberg, *supra* note 30, at 491.

<sup>38</sup>Bazelton Center for Mental Health Law, *supra* note 33, at 5–6.

<sup>39</sup>Center for Mental Health Services, Substance Abuse and Mental Health Administration, *supra* note 6, at 25; Dennis P. Culhane et al., *The Impact of Supportive Housing for Homeless People with Severe Mental Illness on the Utilization of the Public Health, Corrections, and Emergency Shelter Systems: The New York–New York Initiative*, 13 HOUSING POLICY DEBATE 107, 130, 137–38 (2002).

<sup>40</sup>A discussion of the complex question of why states rely on other settings is beyond our scope here. Some of the reasons are the political clout of the nursing home and board-and-care industry; lack of collaboration among state agencies to shift resources from institutional to community settings; bureaucratic inertia; giving people who are homeless priority over people living in institutions for limited supportive housing units; and, in some states, lack of knowledge and understanding of supportive housing.

<sup>41</sup>See Stephen J. Bartels et al., *Community-Based Long-Term Care for Older Persons with Severe and Persistent Mental Illness in an Era of Managed Care*, 50 PSYCHIATRIC SERVICES 1189, 1190 (1999), <http://bit.ly/ONBdX> (describing "transinstitutionalization" from state hospitals to nursing homes).

than state psychiatric hospitals or state institutions for individuals with intellectual disabilities, today they are not the most integrated setting appropriate to the needs of a person with a disability.<sup>42</sup> *Olmstead* implementation should focus on true integration through technologies such as scattered-site supportive housing. Otherwise scarce resources will continue to be wasted on settings that deprive individuals with disabilities of the full lives that they deserve and to which they are legally entitled.

### People with Disabilities Must Have Opportunities to Make Meaningful and Informed Choices About Where to Live

Individuals with disabilities must have an opportunity to make fully informed choices about where to live. Frequently people with disabilities express concerns about leaving institutional settings because they are unfamiliar with the full range of living options and services available outside the institution; among the options and services is the financial support that they will receive for community living. Many people assume that a return to the community will mean a return to what they had experienced before—often homelessness, restrictive or regimented programs, or independent living without services or resources to meet basic needs. Some assume that they would receive in the community only the same small “personal-needs allowance” that they receive in the institution from their

Supplemental Security Income checks.<sup>43</sup> Many lack confidence in their own abilities because they are told that they are incapable of living on their own.

Thus both education and active engagement must be part of the effort made to identify individuals who have disabilities and who want to live in more integrated settings. For individuals who are reluctant to make such a move, efforts must be made to explore the reasons and to give accurate information—and opportunities to visit integrated settings—to help overcome misperceptions. Also, community providers must build trust; many people with disabilities are understandably skeptical that service systems will keep their promises to provide adequate support for community living. Without such efforts, numerous individuals will continue to be excluded inappropriately from community life.



Progress in implementing the ADA’s integration mandate has been disappointingly slow and is likely to remain so unless policymakers and advocates embrace a broader vision for change. We do not attempt here to set forth a comprehensive agenda for *Olmstead* implementation. Instead we identify a few fundamental principles that should be part of any effort to give people with disabilities a real chance to live, as much as possible, “like everyone else”—the fundamental goal of the ADA.

## COMMENTS?

We invite you to fill out the comment form at [www.povertylaw.org/reviewsurvey](http://www.povertylaw.org/reviewsurvey). Thank you.

—The Editors

<sup>42</sup>For a small subset of individuals with disabilities, the cost of providing services in one’s own home may be so costly as to constitute a fundamental alteration. That question should be separated from the question of what is the most integrated setting appropriate to one’s needs. For individuals needing acute care during a psychiatric crisis, hospitalization may be appropriate, but only on a short-term basis.

<sup>43</sup>42 U.S.C. §§ 1396a(a)(50), 1396a(q)(1)(A) (personal-needs allowance).



## Court Decision in New York Advances Community Living for People with Psychiatric Disabilities

New York violated the Americans with Disabilities Act of 1990 (ADA) by denying thousands of adult home residents with mental illness the opportunity to receive services in the most integrated setting appropriate to their needs, according to a federal district court deciding *Disability Advocates Incorporated v. Paterson* on September 8, following a five-week trial (No. 03-CV-3209 (NGC), 2009 WL 2872833, at \*1 (E.D.N.Y. Sept. 8, 2009), [www.bazelon.org/pdf/DAI\\_ruling9-8-09.pdf](http://www.bazelon.org/pdf/DAI_ruling9-8-09.pdf)).

Disability Advocates Inc.—a nonprofit organization that advocates the rights of people with disabilities—brought claims under *Olmstead v. L.C.* (527 U.S. 581 (1999) (Clearinghouse No. 52,203)) and the ADA's integration mandate on behalf of approximately 4,300 people with mental illness living in privately operated “adult homes” in New York City with more than 120 beds (*Disability Advocates Incorporated*, 2009 WL 2872833, at \*1). Adult homes, the court found in a 210-page decision, are “segregated, institutional settings that impede integration in the community and foster learned helplessness” (*id.* at \*18). These homes, the court wrote, bear little resemblance to the homes in which people without disabilities normally live (*id.*). The court found that virtually all of the constituents of Disability Advocates were qualified for supported housing, a setting that is far more integrated than adult homes and in which people with mental illness live in their own apartments with flexible support services, including, in some cases, assertive community treatment,

an intensive service delivery model that provides, through a multidisciplinary team, comprehensive, individualized services for people with serious mental illness (*id.* at \*28). The court also found that the constituents, as a whole, were not opposed to living in more integrated settings and would choose to live in an independent setting such as supported housing if given an informed choice (*id.* at \*47).

Defendants, according to the court, failed to show that offering constituents of Disability Advocates the opportunity to live in more integrated settings would fundamentally alter the state's service system (*id.* at \*51–85). The court found that the state had no comprehensive or effective plan to enable adult home residents to receive services in more integrated settings and that the requested relief would not increase costs to the state (*id.* at \*53–83). In fact, according to the court, the state could redirect funds as individuals moved from adult homes to supported housing, and serving individuals in supported housing would be less costly (*id.* at \*68–69).

The court concluded that Disability Advocates was entitled to declaratory and injunctive relief; the court will order an injunctive remedy following additional briefing from the parties. The decision's detailed and thorough analysis—of, among other issues, why the ADA's integration mandate applies to publicly funded but privately operated facilities—is likely to have an impact on *Olmstead* litigation across the country.

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